

**Social Meanings and Implication of Tuberculosis: A study in Sikkim**

*Dissertation Submitted to Sikkim University in Partial Fulfillment of the  
Requirement for the Award of the Degree of*

**MASTER OF PHILOSOPHY**

**Submitted by  
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**SIKKIM UNIVERSITY**

*[A Central University Established By an Act of Parliament, 2007]*

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Date: 5.02.16

## **DECLARATION**

I declare that the dissertation entitled “**Social Meanings and Implication of Tuberculosis: A study in Sikkim**” submitted to **Sikkim University** for the award of the degree of **Master of Philosophy**, is my original work. This dissertation has not been submitted for any other degree of this university or any other university.

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## **CERTIFICATE**

This is to certify that the dissertation entitled “**Social Meanings and Implication of Tuberculosis: A study in Sikkim**” submitted to **Sikkim University** in partial fulfilment of the requirement for the degree of **Master of Philosophy in Social Sciences** embodies the result of bona fide research work carried out by **Ms. Rinzing Tsoden Bhutia** under my guidance and supervision. No part of the dissertation has been submitted for any other degree, diploma, associate-ship, fellowship.

All the assistance and help received during the course of the investigation have been duly acknowledged by her.

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## **ABBREVIATIONS**

ACSM: Advocacy, Communication and Social Mobilization

AIDS: Acquired Immunodeficiency Syndrome

ASHA: Accredited Social Health Activists

DMC: District Microscopy Centre

DOTS: Directly Observed Treatment Short course

DTC: District Tuberculosis Centre

HBCs: High Burden Countries

HIV: Human Immunodeficiency Virus

IRL: Intermediated Reference Laboratory

MDR TB: Multi drug resistance Tuberculosis

MDGs: Millennium Development Goals

NRHM: National Rural Health Mission

NTI: National Tuberculosis Institute

PHCs: Primary Health Centres

PHSC: Primary Health Sub Centre

PMDT: Programmatic Management of Drug resistance Tuberculosis

RNTCP: Revised National Tuberculosis Programme

STNM: Sir Thutob Namgyal Memorial

TB: Tuberculosis

TBC: Tuberculosis Control

TRC: Tuberculosis Research Centre

WHO: World Health Organisation

XDR TB: Extensively drug resistance Tuberculosis

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# CHAPTER-I

## INTRODUCTION

### 1.1 Background of the Study

Health is considered as one's real wealth. It is one of the fundamental values for laying the foundation for the quality of human life, welfare of one's family and also of society as a whole. Good health generates the economic benefits of the countries and is prerequisites for the national development and individual wellbeing (Najar et al., 2013).

According to World Health Organisation (1948), health is defined as a state of complete physical, mental and social well being and not merely an absence of disease or physical infirmity ([www.who.int](http://www.who.int)). In 1977, the Thirtieth World Health Assembly adopted a resolution in the year 1977 proclaiming that in the coming periods the main social aim of the government and WHO (World Health Organization) should be the attainment of health for all the citizens leading to achieve a socially and economically productive life by the year 2000. Health is one's real wealth and good health increases one's efficiency which contributes to an individual's own progress, to the progress of his family, community and of the nation as a whole generating the productivity and economic prosperity of the country. For attaining a good health, awareness about diseases, physical and social factors like proper housing and a perfect balance, economic conditions, family atmosphere, proper disposal of the wastes, control of vectors, personal hygiene, balanced diet, public cleanliness, regular exercise etc., are essential for healthy life. In all societies it is observed that well-being is a human concern and like others life forms living beings or humans are vulnerable to various diseases or illness. Humans find themselves confronted with diseases or illness (Singh 2005).

In all human society disease or being ill is seen as distressing problems affecting the flow of daily life. The term disease refers to any condition which interferes with the normal functioning of the body and impairs the health. Disease varies from society to society depending upon their climatic conditions, geographical locations, resources, reproduction, ways of productive activities etc., and not just a result of pathogen or physiological disturbances (ibid). There are diseases which have ruined societies from ancient period resulting in terror and death. As such, infectious disease is one of the oldest diseases and is considered as a leading cause of death worldwide killing millions of people, threatening

human morbidity and mortality. Even in the period of modern medicine societies still suffer from infectious disease and has become a threat to human life and prosperity (Singh 2005).

Advancement of the science and technology and modern medicine has brought drastic changes and improvement in the life expectancy and treatment of various diseases but despite these achievements, medicine is seen with doubt and ambivalence. There is a wide-spread belief that bio medicine is a double-edged sword. Instead of focusing in the progress of the technological innovation and medical science public subordinate it through ethical regulations. Medical science has been criticised by medical sociology for neglecting the social influences and not providing the different way of comprehending and addressing health issues and diseases or illness (as cited in White 2002).

Regarding the spread of disease White (2002) states that sociologists have demonstrated that the spread of disease is heavily influenced by the socio-economic conditions or status of the individuals, ethnic tradition or belief and other cultural factors. Various diseases are examined and compared based on the traditional medicine, economics, religion, and culture that are specific to each region. For instance some infectious disease like HIV/AIDS, TB or Tuberculosis, etc., may be seen as a common basis to each region. Some particular diseases may be extremely problematic to certain area while in the other parts the problem related to the disease may not be so extreme.

Tuberculosis is one such infectious disease and is the leading killer among people with weakened immune system mainly the people with HIV/AIDS and people with chronic disease. Tuberculosis is one of the contagious and most common diseases in the world (Schiffman, 2014). “Tuberculosis, or TB, is an infectious bacterial disease caused by *Mycobacterium tuberculosis*, which most commonly affects the lungs. It is transmitted from person to person via droplets from the throat and lungs of people with the active respiratory disease” – WHO ([www.who.int](http://www.who.int)).

Tuberculosis is more common in the crowded city slums areas with unhygienic conditions. In many parts of the countries to become sick with tuberculosis is highly stigmatizing making them excluded and isolated. It is a world-wide health care concern and a major health problem around the world, despite the inception of modern treatment and public health intervention (Daniel 2006). Tuberculosis – the famed disease which was once referred to as “Poor Man’s Disease” is now observed as a lifestyle disease (National Tuberculosis Institute,

2015). However the influences on the lower income group individuals are always higher because the diagnostic facilities and treatment are expensive and therefore it is a financial burden.

## **1.2 History of tuberculosis:**

Tuberculosis is the oldest documented infectious disease known to the humankind since ancient time and remains a major health threat around the world even today (Dodor 2009, Sandhu 2011). The organism causing mycobacterium tuberculosis was into existence since 15,000 to 20,000 years ago and this has been found in relics from ancient Egypt, India and China. Evidences from the archaeological survey shows that tuberculosis in the humans dates back to 2400-3400 B.C where among Egyptian mummies spinal tuberculosis known as Pott's disease was shown. Evidence of the tuberculosis of the cervical lymph nodes or of the neck also called as scrofula even termed as king's evil is considered to be found in the middle ages and there was a belief that the kings of England and France could cure this disease by touching the affected persons. So the disease had a crucial social impact in the historical period which was prominent in arts and politics (Myers 1970, Dodor 2009, [www.news-medical.net](http://www.news-medical.net))

Various numerous terms were created for this disease, Hippocrates in 460-360 B.C termed it as phthisis, the Greek poet Homer portrayed it as "a grievous consumption that separate the body and soul", English speaking people term it consumption and later on entitled it as "the Captain of all the Men of Death" and "the Great White Plague" (Gallagher 1969, Dodor 2009). The concept of tuberculosis was then established or discovered by them and described the disease as the melancholic process characterised by progressive debilitation, coughing, haemoptysis and suppurating lung lesions, however all chronic pulmonary infections come under this disease ([www.news-medical.net](http://www.news-medical.net)). The disease was believed to be an inherited for a long period of time (Mc Kinney et al., 1998, Dodor 2009). Those who suspected the disease to a contagious made regulations to prevent its spread. For example in Italy and Spain the people infected with the disease were isolated and after their deaths, their beds and rooms were burned and re-plastered (Dowling 1977, Dodor 2009).

Benjamin Martin in 1722 developed a germ theory and said that the disease arose from a micro-organism, an air borne contagion. In 1865 Jean-Antinio Villemin demonstrated that the disease was transmitted and spread from patients to animals by using sputum or gaseous

tissues. Robert Koch in 1882 discovered mycobacterium tuberculosis (McKinney et al., 1988, Dodor 2009). Calmette and Guerin in 1919 discovered BCG (Bacille Calmette Guerin) vaccine against tuberculosis and WHO in 1940 promoted mass vaccination with BCG in its campaign in controlling tuberculosis (Dodor 2009). Various others drugs that were used for treating different diseases were also tried on tuberculosis. In 1946, streptomycin was found to be effective drug against tuberculosis. In 1952, isoniazid and in 1965 rifampicin was found to be effective drug making tuberculosis curable and with the availability of these drugs and vaccine infectious disease like tuberculosis was thought to be eradicated from the world (McKinney et al., 1998, Dodor 2009). This thought was captured in the words of Selman Waksman:

*“But most importantly, the ancient foe of man, known as consumption, the great white plague, tuberculosis, or by whatever other name, is on the way to being reduced to a minor ailment of man. The future appears bright indeed, and the complete eradication of the disease is in sight” (McKinney et al., 1998 p.126, Dodor 2009).*

However despite all these the battle against tuberculosis is not yet over and the disease still continuous to remains a major threat to the world.

### **1.3 Global Situation of Tuberculosis:**

Tuberculosis is considered to be one of the leading causes of death world-wide second to HIV/AIDS among infectious disease. In the year 1993, the World Health Organisation (WHO) declared TB as an emerging global problem because of the rapid increase of the disease world-wide. DOTS (Directly Observed Treatment) strategy was introduced as cost effect way to achieve global target of 70% case detection and 85% cure rate by the year 2005 and improve and maintain this performance from 2006. It was estimated that 8.6 million people developed tuberculosis and 1.3 million died from the disease in 2012 ([www.who.int](http://www.who.int)). Data on the overall scenario of tuberculosis in the world in the year 1990 and its recent trends are reviewed by an analysis of the case notification to WHO and TB mortality reports and approximately one third of the world population was infected with mycobacterium tuberculosis. Progress has been made towards 2015 global target set within the context of Millennium Development Goals ([www.who.int](http://www.who.int)). According to the WHO (World Health Organisation), Tuberculosis is a worldwide virulent disease. WHO fact sheet dated March 2010 on tuberculosis stated that overall one third of the world’s population is infected with

the tuberculosis bacillus every year. WHO with its STOP TB strategy has given a vision to eliminate tuberculosis as a public health problem from the earth by 2050 (Sandhu 2011).

In 2013, an estimated 9.0 million people developed TB and 1.5 million died from the disease, 360 000 of whom were HIV-positive. TB is slowly declining each year and it is estimated that 37 million lives were saved between 2000 and 2013 through effective diagnosis and treatment. However, given that most deaths from TB are preventable, the death toll from the disease is still unacceptably high and efforts to combat it must be accelerated if 2015 global targets, set within the context of the Millennium Development Goals (MDGs), are to be met (Global Tuberculosis report 2014, WHO). About 60% of TB cases and deaths occur among men, but the burden of disease among women is also high. In 2013, an estimated 510 000 women died as a result of TB, more than one third of whom were HIV-positive. There were 80 000 deaths from TB among HIV-negative children in the same year (Global Tuberculosis report 2014, WHO).

#### **Collection of global tuberculosis data 2014**

Table 1.3.1: The 2014 round of global TB data collection.

WHO Regions or set of countries	Countries and Territories		Member State	
	Number	No. that reported data	Number	No. that reported data
African region	47	46	47	46
Eastern Mediterranean region	22	20	21	20
European region	54	47	53	46
Region of America	46	46	35	35
South east Africa region	11	11	11	11
Western Pacific region	36	32	27	25
High burden countries (HBCs)	22	22	22	22
World	216	202	194	183

Source: Global report 2014, WHO

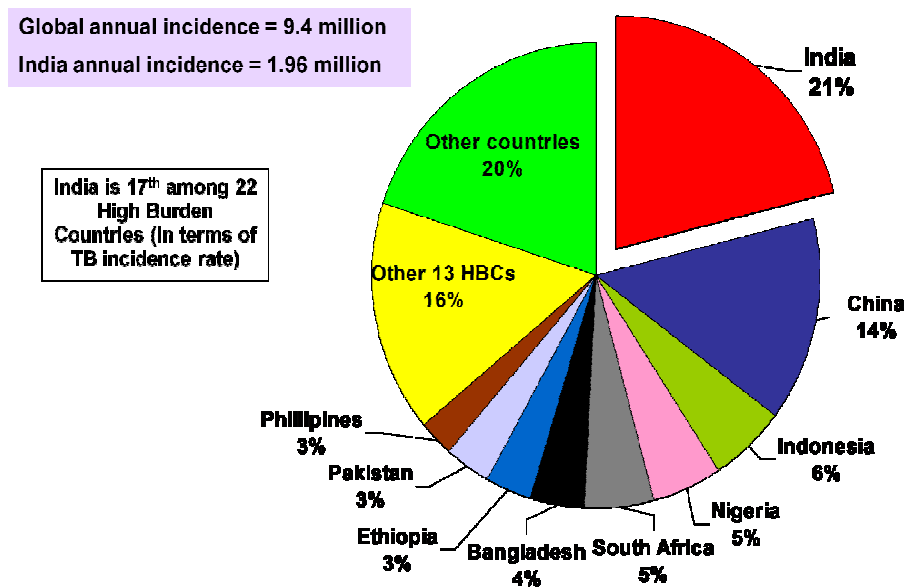
This is nineteenth in series of annual reports by World Health Organizations. This 2014 global TB report uses the data reported by a total of 202 countries and territories including

183 member states that account for 99% the world estimated cases of tuberculosis. HBC's represents high burden countries which includes Afghanistan, Bangladesh, Brazil, China, the Democratic Republic of Congo, Ethiopia, India, Indonesia, Kenya, Mozambique, Myanmar, Nigeria, Pakistan, Philippine, the Russian Federation, South Africa, Thailand, Uganda, the United Republic of Tanzania, Vietnam and Zimbabwe (Global TB reports 2014, WHO).

### 1.4 Tuberculosis Scenario in India

India is ranked as highest burden country accounting for one fifth of the global incidence and two third of the total cases in South East Asian countries. In terms of TB incidence rates India ranks 17<sup>th</sup> among the high burden countries (see Figure 1.4.1) and is considered to be one of the leading causes of death among the population in India ([www.who.int](http://www.who.int))

Figure 1.4.1: Annual TB incidence rates



Source: WHO Geneva; WHO Report 2009, Global Tuberculosis Control; Surveillance, Planning and Financing

As per the TBC (Tuberculosis Control) India reports, it has been estimated that tuberculosis is one of the communicable disease which has highest rate of mortality (Ministry of Health and Family Welfare, 2015). This report highlights that nearly 2 persons on an average of three minutes out of 1000 individuals dies every day. This report has been further substantiated by the Global Tuberculosis Report, WHO, which shows that approximately



38% Indians dies annually due to this infectious pathogen [38,000 individuals out of a population of 1,00,000 individuals] (Global Tuberculosis Report, WHO, 2014).

With reference to the above reports and discussion, the proposed study has focused on exploring and understanding the social implications and meanings of tuberculosis in Sikkim and draws an analysis of socio-cultural and economic correlates of the Tuberculosis infected people and others.

In Sikkim, disease related with inadequate sanitation, tuberculosis, alcoholism conditions, goitre etc continues to inhabit an essential place in the state health profile (Lama 2001). Substantial humidity and frequent rainfall creates a favourable environment an optimal growth conditions for the infectious pathogens like *Mycobacterium tuberculosis*, *Salmonella*, *Shigella* etc. (Mirski *et. al.*, 2012; Petzoldt and Seaman, 2005). Sikkim experiences varied weather conditions ranging from Tundra to Temperate type of climate. The climate plays a very crucial role which has a direct impact on the human health as it influences the incidence of infection and their proliferation among the patients (Mirski *et. al.*, 2012; Epstein, 2001). These types of climatic conditions are very conducive for the Tuberculosis pathogen to propagate and proliferate. Tuberculosis is a major health concern of the state.

The data provided by RNTCP in the state of Sikkim, reports decrease in death rate, however in spite of this over 1000 new incidence of TB has been reported every year and the state is yet to achieve the targeted cure rate of 85% with only 78% of its success rate in 2014 (Agarwal 2015). In Sikkim, whatever information available on the disease offers explanation of the data in statistical or tabulated form. There is limited information on its sociological aspects. Thus the proposed study attempted to give a sociological insight into the disease.

## **1.5 Review of Literature**

For the purpose of the study, the literatures are reviewed from books, research papers, articles and journals which are as follows:

### **1.5.1 Tuberculosis**

Tuberculosis (TB) being a contagious and communicable disease, has caused havoc in the social welfare and well being of the society and it has spread across most of the developed and underdeveloped countries (Rahman, 2010). Tuberculosis is an air borne disease which is

caused by *Mycobacterium tuberculosis* that spreads from one person to another through close contact by air droplets and it usually attacks the lungs but can also attack others parts of the body organ (www.who.int). Gursimrat K Sandhu (2011) in his article: '*Tuberculosis Current Situation, Challenges and Overview of its Control Programs in India*', has discussed about tuberculosis being the most ancient disease. He ranked tuberculosis among 10 killer infectious diseases second to HIV/AIDS.

### **1.5.2 Studies related to Tuberculosis in the Global and Indian contexts:**

World Health Organization 2014 global reports underscore that during the year 2013 an estimated of 9.0 million TB cases and 1.5 million deaths occurred from the tuberculosis emphasizing the load of tuberculosis worldwide(Global TB Reports, 2014).

As per the TBC India reports, it has been estimated that tuberculosis is one of the communicable disease which has highest rate of mortality and it also highlights that nearly two person on an average of three minutes out of 1000 individuals dies everyday (Ministry of Health and Family Welfare, 2015).

Discussing India as the highest TB burden country, Sachdeva *et al* (2012) view tuberculosis to be a most common infectious disease affecting the morbidity and mortality of the country despite it being curable and preventable.

Stekelenburg (2004) through his study mentioned that AIDS epidemic plays a significant role in resurgence of tuberculosis highlighting an increase in the incidence of TB cases over the years. The study reveals that involvement of health staff, family members, and community health workers, as helpful in finding defaulters and noted that defaulting and poor compliance to be major cause for poor success rate of tuberculosis.

Asbroek *et al.*, (2008) on the basis of study conducted on the rural areas of Nepal, bordering India depicts low level of awareness and knowledge of the disease. It also throws lights on to the economic crises faced by the rural Nepalese people highlighting lack of human resources and infrastructure for improvement in health. The study also demonstrates people taking up elaborated source before actually visiting the hospitals for treatment.

Sandhu (2011); Srivastava *et al* (2008); Prasad *et al* (2005) has discussed the current scenario of tuberculosis in India, its control programs and view tuberculosis to be one of the most

ancient and deadly disease and highlights that ingestion of various goods or products like that of unpasteurized milk or dairy product made from raw milk as one of the possible source of TB.

### **1.5.3 Studies on Sociological Dimension of Tuberculosis:**

While looking at the sociological dimensions of tuberculosis it has been seen that there is a stigma attached to tuberculosis. Goffman (1963) describes stigma as “mark or signs which places an individual in a less valued position than the other people and regards those stigmatized individual as blemished humans”. Social stigma is unwanted and unfavourable elements possessed by the individual which reduces one’s status in the society (Goffman, 1963; Dhingra and Khan 2010 RNTCP Status Report, 2005). Dhingra and Khan (2010) in his study in Delhi mentioned that stigma related to tuberculosis as one of the important factors in delaying the initiation of treatment.

An immediate essence to promote the social mobilization for reducing the stigma problems and in decreasing the fear of infection was emphasized by Jaggarajamma *et. al.*, (2008) and Rajeshwari *et. al.*,(2005). Goffman in his book (1963) ‘*Stigma: Notes on Management of Spoiled Identity*’ has used the ideas of ‘social identity’ which according to him is a significant factor in development of stigma. His theoretical understanding of stigma is that which disqualifies an individual from full social acceptances. He talks about two types of stigmatised individuals i.e., discredited and discreditable. The crux of his theoretical understanding of stigma is the feeling of inferiority. He also stressed on the ‘mixed contacts’ which raises concerns between the stigmatized and the normal. Therefore his theoretical concepts on stigma can be applied in the present study to comprehend the impact of stigma in the lives of stigmatized individuals.

Jones *et. al.*, (1998) in their study related to TB associated with stigma has given an exhaustive theoretical framework and identifies six dimensions of stigmatizing conditions. ‘Concealability’ where the stigmatizing characteristics are noticeable like patients with excessive haemoptysis and those can pass off with extra- pulmonary condition, ‘course of mark’ where the mark becomes salient or debilitates over period of time for example lymph node of TB, ‘disruptiveness’ in which the stigmatizing characteristics like acute bouts of coughing interfere with the flow of interpersonal interaction, ‘aesthetics’ which symbolizes

subjective reaction to the unattractiveness of the stigma, 'origin of the stigmatizing mark', and the 'peril' which indicates the perceived danger of stigmatizing conditions to others.

Aryal S. et al., (2012) in their study 'Stigma related to tuberculosis among the patients attending the DOTS clinic of Dharan Municipality' mentioned that the stigma associated with tuberculosis creates hindrance for successful treatment of the people suffering from the disease. The study also demonstrated that the social and cultural factors functioning in the society plays a significant role in level of mental discomfort by the tuberculosis patients.

Babbar (2014) in his study remarked that the stigma attached to tuberculosis follows like a shadow throughout ones lives as it continues even after patients was declared to be cured from the disease. Not disclosing the disease with fear of stigma can have an impact on the psyche of the individuals leading to agony adding more to their suffering.

Department of gender and women health, WHO (2003) on 'Gender and Tuberculosis' examines that gender dimensions of tuberculosis as significant for overcoming hindrances for effective coverage, prevention and treatment of the disease. It indicates that socio and economic consequences of the disease varies by gender difference in roles and responsibilities and division of labour.

Somma *et. al.*, (2008) on the study on gender and socio cultural determinants of TB -related stigma in Bangladesh, India, Malawi and Colombia highlights the effect of social stigma in delaying patients in seeking health care compelling them to conceal their illness from their friends and their families. They noted that TB related stigma to be worst for females than for males. Johansson *et. al.*, (1999) has also emphasized that tuberculosis is more stigmatizing for women than for male. It was also observed that the various categories of distress, perceived causes and prior help-seeking affected the magnitude and nature of patients and social discrimination having adverse impact on the quality of patients lives.

#### **1.5.4 Studies related to Traditional Healers in treatment of Tuberculosis:**

It is observed in various studies like studies on '*Traditional healers knowledge and implication to the management and control of HIV/AIDS in Tanzania*' by Uiso et al., 2006); '*The importance of traditional healers in Thyolo, Malawi*' by Zachariah et al., 2002; '*Health care seeking behaviours of TB patients in Chandigarh*' by Kaur et al., 2013 et..., people often

seek alternative ways or help from indigenous health practitioners commonly called as traditional or faith healer, for treating any illness or diseases before visiting the hospitals.

WHO describes the Traditional healer as any individual from an indigenous community who uses biotic or abiotic components based on the particular belief system and traditional knowledge passed from old generations to cure illness (McClean and Bannerman, 1982). Traditional healers occupy a significant position due to their holistic and culturally accepted methods. They play a positive role in promoting the folk medicines and belief systems. Moreover it has been observed that there is a gender bias preferences among these dwelling communities as more women prefers traditional healers to cure their illness than men. (Stekelenburg, 2004; Uplekar *et. al.*, 2001).

Some studies have looked at the disease from a religious dimension based on past like karma and misdeed or even as a heinous sin inflicted upon individuals who has not followed the cultural rules. For example in the case of South African, traditional healers have a strong belief that Tuberculosis patients suffer because they violated the cultural rules and had sex after death of family members and in case of women having continuous abortions (Babbar, 2014; Smart and Wenger, 2000; Farmer, 1997; Hudelson, 1996; Jaramillo, 1999; Rangan and Uplekar, 1999).

Hassnoot *et al.*, (2010) on their study on the knowledge, attitudes and practices of tuberculosis among the Maaasai in Simanjiro districts, Tanzania indicates that traditional healers plays a vital role among the Maasai. The traditional healers take a key role in the treatment of tuberculosis patients as these tribe considered the disease to be a punishment from god and can be treated with herbs roots and barks.

### **1.5.5 Studies related to Tuberculosis in Sikkim:**

Sikkim has diverse and multiple ethnic groups with their own unique lifestyles having different socio cultural traditions and practices. It is widely accepted that the state has diversified folk healers belonging to different communities. Lama (2001) mentioned about prevalence of different traditional healers among different communities or groups in the state like *Jhankri* (Nepali), *Fedongma* (Subba), *Pow* and *Nejum* (Bhutia), *Boomthing* (Lepcha) and other pundits. A recent studies conducted on the Traditional healers in Ribdi- Bhareng , a

place in the West Sikkim, it was found that 8 traditional healers out of the total of 21 healers could cure or have formula of treating tuberculosis ( Rai *et. al.*, 2014).

Tobgay *et al* (2011) in their article entitled '*Predictors of treatment delay for TB in Sikkim*' a study conducted on the East districts of Sikkim has looked at the factors related with delays between commencements of symptoms, patients delay to medical facilities and delay in diagnosis of tuberculosis as connected with self-medication.

A survey conducted in all the four districts of Sikkim on Sikkim Tuberculosis health database reports that during the study from 2002 to 2010 in all the four districts of Sikkim; a total of 6827 cases were registered for pulmonary tuberculosis and observed 27.1% of the total retreatment rate in the state (Dolma *et. al.*, 2013).

Najar *et. al.*,(2013) through their study in Sikkim has discussed the various risk factors contributing to various infectious and non infectious diseases and noted that TB, cholera, conjunctivitis, gastroenteritis as most prevalent infectious disease in health profile of Sikkim.

Agarwal (2015) in his article has mentioned over 1000 new tuberculosis cases being registered in the state health profile despite of the various activities by RNTCP to curb the hazard and its decline in death toll rate. He also noted the failure of the state in achieving the targeted cure rate of 85% with only 72% of success rate in the year 2014.

The above reviewed literatures reveals a comprehensive study on various issues related to tuberculosis but an in-depth study related to sociological aspects is rather limited in the state of Sikkim. Thus this research work will be helpful in exploring the social meanings and implications of Tuberculosis in Sikkim which could be useful for future exploration.

## **1.6 Rationale of the Study**

Tuberculosis is a distressing public health concerns across the world in spite of its inception of modern treatment. It is infecting about a one third of global population and is causing an estimated of two million deaths every year. To become sick with tuberculosis can impose tremendous socio- economic burden on individual. In developing countries like India tuberculosis is highly stigmatizing.

Tuberculosis is a major health threat in the state of Sikkim as 1631 new cases of the disease were reported in 2014 with cure rate of only 78% (Agarwal 2015). Sikkim's government

policies on health and family welfare are one of the well framed ones which proposes better treatment facilities for the TB patients but despite of all these initiatives and its inception of modern treatment and free DOTS strategy and various activities by RNTCP to restrain the hazards, there is still an increase in the incidence of TB cases in the state which therefore warrants an in-depth study.

Tuberculosis is a disease which is highly stigmatizing (Dhingra and Khan 2010; Babbar 2014; Somma et. al., 2008). It is a disease connected in the psyche of people with negative stereotype making the patients feel excluded and isolated which might have an indirect impact on the patients mind adding more to their suffering therefore the study tries to explore the impact of social stigma attached with the disease, its effect on the treatment of the patients and its influence on the process of social interactions. Epidemiology evidences about this disease is known but despite of all the economic and social awareness programmes, there is dearth of information on its sociological aspects. Thus, a sound database on the status of the sociological conditions of the TB patients is needed.

Sikkim is a multi-ethnic society having various traditions and practices and every ethnic group has its own faith healers. It is widely accepted that the faith healers occupy a culturally and traditionally acceptable position in the healing practices. It is an observation that the tuberculosis patients in Sikkim before actually going to hospitals seek help from traditional healers; the study therefore will also try to assess the help seeking behavior or pattern among the patients.

Thus, the scope of the study is to collect the data about the concerned research queries and analyze them scientifically to rationalize the statistics obtained.

## **1.7 Objectives**

The specific objectives of the study are as follows:

1. To study the level of awareness and perception about the disease among the TB patients and others
2. To explore the health seeking pattern prevalent among the TB patients.
3. To study the impact of the disease on the economic status of the affected person and their family.

4. To understand the impact of social stigma attached with the disease and its influences on social interactions.
5. To examine whether there exists a gender differentials among the tuberculosis patients in the treatment process.

## **1.8 Research Questions**

1. How do tuberculosis patients and other people perceive the disease?
2. What types of health seeking patterns are prevalent among the tuberculosis patients?
3. What are the economic implications of the disease on the patients and their family?
4. What are the various factors that influence the patients' social interactions with others?
5. Is there any gender differential among the TB patients in seeking treatment?

## **1.9 Methodology**

Research is an attempt to diffuse knowledge. The present study tries to sociologically analyze the scenario of tuberculosis in Sikkim. For this purpose both primary and secondary sources of data was employed. The primary data was collected from fieldwork using interview schedule, observation, focus group discussion and collection of case studies. For the secondary source books, journals, article, government data, internet source were used. Both qualitative and quantitative methods were used for collecting and analyzing the data. In the qualitative method Erving Goffman's theoretical concept of stigma was used to understand the impact of stigma on the patients and to examine how stigmatized person perceive themselves.

The sample size consists of around 150 respondents. Purposive sampling was used to identify the respondents for the study. The primary respondents were the TB patients, secondary respondents were their immediate family members and FSG (Focused Group Groups) selected from their society and tertiary respondents were the medical representatives/traditional healers dealing with the primary respondents. Semi-structured interview schedule containing closed ended and open ended questions, observation, and focus group discussion was used to collect data. The statistical technique like tabulation has been used for analyzing the data and writing report.



## **Field Area:**

The field area of the study are the four districts of the state i.e. Gangtok (East); Mangan (North); Namchi (South) and Geyzing (West). The survey was conducted at the DOTS centre and districts hospitals as the information of the respondents will be available from the official records of the DOTS and it was easy to locate the respondents then. The researcher also a field survey in villages and for this snowball sampling method was used to identify the TB infected persons. The views of others people not infected with the disease is also taken into considerations.

### **1.10 Theoretical Perspectives:**

Erving Goffman's theoretical work on stigma has been applied in understanding the impact of stigma attached with the tuberculosis patients in Sikkim. Goffman describes stigma as "mark or signs which places an individual in a less valued position than the other people and regards those stigmatized individual as blemished humans" (Heatherton *et. al.*, 2000).

In the book '*Stigma: Notes on Management of Spoiled Identity*', Goffman has used the ideas of 'social identity' which according to him is a significant factor in development of stigma. He believes that an identity an individual carries with him categorizes that person. Thus, he views stigma as something that disqualifies individuals from full social acceptance. The crux of Goffman's theoretical work on stigma consists of the feeling of inferiority and this inferiority feeling raises the question of acceptance of the stigmatised individuals by the normal. According to him stigma operates in relations to the perspectives of other about the person although it can take place in the absence of other but it is mostly associated with the feeling in the social intercourse with other (Goffman, 1963 and also cited in Crocker, Major, & Steele, 1998; Hebl & Dovidio, 2005).

Tuberculosis in Sikkim state is a major threat. Rai (2012) has stated that social stigma is one of the main causes for the spreads of tuberculosis and increasing number of cases of death due to the disease. People infected with tuberculosis lives the life of ambiguity, unsure about whether they will be accepted or rejected by the other people. The stigma attached to the disease acted as a hurdle in seeking treatment from the health practitioners. The inferiority feelings among the people made them conceal their sickness due to fear of being isolated and rejected by their friends and others. Thus the fear of being stigmatised acted as a barrier in

seeking treatment and this fear of stigma was the major concern among the tuberculosis infected people and their family members and this could be one of the major reasons for delay in diagnosis of the treatment leading to an increase in number of cases in MDR-TB (Multi-Drug Resistant Tuberculosis) and XDR-TB (Extensively- Drug Resistant Tuberculosis). The stigma attached to the disease affected the social intercourse or interactions between the members of the infected persons and other resulting in many social problems in the society (Rai, 2012; Tobgay *et. al.*, 2011).

Applying Goffman's theoretical understanding of the stigma, the purposed study tries to explore and examine the impact of social stigma attached with tuberculosis and its influences on the social interactions among the individuals infected with the disease i.e., the stigmatised individuals and other i.e., the non- stigmatised individuals.

### **1.11 Limitation of the Study**

Sociological research is an exhaustive and intensive study about social phenomena and it needs ample time for proper justification. However the research was conducted amidst several limitations. The time factor was one of the pertinent limitations that affected proper justification. Since tuberculosis is a communicable disease there might be a high risk of interviewing the TB patients as the researcher might be infected with disease. Therefore this constraint was also one of the vital factors that affected the proper rationalization of the research report.

However the whole period which I have spend to collect the relevant facts and the interactions with the respondents was enriching and pleasurable experiences that has given me rich exposure to the research problem.

## **CHAPTER –II**

### **THE SCENARIO OF TUBERCULOSIS IN SIKKIM AND SOCIO-ECONOMIC PROFILE OF THE RESPONDENTS**

#### **2.1 Sikkim: A Brief Introduction on Health care services**

Sikkim – the landlocked state of the Northeast India is a multiethnic and multi-linguistic zone where there has been an amalgamation of diverse cultures at the helm of 21<sup>st</sup> century. A small state bounded on the four sides by Nepal in the West, Bhutan in the East, Tibet in the North and Darjeeling districts of West Bengal in the South. Sikkim government policies on health and family welfare are one of the well framed one which recommends on the better health care institution in the state. There has been a considerable improvement in the health institutions in the state since its merger with the Indian Union. The health care system in Sikkim was almost absent when the state became the protectorate of the British in the 19<sup>th</sup> century. Health care received its importance in Sikkim with the intervention of the British rule. Under the patronage of J.C.White, the first political Officer of Sikkim, the effort was made to instigate health care services in Sikkim which was in fact envisaged by the British on a larger part as a latent means of achieving their goals by gaining the assurance and confidence of the Sikkimese people by organizing free medical services which helped them in attaining indigenous consent to British rule, and this ‘political’ role became the most important reason for the presence of Medical Officers in the state (McKay, 2004).

Gradually various government dispensary were set up in Sikkim with basic health facilities and on 24<sup>th</sup> September 1917, the first official hospital of Sikkim known as Sir Thotob Namgyal Memorial Hospital was opened at Gangtok by the then Chogyal, Sir Tashi Namgyal and it was later expanded with few specialised departments with basic health services and not well developed infrastructures. Tuberculosis ward in the late 1920s was added to the hospitals. At present there has been considerable improvement in the state health care institution, in providing health care services to the people and in meeting the unmet needs for health. There has been substantial development in the state public health care infrastructure and there has been an increase in number of establishment of PHCs (Primary Health Centre) and PHSC (Primary Health Sub-Centre) over the years in the state. There are total of 179 recognised health institutions at present with well functioning primary health care system. Each district has one district TB centre (DTC) for diagnosis and treatment of tuberculosis and

one tuberculosis centre established at Namchi in the south districts. The state has its state TB cell at Gangtok in east districts and there are there are few private medical institutions or clinics operating in the state that is catering to the health needs of the people (Department of Health Care, Human Services & Family Welfare, Government of Sikkim, 2014; Department of Economics, Statistics, Monitoring and Evaluation Govt of Sikkim, 2013).

The above paragraph gives a brief introduction about Sikkim and briefly discuss about the health care services in Sikkim. The following paragraphs discuss the scenario of tuberculosis in Sikkim.

## **2.2 Tuberculosis Scenario in Sikkim**

Tuberculosis is a major health concern of the state. According to Sikkim Human Development Report 2001 death of patients dying from Tuberculosis were recorded higher than the other diseases or illness that were prevalent at that time in the state referral hospital i.e., Sir Thutob Namgyal Memorial (STNM) hospital ( Sikkim Human Development Report, 2001). Despite the inception of modern treatment and public health intervention tuberculosis still remains or is the significant public health threat in the Sikkim state as over 1000 new case of TB incidences is being reported every year (Agarwal, 2015).

As stated by scholars like Epstein (2001) and Mirski *et. al.*, (2012) that the type of climatic condition recounting to certain geographical location plays a vital role in having an impact on the human health. Sikkim experiences miscellaneous weather conditions and a frequent rainfall and these types of climate encourage the tuberculosis pathogens to proliferate and disseminate. Investigation reports on Sikkim Tuberculosis health database relates that during the study from 2002 to 2010 in all the four districts of Sikkim; a total of 6827 cases were registered for pulmonary tuberculosis. Out of these cases, 6051 (88.6 %) were cured; 205 (3%) had died; 399 (5.8%) had failed; 124 (1.8%) had defaulted and 48(0.7%) were lost to follow up. The total retreatment rate of Sikkim is 1855 (27.1%) (Dolma *et. al.*, 2013).

The delay in seeking health care and the case of those patients who were lost to follow up leads to higher transmission and spread of the disease thus resulting in the increase in number of cases of tuberculosis incidence (Rai, 2012). The RNTCP report 2013 indicates that the state has 5 TB units, 20 designated microscopy centres, and 698 DOTs centres (State TB Cell Reports, 2013). However inspite of these curbing of Tuberculosis completely is still a

challenge for the Sikkim state. The total TB patients registered from 2009 – 2013 has been shown in the table below

Table: 2.2.1: Distribution of registered TB patients from the year 2009-2013

Indicators	2009	2010	2011	2012	2013
Total TB registered patients	1720	1646	1642	1832	1637
Cure rate	85%	86.9%	84%	84%	79%

Source: State Tuberculosis Cell, 2013.

The table 2.2.1 indicates the total Tuberculosis patients registered during the year from 2009 - 2013 and the cure rate during each year. It is clear from the table that highest cure rate was achieved in the year 2010; however there has been decrease in the TB cure rate from then onwards. The data depicts the variation in the total number of cases of registered Tuberculosis patients during different years. There are individuals who are infected with tuberculosis but are hesitate to seek medical help due to many problems like economic problems, social problems and various others problems. Therefore taking into account both the registered TB patients and those not registered, it can be said that a disease like tuberculosis is a major threat and one of the top killer disease in the Sikkim state despite having a cure for it and this might threatened the mortality rate of the state. The failure and default case has led to increase in number of MDR-TB (Multi drug resistance tuberculosis) and XDR-TB (Extensively drug resistance tuberculosis) in the state (Agarwal, 2014).

The above paragraphs present a brief description about the situation of tuberculosis in Sikkim and the following paragraphs deals with the socio economic profile of the respondents.

### **2.3 The Socio-Economic Profile of the Respondents**

The analysis of social and economic dimensions of the group under study is essential in understanding the burden of tuberculosis in the society. An attempt has been made to identify the socio-economic profile of the 150 respondents but in the work only the socio- economic profile of 80 respondents i.e., tuberculosis infected individuals has been described using interview schedule which involves variables like respondents age, educational qualification,

occupation, income, marital status, family type, housing status of the respondents, and the standard of living. This information on the socio economic background has been directly elicited from the tuberculosis infected individuals which has been portrayed in the following tables:

Table 2.3.1: Age Group of TB Infected Respondents

Age Group	Frequency	Percentage
15-35	52	65%
36-55	14	17.5%
56-75	9	11.25%
76-95	5	6.25%
Total	80	100%

Source: Field work, June- July, 2015

To begin with, Table 2.3.1 portrays an insight into the age-wise distribution of only 80 respondents i.e., the tuberculosis infected individuals. The table shows that the majority of respondents (65%) are in the age group of 15-35 followed by the respondents belonging to the age group of 36-55 and 56-75 each constituting 17.5% and 11.25% respectively. The 6.25% of the respondents fall in the age category of 76-95. It is clear from the available data that majority of the respondents infected with tuberculosis are between 15-35 years of age category.

Table 2.3.2: Educational level of the tuberculosis patients

Sex	Illiterate	Primary level	Secondary	Senior secondary	Graduate	Post graduate
Male	5	16	2	5	3	1
Female	15	23	4	2	2	2
Total	20	39	6	7	5	3
Percent age	25%	48.75%	7.5%	8.75%	6.25%	3.75%

Source: Fieldwork, June-July, 2015.

Education has been given top prominence in Sikkim. As per the Census (2011) Sikkim ranks among the highest, earning 13<sup>th</sup> place among all states in India recording literacy rate of

82.2%. Regarding the educational qualification of the respondents we can see that majority of the respondents (75%) are literate with varying levels of formal education. The data in the table 2.3.2 also indicates 25% of the respondents as illiterate. Amongst the literate, 48.75% of the respondents have received primary education and the respondents with secondary and senior secondary education form 7.5% and 8.75% respectively. There are few respondents with higher level of education i.e., 6.25% graduate and 3.75% post graduate. The educational qualification of the respondents is essential for understanding the level of awareness and perception of the disease among the people.

Table 2.3.3: Occupational Background of the Tuberculosis patients

Occupation	No of respondents	Percentage
Agriculturalists	20	25%
Govt. employee	6	7.5%
Business	3	3.75%
Students	16	20%
Private job	5	6.25%
Driver	4	5%
Labourer	16	20%
Unemployed	10	12.5%

Source: Fieldwork, June-July, 2015

After identifying different occupation, the research reveals that 25% of the respondents were engaged in agriculture and 20% respondents were labourers working on the contractual basis. 7.5% of the respondents were employed in state government services, some on regularised basis and some on contractual basis and 6.25% of the respondents had a private job. 3.37% respondents consist of small business owners and small proportion of respondents i.e., 5% were driver by occupation and 20% of the interviewed tuberculosis patients were students.

Table 2.3.4: Distribution of respondents by income

Income per month in Rs	Frequency	Percentage
Above 45000	2	2.5%
35001-45000	5	6.25%
25001-35000	1	1.25%
15001-25000	2	2.5%
50001-15000	35	43.75%
Up to 5000	9	11.25%
No Income	26	32.5%

Source: Field work, June-July, 2015.

Table 2.3.4 indicates that majority of the respondents i.e., 43.75% had the monthly income between Rs 50001-15000 followed by 11.25% earning up to Rs 5000 per month and 6.25% generating income between Rs 35001-45000 per month. 1.25% had monthly income around Rs 25001-35000. 2.5% had a monthly income above Rs 45000 and another 2.5% consist of income between Rs 15001-25000. It is clearly evident from the research that majority of the respondents are dependent on other for their needs as 32.5% of the respondents do not have an income of their own.

Table 2.3.5: Gender-wise distribution of the TB patients

Gender	Frequency	Percentage
Male	32	40
Female	48	60
Total	80	100

Source: Fieldwork: June-July, 2015

Most of the TB cases and death occur among men but the burden of this disease among women is also high. An estimated of 2.9 million new cases of tuberculosis and 410,000 deaths from the Tuberculosis were found among women (Global TB report, 2014). Table 2.3.5 represents the gender-wise distribution of the respondents. The available data shows 40% of the respondents who were infected by tuberculosis was male and 60% were female. This indicates that the burden of disease is equally high among the female patients.



Table 2.3.6: Marital status of the respondents

Marital Status	Frequency	Percentage
Married	22	27.5%
Single	55	68.75%
Divorced	3	3.75%
Total	80	100%

Source: Fieldwork: June-July, 2015

Table 2.3.6 highlights the marital status of the respondents infected with tuberculosis. Regarding the marital status the data enumerates that 68.75% of the respondents being single. 27.5% of the respondents were married and 3.75% were divorced or separated. It is also pertinent to cite that those infected with tuberculosis had some problems in their marital life as this is reflected by the presence of divorce or separation case among the patients.

Table 2.3.7: Distribution of respondents by religion

Religion	Frequency	Percentage
Hindu	37	46.25
Buddhist	41	51.25
Christian	2	2.5
Total	80	100

Source: Fieldwork, June-July, 2015

Sikkim is a multi cultural society with people following different faith. The table 2.3.7 shows that 46.25% of the infected individuals are Hindu by faith whereas 51.25% i.e., the majority of the respondents belong to Buddhist religion. The remaining 2.5% were Christian by faith. It is evident from the table above that respondents following the Buddhist religion were mostly infected with the disease.

Table 2.3.8: Distribution of respondents by family type

Family type	Frequency	Percentage
Nuclear family	44	55
Supplemented Nuclear family	31	38.75
Joint family	5	6.25

Source: Fieldwork, June-July, 2015

Table 2.3.8 portray the distribution of 80 tuberculosis infected persons into various family types. Data shows that 55% lives in a nuclear family whereas another 38.75% stays in supplemented nuclear family, which means that their mother or father or their unmarried brother or sisters are living with them. 6.25% living in a joint family were found. Therefore it can be stated that with the passage of time the trend for the nuclearisation of family is clearly evident among the people of Sikkim as this is indicated by the high prevalence of nuclear family among the respondents interviewed.

Table 2.3.9: Distribution of respondents by Place of Residence

Place of Residence	Frequency	Percentage
Rural	38	47.5
Urban	42	52.5
Total	80	100

Source: Fieldwork, June-July, 2015

Table 2.3.9 depicts that 52.5% of the respondents under study are from rural areas and the other 47.5% respondents are from the urban setting.

Table 2.3.10: Distribution of respondents by the type of house

Type of House	Frequency	Percentage
Thatched	7	8.75
Kutchha	14	17.5
Pucca	38	47.5
Semi pucca	21	26.25

Source: Fieldwork, June-July, 2015

The data on the type of house has been illustrated in table 2.3.10 given above. It is vivid from the table that 47.5% of the respondent live in pucca type of house whereas 26.25% dwells in semi pucca type. The other remaining 8.75% and 17.5% lives in thatched and kutcha house.

Table 2.3.11: Housing Status of the respondents

Housing status	Frequency	Percentage
Own house	23	28.75
Rented	57	71.25
Total	80	100

Source: Fieldwork, June-July, 20

As far as the respondents housing status is concerned, majority of the respondents (71.25%) lived in a rented house. The other remaining 28.75% of the disease infected individuals have their house.

Table 2.3.12: Source of drinking water Facility

Source	Frequency	Percentage
Public tap	8	10
Tap in dwelling	69	86.25
Pond, river, streams	3	3.75

Source: Fieldwork, June-July, 2015

Table 2.3.12 highlights the source of drinking water facilities of the respondents. The table shows that 86.25% of the respondents have their source of drinking facility from the tap in their house itself. However 3.75% of the respondent had their water source from the river, streams, and ponds nearby to their dwelling whereas around 10% uses public tap.

## 2.1 Conclusion

To sum up the analysis and discussion on the socio-economic profile of the respondents the following findings are observable. The research reveals that maximum number of sample infected with the disease fall under the category of 15-55 age groups and this might be considered as a matter of serious concern as this category age group is seen as the most productive segments of population. When it comes to the occupation, the sample sizes of 54

respondents were found to be engaged in an array of vocation. But at the same time the other 26 respondents were found to be dependent upon their family members as they did not hold any kind of jobs. The income level of the respondents varies as per the kind of jobs they were into; therefore the standard of living of the respondents varies according to their income level. Regarding the distribution of respondents into the gender type, the burden of such infectious disease was found to be high among the female as compared to male. Some variables of the social and economic profile of the tuberculosis infected people were thought or expected to be causing an impact on their life, health seeking behaviours etc., which will be conversed elsewhere in the other chapters.

## CHAPTER III

### A SOCIOLOGICAL ANALYSIS OF TUBERCULOSIS IN SIKKIM

The keen interest in the social and cultural dimensions of tuberculosis began due to industrial revolution and public problems associated with it (Vecchiato, 1997). It was no more associated with romanticism but was rather considered as a contagious disease, a disease always related with diet, deep notch, and pollution and to some extent unholy. It was disease which is attached with the stigma, socially produced by the society. The label 'TB' (Tuberculosis) incorporated into the personality of those individuals infected with the disease had an adverse impact on their lives. Tuberculosis was also considered to be a punishment or curse and was thought to be inflicted by other due to jealousy. It was considered to be a disease attached with stigma (Babbar, 2014; Dubos, 1959).

For deciphering or interpreting the sociological aspects of tuberculosis, the various works on stigma related to tuberculosis, gender differentials, level of awareness or knowledge, perception regarding the disease, and various methods used for treating the disease has been taken into consideration which has been discussed below in the following paragraphs in this chapter. Also a sociological analysis of Tuberculosis in Sikkim has been discussed based on the field work and empirical research done on 150 respondents in all the four districts of Sikkim using research techniques like observation, interview and collection of case studies. Information has been collected directly from the respondents which has been tabulated and analysed in the following:

#### **3.1 Tuberculosis and Stigma**

Tuberculosis is considered to be one of the most public health threats or problems across the world. It is taken to be a typical example of the disease with “both medical and social dimensions, characterized by its close relationships to the poor socio-economic living conditions and in many cases the individuals infected with the such infectious disease has to face many problems and one such problem which the tuberculosis infected persons faces is the stigma attached to the disease. Goffman describes stigma as an attribute that an individual possesses that is detrimental and discrediting which reduces an individual status from normal or usual persons to a discounted, tainted, polluted or infected one (Dhingra, 2009). There are

various works on tuberculosis related stigma by scholars like S.K. Babbar (2014), V.K Dhingra (2009), and Abebe et.al., (2010) etc., however despite such works and the excellent performance of RNTCP, stigma attached to tuberculosis is still a major problem and the main cause in delaying the initiation and adherence to treatment. Tuberculosis can be seen as highly stigmatizing which limits the social interactions of those infected with other normal individuals, thus encouraging or resulting in social isolation and exclusion (Druss *et al.*, 2000; Cogan and Herek, 1988).

Tuberculosis is considered as one of the major health issue in Sikkim. Social stigma surrounding TB is seen as a significant cause for delay and increase in number of TB incidence and higher transmission and spread of disease and deaths. Because of the stigma the infected individual and their relatives hesitate to disclose their disease to other member of the society (Rai, 2012). The interpretation of the data related to stigma surrounding TB which has been collected from the respondents in the field or research study has been analysed below using various variables which are as follows:

Table 3.1.1: Distribution of respondents who disclosed or undisclosed their disease

Variables	Frequency	Percentage
Disclosure of disease	87	62.14
Concealed the disease	53	37.85

Source: Fieldwork, June-July, 2015

As already discussed that tuberculosis is a highly stigmatizing disease and this stigma factors make the person infected with this disease conceal their sickness from other. Table 3.1.1 depicts the distribution of respondents who disclosed or concealed the disease. The available data shows that 62.14% of the respondents feel comfortable in disclosing the disease to the other people whereas 37.85% respondents preferred to keep people away from knowing their disease.

Table 3.1.2: Distribution of TB patients on the basis of sharing their disease

Person	Frequency	Percentage (%)
Family member	42	52.5
Close friends	16	20
No one	22	27.5
Total	80	100

Source: Fieldwork, June-July, 2015

People infected with tuberculosis hesitate to share their sickness to other people. Stigma associated with the disease places the infected individuals in a dilemma about their acceptance or rejection by the other or normal members of the society. It can be presumed that tuberculosis patients become secretive in sharing their disease to other. Table 3.1.2 indicates the distribution of the tuberculosis infected people with whom they shared their disease first. The table enumerates that 52.5% disclosed their disease first with their family members and 20% of them with their close friend whereas 27.5% did not shared their problems with anyone. 27.5% not sharing their problems with anyone around them reflects the apprehension associated with the disease.

Table 3.1.3: Problems faced by both the patients and their relatives due to nature of disease

Items	Frequency	Percentage
Avoidance	75	53.5
Difficulty in getting married	50	35.7
Problems on family members	72	51.4
Problems on marital life	25	17.8
Problems in education	20	14.2

Source: Fieldwork, June-July, 2015

Tuberculosis is a disease which people want to avoid. Besides avoidance there are many other problems faced by the respondents which has been identified and highlighted in the table 3.1.3 which takes into account the data from 80 tuberculosis infected people and their 60 relatives. The findings reveal that 53.5% respondents felt avoidance from their friends and neighbours. Another 35.7% of the respondent had problems in getting married whereas for

17.8% their marital lives was at risk as being infected with the may result in broken relationship taking divorce case as discussed in the table 2.3.6 in the previous chapter. The data also reveals that 14.2% of the respondents faced problem in completing their education resulting in drop out case which correlates with the table 2.3.2 in the second chapter that shows maximum number of respondents having received primary education and 51.4% felt that disease created problems on the family members. Thus the available data on stigma related to tuberculosis illustrates that tuberculosis is highly stigmatizing and to support this, the following case studies of the respondents have been described below and keeping in mind the ethical principle the sudo name has been used for the respondents in all the case studies described in this dissertation

#### Case Study I

Kritika Bishwakarma who works as a labourer at the constructions site felt stigmatised as she was infected with the disease. Being infected with the disease has affected her life a lot as she says “*My friends started to avoid me and even my husband broke up relations with me as he considers me to be a problem in his family. I am now living with my father but he worries about my younger sister marriage*”. Regarding the DOTS course, Kritika said that the PHC is very far from her village and she does not get time to go there regularly. She feels that having being infected with the disease is like a curse. She feels guilty about becoming a problem to her family.

#### Case Study 2

Sangeta a 14 years old student studies in a government school. After being diagnosed with the disease she did not disclose her disease to her friends at school. However due to long absence from the school, the disease was disclosed to her friends. When she joined the school she felt isolated and rejected as her friends started avoiding her. She says “*My friends call me ‘Tek Bahadur’<sup>1</sup> in the school*”. Her mother is very concerned about her as she has left the school and consoled her daughter saying that they will be putting her into the another school soon. However, deep insight Sangeta fears that in the new school also she will be facing same situation.

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<sup>1</sup> *Tek Bahadur*: it refers to a Nepali word and full form of TB used by some people and is just a sarcasm made towards tuberculosis infected people.



### Case Study 3

Pempa Lhamu Sherpa, 23 years old and is unable to speak and hear by birth. Her father is a farmer. He says that after her daughter is diagnosed with the disease, her mother is totally shattered and both the parents blame themselves for the situation or problems that their daughter is suffering from as she says *“It is because of our past actions or karma, our daughter is facing with so many problems”*. She is receiving her DOTS course from nearby primary health centre. They feel very bad when their daughter becomes the topic of gossip in the any functions held in the village and so they do not take her to any functions or gatherings in a village. Her mother with almost tears in her eyes says *“Many people often call her “lowdaray”<sup>2</sup>*.

### Case Study 4

Lakpa Sherpa, a resident of Tingley village in South Sikkim believes the disease to be a curse. He reminisces to the comment made by his friend as calling him “rogi”<sup>3</sup> bleat about the statement made by his friends that *“dead body of TB infected individuals should not be burned as the infectious disease of the dead person will spread to other people”*. Although, he did not react but he felt humiliated and stigmatised for being infected with the disease.

### Case Study 5

Kenrap lasopa is MDR TB respondent around the age of 20 years and is a drop out students and is staying in his aunt house as he do not like the way his step mother treats him. He always felt rejected and isolated as he has nobody to share his grievances and problems and says *“I have even tried to commit suicide because nobody loves me as I am infectious. my aunt gives me money to go to the DOTS centre sometimes but that is not sufficient for I have to go regularly to the centre for drug”* He tells that because of his relapse in treatment process his condition has become worst. Psychologically and physically he was feeling weak and believed that it is rather to die than to live such kind of life.

From the above case studies it can be said that stigma surrounding or attached to tuberculosis costs heavily upon the quality of lives of the people in terms of personal, interpersonal and social context. The stigma attached to the disease represented an importunate sticky situation

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<sup>2</sup> Lowdaray, refers to a Nepali term. This word does not have the exact meaning but an equivalent meaning of the term is bad luck or unluckiness.

<sup>3</sup> ‘Rogi’: It’s a Nepali word which refers to the person who is not in a good state of health.

in the lives of person affected by it. The term like ‘*lowdaray*’ and ‘*tek bahadur*’ categories an individual’s into certain using Goffman term “*social identity*” which can be said to be a significant factors in escalation of stigma. Having infected with the disease an individual has to face various level of rejection from families, friends, neighbours and society. There exists a fear of divorce or spoiled marriage prospects and also isolation at home that forbids sharing utensils or sleeping space. It can be drawn that the stigma associated with the disease produced pain which was can be considered more sensitive than biological disabilities associated with tuberculosis.

Stigma related to tuberculosis is extensive and the nature and pervasiveness of stigma likely reflects the local gender roles. Several studies like Perception of Gender and Tuberculosis in South Indian Urban Community by Ganapathy et al., (2007) Sociological Dimensions of tuberculosis by Babbar (2014) etc., shows that TB- associated with stigma is worse for the females than for male. However data on gender and tuberculosis relating to different variables has been analysed below:

### 3.2 Gender and Tuberculosis

Table 3.2.1: Gender wise distribution of Respondents related to Stigma

Gender	No of respondents	Percentage
Male	22	31.4%
Female	48	68.5%
Total	70	99.9%

Source: Fieldwork, June-July, 2015

The table 3.2.1 highlights the gender wise distribution of the tuberculosis infected people who felt excluded and experienced avoidance. Regarding the stigma experienced by the respondents, the sample size of only 80 tuberculosis infected patients has been taken into consideration and the data shows that 87.5% respondents have experienced being stigmatised after being infected with the disease which includes 31.4% male respondents and 68.5% female respondents. The remaining 12.5% respondents infected with the disease which has not been included in the table above did not experience any kind of stigma due to tuberculosis. It can therefore be stated that there is gender bias in the stigma being experienced by the disease infected individuals as it is pertinent from the above data that more women than the men felt being stigmatised due to the disease.

Table 3.2.2: Gender wise distribution of respondents who disclosed or concealed their disease

Gender	Disclosure	Percentage	Concealed	Percentage
Male	58	41.43	17	12.14
Female	29	20.71	36	25.71

Source: Fieldwork, June-July, 2015

Regarding the disclosure and concealing of the disease table 3.2.2 shows that 41.43% of the male disclosed their disease to other whereas 12.14% concealed the disease. 20.71% female respondents disclosed while 25.71% wanted to keep people away from knowing their disease. Thus, from the table it can be said that majority of the female than the male concealed their disease whereas regarding the disclosure about the disease more male than female were found to be comfortable in letting people know about their illness.

The respondents had their own valid viewpoints regarding gender and tuberculosis; however the case study of the respondents on gender and tuberculosis has been discussed below

#### Case Study 1

Nedup Bhutia responds “*Girls these days do not take a proper healthy diet so they become physically weak or not fit and easily attracts tuberculosis*”. Regarding men being infected with the disease he considers that as men have greater responsibility and bears the household burden and family burden and so because of these men are hit by such infectious disease. He says “*men do have enough time to rest; they are always busy and burden with families issues*”.

#### Case Study 2

Jigmee Bhutia holds a very different viewpoint. According to him “*addiction to smoking, drinking alcohol, drugs and indulgence into any other bad dietary habits cause TB*”. However he views that being born as a girl is a problem and being infected with the disease and termed as “*rogi*” is like a burden for the females. He regards that although both the genders are infected with the disease but women face more problems than the men.

### Case Study 3

Depika Biswakarma, a Hindu by religion regards the tuberculosis to be a very common disease which can be cured. She responded that *“being a girl from the low caste that too with such infectious disease is like a curse upon curse”*. She views that the disease has an adverse impact on all those infected people but the burden of it is more among the female than the male and she says, *“whatever may be the cause it’s the women who have to face the difficulty”*. Although tuberculosis is a burden on both male and the female but the disease cost heavily among the females than the male regarding various issues like marriage. From the above case study it can be drawn that both the gender hold different perspectives and both agrees upon the gender bias which an infectious disease like tuberculosis has retained.

Tuberculosis related to gender and stigma has been discussed above, however for deeper understanding of the sociological aspects it is necessary to comprehend the perception and knowledge of the respondents regarding the disease. Lack of knowledge or awareness about the disease is one of the significant factors in gender differences in concealing or disclosing the disease.

### 3.3 Level of Knowledge about tuberculosis

There are various factors which make people susceptible to disease. Knowledge regarding tuberculosis was focused to comprehend respondent awareness and understandings about the disease. The variables like treatment, preventive methods, and mode of transmission, causes, symptoms and type of disease were taken to identify the level of knowledge of the tuberculosis patients.

Table 3.3.1: Respondents knowledge regarding mode of transmission

Mode of Transmission	Frequency	Percentage
Airborne/droplet infection	81	54
Unclean food and water	21	14
Interaction with TB patients	23	15.33
Sitting on the hot stool of TB infected persons	21	14
Sex with the TB patients	4	2.66

Source: Field work, June-July, 2015

Regarding the mode of transmission of the disease table 3.3.1 shows that majority of the respondents i.e., 54% knew that the disease is transmitted through droplets infection whereas 15.33% considered it to be transmitted through interaction with another TB patients. 14% of the respondents opined that the disease was transmitted to people by consuming unclean food and water and another 14% respondents believed that the disease was transmitted by sitting on the hot stool of some person who is infected with tuberculosis and 2.66% respondents answered that tuberculosis is transmitted by having sex with the TB infected person. It can be said that respondents have their own perception about the mode of transmission of disease.

Table 3.3.2: Respondents knowledge about the symptoms of disease

Symptoms	Frequency	Percentage
Cough for 2 or more weeks	50	33.33
Fever	32	21.33
Chest pain	21	14
Weight loss	31	20.66
Blood in sputum	16	10.66

Source: Fieldwork, June-July, 2015

Table 3.3.2 shows that regarding the knowledge on the symptoms of the disease majority (33.33%) answered cough for 2 or more weeks followed by 21.33% as fever which is again followed by (20.66%) weight loss followed by 14% and 10.66% chest pain and blood in the sputum respectively which shows that respondents knew common symptoms of tuberculosis.

Table 3.3.3: Respondents knowledge on mode of prevention of Tuberculosis

Mode of Prevention	Frequency	Percentage
Use of mask	93	62
Limiting interaction with TB infected persons	27	18
Safe disposal of sputum	24	16
Avoid sex with TB Patients	4	2.66
Don't know	2	1.33

Source: Fieldwork, June-July, 2015

Respondents knowledge on mode of prevention indicates that the majority (62%) respondents answered that TB patients should use mask, followed by 18% respondents who felt that interaction with the TB patients should be limited and 16% regarded safe disposal of sputum as correct mode prevention and 2.66% view that any physical intercourse with TB patients must be avoided whereas 1.33% did not have any opinion on the mode of prevention of disease.

Table 3.3.4: Respondents knowledge regarding TB as a curable or non curable disease

Curable	Agree	Disagree	No Idea	Total
Frequency	65	50	35	150
Percentage	43.33	33.33	23.33	99.99

Source: Fieldwork, June-July, 2015

Table 3.3.4 depicts the respondent's awareness or views on tuberculosis as a curable disease or not. The available data shows that majority of the respondents (43.33%) considered that the disease can be cured whereas 33.33% respondents do not think that there is a cure for the disease. However, 23.33% respondents had no knowledge or idea about whether tuberculosis is a curable disease or not.

Table 3.3.5: Source of information about the disease

Source	Frequency	Percentage
Television	66	47.14
Health workers /medical professional	5	3.57
Internet	2	1.42
Newspaper	8	5.71
Friends	18	12.85
School	5	3.57
Cured persons/other persons	36	25.71
Total	140	99.97

Source: Fieldwork, June-July, 2015

Table 3.3.4 indicates that for 47.14% television was the source of information. 3.57% knew about the disease through health workers or doctors and another 3.57% from the school. 25.71% of the respondents heard about the disease from the cured TB patients and others while 12.85% of the respondents knew about it from their friends and 1.42% through internet. It was essential to comprehend the respondent's level of knowledge so as to interpret the respondent's awareness regarding the disease. The case study related to respondent's level of awareness about the disease has been described below:

#### Case Study 1

Deepa Basnet says that when she had persistent cough for two weeks, she did not take it seriously and took cough syrup from a nearby medical shop. However when her condition became worst she was then advised by her friend who had diagnosed with TB to go for a check up. After that she was diagnosed with the disease. She believes that the disease was transmitted to her from her friends as she responded "*I regret having sat in the stool where my friend sat*".

#### Case Study 2

Dil Bahadur, a relative of tuberculosis patients viewed that "*one should limit the interaction with the TB patients*" and he believes there is no cure for the disease as he remarks "*if once people get infected with TB then they will never be cured no matter what precautions they take up*".

#### Case Study 3

Chokey Bhutia, remarks "*it is now very common disease and can be cured but one needs to complete the drugs on time but at the same time maintain distance from the infected people*". She regards disease to be curable but at the same time also makes distance from her relative who is infected with the disease due to fear of being infected with the disease.

### **3.4 Perception about Tuberculosis**

Tuberculosis is also believed to be a curse upon the individuals because of his past karmas which seems to affect not only the individual's life but also the lives of other member of their family (Babbar, 2014). In the present study there were respondents whose entire family members were infected with the disease and they perceived that the disease has been passed

on to their families through generations. The following table shows the perception about the disease among the respondents.

Table 3.4.1: Distribution regarding the perception of tuberculosis among the respondents

Variables	Agree	Percentage	Disagree	Percentage
Curse	86	57.33	64	42.66
Hereditary	78	52	72	48

Source: Fieldwork, June-July, 2015

The table 3.4.1 enumerates the perceptions regarding tuberculosis of all the 150 respondents which includes the patients, relatives of the patients, and the health professional. Respondents had their own perception about the disease. Reflecting on the disease as curse, it was found out that from all the 150 respondents interviewed 57.33% respondents believed the disease to be a curse whereas 42.66% respondents did not agree the disease to be infected upon the individuals because of curse. The disease was also considered as a hereditary disease which has been passed onto the infected individuals from their past generations and this is clearly visible from the research done as the above data reveals that from those 150 respondents 52% respondents believed the disease to be hereditary which means that the person is infected with such illness because their past generations has suffered from the same disease and 48% respondents did not think that it was passed to them from their older generations. People had their own perception about the disease. Some thought it to be a curse while other took it to be a disease which has been passed onto them from their older generations. Respondent also had their own perception regarding the high incidence of tuberculosis among different religion. Few case studies have been done for better understanding the perception of the people regarding the disease.

#### Case Study 1

Tensung Palden Bhutia is economically sound person and his whole family is infected by the TB which includes his son, daughter and even his grand children. He perceives the disease to be a curse on his whole family members and he believes it as a result of his own past karma



or actions. According to him, only the ‘jhakri’<sup>4</sup> or ‘rimpoche’<sup>5</sup> can cure or save them from their curse and holds the opinion that medicine or the drug is not going to work upon their family. There is still a belief among the people that such curable disease is a curse which is highly attached with social stigma. He recollects that while communicating with his friends and neighbour he has come across many embarrassing situation due to the disease and regrets having done wrong to someone who was innocent as he remarks “*I wish I had not blamed and punished that innocent person and now my family is suffering because of me*”.

#### Case Study 2

Dal Bahadur Chettri, when giving his viewpoint regarding tuberculosis assumes migration to one of the significant factor in spreading and transmitting the disease. According to him, a disease like tuberculosis was inherited in Sikkim with the migration of large number of people from the Tibet. He also perceives those people who consume meat are highly infected with the disease.

#### Case Study 3

Comparing the above case study a contrary view was held by another respondent. Palden Norbu Bhutia, a Buddhist by religion had different perspective. He perceives tuberculosis to be highly prevalent among those individuals who do not eat meat particularly the Hindus. He believes that consuming ‘beef soup’ will cure the disease. He too considers migration to be the cause for spread of disease. Both of the respondents had their own myth or tale regarding the high incidence of tuberculosis among different religion but at the same time both holds same viewpoint about the spread of disease.

#### Case Study 4

Kunchok Lepcha, perceived the disease to be a hereditary disease and says that “*The disease has been transmitted to us from our older generations, it is in our blood. Our forefather suffered from the same disease and died due to it and we are also suffering now and in future our children will also suffer from the same*”. She also says that since the disease is hereditary, there is no escape from it and no medicine will be able to cure it.

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<sup>4</sup> ‘Jhakris’: They are the traditional Healers among the Nepali community.

<sup>5</sup> ‘Rimpoche’: the religious head among the Bhuddhist.

Factors related to stigma, gender difference, level of knowledge or awareness and perception of the respondents regarding the disease can be considered as a significant factor delay in adherence to treatment. Nonetheless being infected with tuberculosis was seen as imposing financial burden on the individuals. Although medicines are available free of cost during the treatment process the disease seems to have many other expenses (Singh, 2014). The financial burden of the disease is also been seen as a barrier in receiving health care by some respondents. Some case studies related to financial burden of disease has been discussed below:

#### Case Study 1

Bijay Subba responds that having being infected with the disease has affected his monthly family expenditure. He says that *“being the only bread earner in the family is a problem, medicine is free but who gives a free ride to go to the health centre for the medicine”*. He also says that half savings goes into paying the taxi driver and also buying nutritious vegetables.

#### Case Study 2

Deowkit lepcha, another respondent is a widow suffering from the disease. Even her two children is also suffering from the same. She remarks *“Having three TB patients in a house is a burden, economically and emotionally”* her saving goes in paying taxi fare to get the drug and buying vegetables as she says *“Vegetables these days have become so expensive and making expenses on taxi that too for three person regularly is a huge economic burden”*. She also recollects having stopped taking medicine for a month but as her son’s health became critical, all of them had to restart DOTS Course.

#### Case Study 3

Man Bahadur Subba, brother of a TB infected respondents considers that the disease has huge economic burden. In the words of Man Bahadur *“Since both our parents has expired so it’s my responsibility to look after my younger brother and sister. Medicine for TB id free but I have to give him taxi fare, buy healthy food and have to make extra expenses as he suffered from depression after being infected with TB”*

### **3.5 Conclusion**

To sum up the above discussion on the various issues which are thought to impact treatment of the TB patients, it can be highlighted that social stigma towards tuberculosis, respondent's level of knowledge and awareness about the disease, the perception about the disease; financial problem does affect the treatment process of the TB infected people. Stigma attached to the disease affected the marital lives of the individuals. Stigma surrounding the disease affected the education of the respondent. It can also be observed that the various term like '*lowdaray*'; '*tek bahadur*' and '*rogi*', identified the persons into certain categories and this can be said to be creating an inferiority feeling among those TB infected persons. There existed a gender differences in stigma being experienced by the respondents. Another generalization drawn from the above analysis is that being infected with tuberculosis not only affected the lives of those TB infected persons but it has its impact on their relatives too. Respondents had their own perception about the disease. They hold different perspectives regarding the disease as some thought it to be a curse while other took it as a hereditary. The study also depicts that some of the respondents were found to be afflicted by the depression due to the disease and so the respondents had to undergo financial constraints for availing treatment for the depression as observed from Dowkit's case and Man Bahadur case. Thus, all the factors given above could be said to a significant factor in delay in adherence to treatment or health care.

## Chapter –IV

### HELP SEEKING PATTERN AMONG THE RESPONDENT

#### 4.1 A Brief Introduction on Health Seeking Pattern

Sikkim government policies on health and family welfare are one of the well framed one which recommends on the better health care institution in the state. There has been a considerable improvement in the health institutions in the state since its merger with the Indian Union. The number of beds strength has expanded with a comprehensive array of specialised services. However along with the development in health care services and indigenization of western medicine, the traditional medicine or traditional system or practices continued to play a significant role in the treatment process. The ancient traditional medical system of treatment and of seeking help from the traditional for treating the disease, illness etc is still prevalent in Sikkim (Mckay 2004; Department of Economics, Statistics, Monitoring and Evaluation Govt of Sikkim, 2013). Sikkim is a multi ethnic society and thus it can be stated that help seeking pattern or behaviours may be related to the cultural or religious values of each ethnic groups.

In Sikkim system of healing and medical practices and their related cultural or religious values are centred on Sikkim's three major communities, Bhutia, Lepcha and Nepalis. Like for instance in Nepali community which is diversified into different sub groups there is "Jhakri", "Fedongma"<sup>6</sup> etc., as a traditional healers and "Pau and Nejum"<sup>7</sup> in Bhutia community and "Bongthing"<sup>8</sup> in the Lepchas and 'Jhar Phuk' is the key phrase or word for these influential faith healers. Regarding the help seeking pattern in Sikkim, traditional healing practices were found to occupy a significant position in the state. Therefore, Sikkim is also considered to be a land of faith healers. The Sikkimese people in many parts particularly in the remote areas seek the help of traditional healers before actually seeking help from medical practitioners (Lama 2001; Tobgay et. at., 2006; Panda & Misra, 2010; Sherpa et. al., 2014).

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<sup>6</sup> 'Fedongma' are the traditional healers in the Limboo community.

<sup>7</sup> Pau is referred to the male priest and Nejum refers to the female priest in the Bhutia Community

<sup>8</sup> Bongthing refers to male priest in the Lepcha community.

Traditional healers play a major role in help seeking pattern prevalent in Sikkim. A recent study conducted on the traditional healers in Ribdi- Bhareng, a place in the West Sikkim, it was stated that 8 traditional healers out of the total of 21 healers could cure or have formula for treating tuberculosis (Rai *et. al.*, 2014). The help seeking pattern or behaviours among the respondents has been discussed by evaluating number of respondents seeking help from the faith healers, reasons for seeking help from the healers, reasons for seeking medical help:

Table 4.1.1: Gender wise distribution of respondents seeking treatment from Traditional Healers

Gender	No of respondents	Percentage
Male	40	37.0%
Female	68	62.9%
Total	108	99.9%

Source: Field data, June-July, 2015.

Table 4.1.1 indicates the number of respondents who seek out for help from the traditional healers for treatment of tuberculosis. The table shows that from the total of 140 respondents which excludes 10 health practitioners, 77.14% respondents took help from the faith healers among which 37% of the respondents were male and 62.9% were female respondents seeking their treatment from the healers. The available data clearly portrays the gender differences or bias in preference for traditional healers for treating the disease.

Table 4.1.2: Reasons for seeking help from the Traditional Healer

Reasons	Male	Female	Total	Percentage
Not expensive	3	8	11	10.18
Stigma	28	49	77	71.29
Not aware of modern treatment	-	-	-	-
Parents decision	8	9	17	15.74
Doubt modern ways of treatment	1	2	3	2.77

Source: Field data, June-July, 2015.

Table 4.1.2 depicts the reasons given by those 77.14% respondents for seeking help from the traditional healers in treating their illness. The available data illustrates that almost all the respondents were aware of the modern ways of treatment; however 2.77% respondents doubted the modern method of treatment. the research reveals that majority of respondents (71.29%) seek help from traditional healers because of the stigma associated with the disease. 10.18% respondents consider traditional healing to be an inexpensive ways of treatment.

Table 4.1.3: Factors leading to TB health centre

Variables	Frequency	Percentage
Critical condition	29	36.25
Advice from other	28	35
Laboratory result	23	28.75
Total	80	100

Source: Fieldwork, June-July, 2015

Regarding the respondents going for a medical check up the table 4.1.3 illustrates the factors that maximum number of respondents 36.25% looked for medical help only when their health became critical whereas 35% respondents seek for medical help after the advice from the other. It was also found that 28.75% respondents seek for medical help immediately after they were diagnosed as being infected with the disease from the laboratory test.

The discussion on the help seeking pattern throws light into the important role played by the traditional healers in treating the disease. The faith healer does occupy a significant position and few case studies related to the importance of the healers has been discussed below:

#### Case Study 1

Wangchuk Bhutia, a 17 years old boy tells that at first his parents thought he was given “*thuk*”<sup>9</sup> and so immediately they seek help from the “*Pau or Nejums*” (traditional healers in the Bhutia Community). When his condition became worse, he was taken to head lama to see

<sup>9</sup> Thuk’: It is a Bhutia word meaning poison. There is a beliefs among some people , particularly the Bhutias in the North Sikkim that people give ‘thuk’ to other people inorder to to become rich and once the people giving the person having the ‘thuk’ has to give that ‘thuk’ to some person or the other, if it is not given then it’s believed to bring misfortune in that person’s life who have the thing called thuk..

“*jokhana*”<sup>10</sup> whether it’s convenient to seek for medical help or not and so on advice of head lama, he was taken to hospital and was diagnosed with the disease. Since then, he has been taking the drug but at the same time his parents also seek help from the healers. He regrets having gone to the hospital because he feels isolated and avoided by his friends but at the same time he fears that his disease might spread to his family members , so he excluders himself from others. Case Study 2

Nimkit Lepcha , a 65 years old respondents remarks “I am punished for disrespecting the ‘*Lungzee*’<sup>11</sup>” and therefore he seek help from the ‘*Bongthing*’ in order to be cured and also makes offering to the god so that he will be relieved from the punishment.

#### Case Study 3

Khedup Bhutia, 21 years old responds that when he was suffering from fever and had lost weight, his parents took help from the ‘pau’ (traditional healer) and they also performed “*phuphi*”<sup>12</sup>. He remarks “*my parents thought that it was because of the “shanday”<sup>13</sup> that I had fever and vomiting at the same time*”.

#### Case Study 4

Ramesh Sundas, responded that he had to take help from the healers as he was left with no other option. He says “*I waited for so long to get my wife admitted since her conditions was very critical but it was in vain as the bed would be reserved by other who is economically sound and has someone in the hospital through whom the seats would be reserved*”. Thus for him it was a necessary to seek alternatives help.

From the above given analysis and the case studies it is clear that traditional healers holds a dominant position if we take into consideration the help seeking behaviours or the pattern among the respondents. These healers are given first preferences in treating the illness. However besides taking help from the traditional healers the respondents had also their own

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<sup>10</sup> ‘Jokhana’, A Nepali term which does not hold exact translation in English but it somewhat means seeing fortune.

<sup>11</sup> In the Lepcha community, “*Lungzee*” is considered to be semi divine being or guardian spirits in the form of huge trees or a clusters of trees, grass, a tam, cave or small hill and other natural objects.

<sup>12</sup> ‘*Phuphi*’ is a rituals performed by the healers in the Bhutia community by offering money, clothes and eggs to demons or the evil spirits circulated thrice over the patients heads and thrown out.

<sup>13</sup> ‘*Shanday*’ refer to the Bhutia term, and there is no such exact meaning and translation of the word in English. However it somewhat means someone having an evil eye or intention on the other persons while the person is eating.

methods of treating the disease which has been discussed in the subsequent paragraphs. There are medicines which are developed based on the indigenous or the local resources filled with strong spiritual components.

## 4.2 Methods or ways of treating tuberculosis

Sikkim represents an exclusive eco-system rich in medicinal plants and in some rural parts of Sikkim, people use some of these medicinal plants or herbs in treatment of tuberculosis. For instance in, medicinal plants like ‘Kalo hardi’ and ‘Chimping’<sup>14</sup> is taken as a medicine by the tuberculosis patients (Panda, 2012). Nonetheless the present study also highlights some of the methods or ways the people has been carrying out in treating tuberculosis which has been given below. In some parts of the rural areas in Sikkim, people had their own method of treating the disease or any kind of illness.

Table 4.2.1: Distribution of respondents who uses local medicine in treating tuberculosis:

Medicine\ Method	No. of respondents	Percentage
Local medicine available		
Chimping	38	47.5%
Kalo hardi	-	-

Source: Fieldwork, June-July, 2015

The table 4.2.1 indicates the distribution of tuberculosis infected respondents who use local medicine for treatment. The table shows that the 47.5% of the tuberculosis patients has used ‘chimping’ as a tonic for treating the disease. The other medicinal plants were also known to some respondents but it was not used by any at present.

Table 4.2.2: Respondents having their own methods of treatment

Other local Method of treatment	No of respondents	Percentage
Monkeys meat	8	10%
Beef soup	42	52.5%
Fox flesh	3	3.75%

Source: Fieldwork, June-July, 2015

<sup>14</sup> ‘Kalo hardi’ and ‘Chimping ‘ are local names of the medicinal plants found in Sikkim and is used by the healers for tuberculosis patients and other sickness like fever diahorreas



Table 4.4.2 enumerates the respondents who have their own method of treating the disease. The research reveals that from the interview conducted 10% of people have taken monkey's meat for treating the disease. 52.5% of the patients have been taking beef soup since they were infected with the disease. From the 80 tuberculosis patients interviewed 3.75% of the respondents has eaten or were given fox flesh for treatment of tuberculosis. However to substantiate this data further, few case study of the respondents has been done.

#### Case Study 1

Mingma Tamang, another respondent around the age of 61 is a farmer by occupation, when he was diagnosed with the Tuberculosis he immediately did not take drug prescribed by the doctors but instead applied his own methods of treating the disease as he doubted the modern methods of treatment and seek help from the “*Jhakris*”. According to him, consuming the flesh of monkey is the best method of treating the disease which he learned from his past generations.

#### Case Study 2

Dipesh Gurung recalls having beef soup as a treatment for the disease. He remark “ *I was vegetarian but as soon as I was diagnosed with TB my mother convinced me to take beef soup*”. However he does not actually believe that this is going to cure him.

#### Case Study 3

Renuka Pradhan, a relative of TB infected persons responds that since going for a check up and waiting for laboratory test result takes a long time and so thinks applying their own methods of treating the disease will be convenient if they think that a person is showing symptoms of TB.

### **4.3 Conclusion**

Regarding the help seeking pattern, it was observed that in Sikkim people actually go and give their first preferences to the traditional faith healers before seeking help from the medical practitioners. The traditional healers occupy a prominent position and act as an effective mechanism in providing health care services to the people. Respondents also rely on their own ways or methods of treatment which they learned from their past generations.

## **Chapter-V**

### **ROLE OF STATE IN CONTROLLING TUBERCULOSIS**

#### **5.1 Introduction**

In the area of health, it is observed that Sikkim has added numerous feathers in her cap. There has been substantial development in the health care infrastructures and in meeting the unmet needs of the people. The services are provided free of cost to the people through various hospitals or PHCs or PHSCs. Sikkim can blow its trumpet for being the only state to achieve the National Norm of establishment of 1 PHC for 20,000 populations and 1 PHSC for 3000 (Sikkim Human Development Report, 2001). Sikkim follows the guidelines of government of India regarding health related issues. It is well known that government has a significant role in formulation of innovative health policy and in implementing an effective capacity for preventing the epidemic of diseases. The government policy in public health services has always remained a major process of Human Resource Development. Through the intensive act of the Government, the major health problems like leprosy, malaria maternal and child mortality, tuberculosis and human immunodeficiency virus (HIV) has been addressed or acknowledged. Since Independence, a rapid stroll has been made in improving the quality health services to the people. Government has achieved success in controlling communicable disease.

The role of Revised National Tuberculosis Control Programme in minimizing the epidemic of tuberculosis cannot be ignored. The programme has made tremendous progress in decreasing the number of deaths cases. Taking into account the above discussion on the role of RNTCP, the following paragraphs of the present chapter make an attempt to study the role of public policy i.e. RNTCP in controlling the epidemics of tuberculosis in Sikkim. At the outset the basic principle to control the disease is to identify people with infectious TB and to cure them so that others are not infected with the disease. Therefore the first target is the 85% of cure rate of TB. A detail about the programme has been discussed below:

## **5.2 Revised National Tuberculosis Control Programme (RNTCP):**

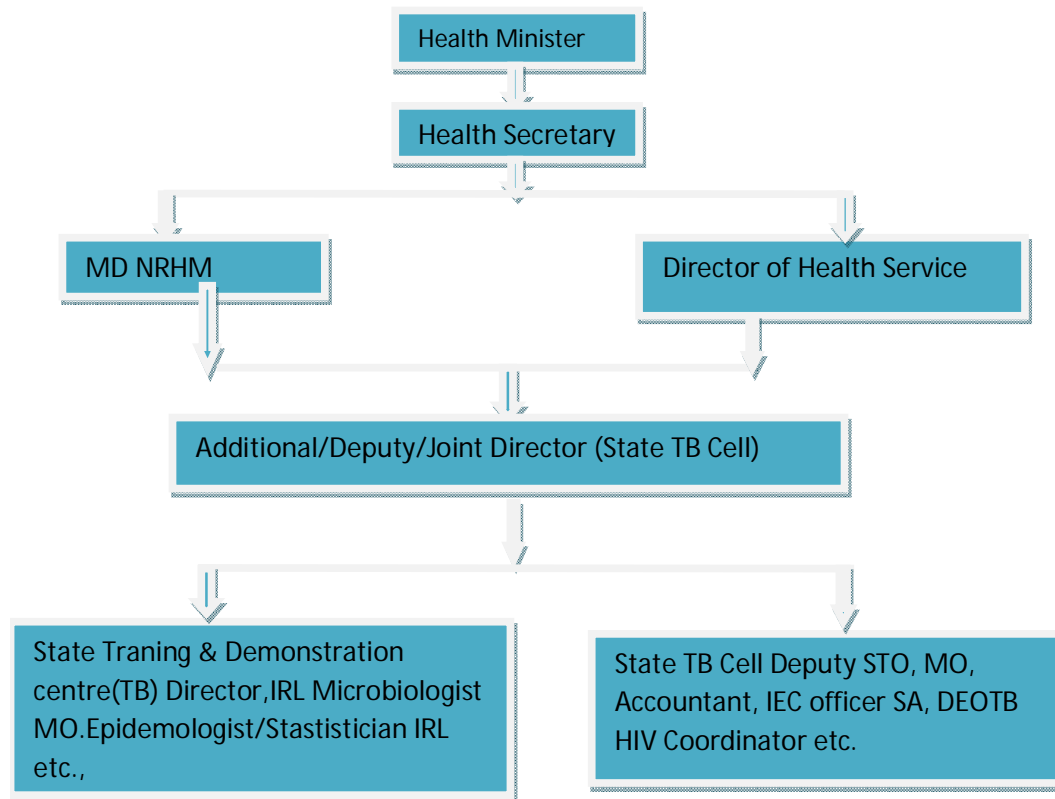
Revised National Tuberculosis Control Programme is a revised strategy of National Tuberculosis Programme by the government of India for controlling the pestilence of tuberculosis. The programme is an application of WHO recommended strategy of DOTS in India. This programme was launched in 1997 and expanded across the country in phased manner. The full nationwide national coverage was achieved in March 2006. The goal of TB control programme was to decrease mortality and morbidity due to tuberculosis and cut transmission of infection until TB cases to be a major public health problem in India. The objectives of the programme was

- To achieve and maintain the cure rate of at least 85% among new sputum positive (NSP) patients and
- To maintain and detect tuberculosis cases at least 70% of estimated NSP cases in the community.

Revised National Tuberculosis Control Programme started as pilot in October 1993 and it was first implemented in a population of 2.35 million in five sites in different state of Delhi, Kerala, West Bengal, Maharashtra and Gujarat. It is considered to be the largest tuberculosis control programme in the world placing more than 100,000 patients on the treatment every month (Dolma et al., 2013). The annual report to the people on health reports that under RNTCP, TB mortality rate reduced from 5 lakh deaths every year from the beginning of the programme to 2.8 lakh despite population growth (Ministry of Health & Family Welfare, Government of India 2011). Civil Society Perspective of TB Care & Control in India: Challenges & Solution Report (2011) state India as successful in improving access to TB detection and treatment across countries under RNTCP, based on the strategy implemented through general health system of the state under National Rural Health Mission. The organizational structure of RNTCP in the state level has been shown in the Figure 5.2.1.

Figure 5.2.1: The Organization Structure of RNTCP at the State level:

**RNTCP Organization Structure: State Level:**



Source: RNTCP, Government of India

**5.3 RNTCP in Sikkim**

Sikkim was brought under the umbrella of the Revised National Tuberculosis Control Programme from 1<sup>st</sup> March 2002 and the programme has recently adopted a new strategy of universal access to quality diagnostic and treatment to all tuberculosis patients covering all four districts. Under RNTCP/DOTS the cases of patients dying from the disease, failure cases and the defaulted cases amongst the TB registered patents were recorded to be smallest in Sikkim and highest while taking into account the annual smear positive detection rate (RNTCP, Annual Report 2011).

To attain the objective of RNTCP in the state a defined infrastructure has been established in the state. The state has State TB Cell that oversees the RNTCP programme which is headed by Additional Director-cum State TB Officer and District Tuberculosis Officers oversee the TB control activities of the all the four districts. Five tuberculosis unit which is a nodal unit in

TB control programme where registration of patients are done have been set up in the state and at present there are 31 microscopic centre out of which 20 are designated funded by dual source. Programme components are funded by World Bank via Central TB Division DGHS, as centrally sponsored scheme. State Government provides funds for basic infrastructure for delivering services and payments of salaries for regular and MR employees. The funds provided by World Bank are channelled through State Health Societies –NRHM (RNTCP). Funds are received in State Health Society and allocated to Districts Health Societies as per RNTCP guidelines (State TB Cell, 2014; Department of Health Care, Human Services & Family Welfare Department, Govt of Sikkim 2014). The number of TB patients registered during the month from January to June has been given in the figure 4.3.1. The figure gives the data of the TB patients registered during the month of January 2015 to June 2015 collected from the DTC (District Tuberculosis Centre) from all the four district of Sikkim.

RNTCP has been playing a significant role in controlling the disease. It has implemented PMDT (Programmatic Management of Drug Resistant TB) DOTS Plus erstwhile in all the four district of the state. The PMDT is programmatic management of MDR TB patients using the RNTCP standardized regimen of second line drugs supplied by government of India. Further the programme have achieved following milestone in managing such patients:

- a) Intermediated Reference Laboratory (IRL) has been established and all the equipments have been installed and shall be functioning soon. The Gene X Pert machine (it is a fully automated machine for diagnosis of MDR TB within 2 hrs) shall be established at IRL, STNM. Microbiologists and laboratory have been trained at TRC (TB Research Centre), Chennai and NTI, Bangalore.
- b) The ten bedded DR-TB Centre (MDR TB ward) is established at STNM hospital complex and is plan and functioning since February 2012 for the management of MDR TB patients registered under PMDT.
- c) The state Level Coordination Committee and the DOTS Plus Site Committee have been established.
- d) Central registration for MDR TB patients has been established at STNM hospital to ensure the proper follow up of MDR TB patients registered under the state.

The RNTCP, in Sikkim has been contributing a lot in controlling or curbing the distressing health issues like tuberculosis. The ASHA or Accredited Social Health Activists, initiated under NRHM (National Rural Health Mission) also has a significant role in controlling

tuberculosis. They provide TB drug or medicine to the people infected by the disease at the doorsteps particularly in the rural areas. However despite of such programme and health activists' disease like tuberculosis is spreading and increasing day by day and. Though RNTCP at present records promising result in cure rate of the disease, it also aims at improving and achieving 85% cure rate of such case. However to maintain this, the programme had set up five strategies (2013-2014) which are as follows:

- a) Strengthen the quality of DOTS in the state.
- b) Expedite the functioning of the Intermediate Reference Laboratory for the culture and sensitivity testing for DOT-Plus programme and subsequently to incorporate liquid culture and other latest molecular methods.
- c) Enhancement and intensification of the Advocacy, Communication and Social Mobilization (ACSM) activities at community level.
- d) Plans for elimination of TB with three broad components:
  - TB Central Registry
  - Community Participatory Education Programme
  - Migrant Labour Monitoring Programme.The elimination level is placed at less than 1 case per 10,000 populations by 2017.
- e) Establishing additional DOTS Plus site at Namchi Districts Hospital (State TB cell, 2014).

In the light of above discussion, it can be said that under RNTCP the state has made achievement in terms of infrastructure, and management of MDR TB patients. However against the milieu of such achievements under RNTCP, prowl the harsh realities of Tuberculosis still being the dominant disease constituting major public health issues as over 1000 new case of TB is been reported in the year 2014 (Agarwal, 2014). Various awareness programmes and activities are held on World TB day in the state with different theme in controlling the disease. Figure 5.3.1 shows images of awareness programme held on world TB day:

Figure 5.3.1: Awareness Programme held in the State in World TB day



Source: RNTCP, 2012-2015, government of Sikkim

RNTCP has been organizing various programmes in the state for making people more aware about the disease. However a contrary perspective was found among the respondents regarding the awareness programme. For some respondents such awareness programme seems to have an adverse impact on their interactions with the people. In the words of Pempa,

one of the respondents *“awareness programme is good but it will make us feel more isolated as people will avoid us”*. While the other respondents perceives that such awareness programme is necessary to make people more aware about the disease, for instance Dawa Sherpa a TB infected respondent opines that *“ people should be aware of such disease so that they will not suffer like I am suffering now”*.

#### **5.4 Health Practitioner’s views on relapse, default and increase in incidence of Tuberculosis**

Various reasons were mentioned by the health practitioners for alarming increase in number of case of tuberculosis. In the words of one of the doctor, *“People are not conscious about their health and their delay in seeking proper medical help is one of the reasons for maximum number of TB case”*. She also stressed that that the habit of spitting everywhere also spread the disease which leads to number of cases.

The carelessness of people about their health is considered to be another major problem among the tuberculosis infected people. One of the ASHA members says that she finds problem with the alcoholic patients as some patients often discontinue their drug regime. She says, *“Some do not want to give up drinking habits and they discontinue their course and so now they are suffering from Multiple Drug Resistance Tuberculosis”*. Other health practitioners also considered discontinuation of the disease leading to MDR TB and XDR TB.

The environmental or the geographical location also plays a major role in having an impact on the human health as responded by one of the Doctors. She says, *“When it’s cold and rainy people normally close the windows and doors and stay very cosy which influence the incidence of infection and their proliferation among the patients which leads to increase in number of TB case and also MDR TB and XDR TB and thus people have wrong notion that TB is hereditary”*.

One of the health practitioners considers that working with the TB patients particularly with MDR TB and XDR TB patients is a challenging job for her. She says *“ Being with them always and making them aware about the spread, transmission and prevention of the disease is a high risk as I might also get infected with it”* . Regarding the relapse or default cases she says *“some patients after taking few months course starts to feel better and thus discontinue*



*their drug and only after a year when their health starts deteriorating they come to continue their medicine”*

Regarding an increase in number of TB incidence, one of the doctors said “ *The TB infected people use mask only at the TB centre or hospital, many of the patients do not use mask in the public places, may be they feel awkward and so the disease is spread resulting in number of TB incidence”.*

From the responses given by the doctors it can drawn that people need to cautious regarding their help seeking behaviours or pattern. Awareness programme could help in giving information regarding spread, prevention and transmission of disease which could also help in building up people knowledge about the disease making them more careful.

## **CHAPTER-VI**

### **CONCLUSION**

Tuberculosis is one of the oldest and infectious diseases which have co-evolved with humans for millions of years. It is one among the top killer disease in the world and is a second leading cause of deaths worldwide nearly killing 1.4 million people per year. It account for 40% of all mortality from communicable disease representing 44,000 deaths largely because of the prevalence of MDR TB and XDR TB (Sandhu 2011; WHO, 2013). Tuberculosis has been one of the major public health concerns. Although various strategies has been adopted to control the epidemic but still the global burden of the disease remains very high. It is still a major public health problem with grave socio-economic consequences (Rahman, 2010; WHO, 2013).

The disease was also taken to be highly stigmatizing. In India the disease was always perceived in shades of grey. It was always thought as dirt and highly contagious. The disease was one of the devastating public health problems and a significant cause of death in the country. To curb such problem, Revised National Tuberculosis Control Programme was launched by Government of India which was on internationally recommended Directly Observed Treatment Short Course Strategy, along with various other strategy and programme and awareness campaign related to tuberculosis (Babbar, 2014). However despite this tuberculosis remains a major public health threat.

There is resurgence of tuberculosis all over the world and this reappearance of the disease is not exceptional to the state of Sikkim too. Tuberculosis is one of the major health problems in Sikkim and it seems to be affecting the quality of life of the people. Looking at the scenario of tuberculosis in Sikkim, there are epidemiological data or information about this disease but the information on its sociological aspects is very limited. In the view of this, the present study is premeditated towards understanding the social meaning and implications of tuberculosis in Sikkim. The study divulges that tuberculosis is a major public health concern and it affects the quality of lives of those infected with the disease.

The analysis on the data concerning the socio-economic profile of the respondents reveals that the most productive portion of the population are infected with the disease as majority of the respondents infected with the disease belonged to the age category of 15-55. The research

also reveals that majority of the respondents were found to be literate with varying levels of formal education and maximum number of respondents was engaged in an array of vocation and their income varies as per their job they were engaged in. The standard of living of majority of the respondent was found to be moderate class as many of the respondents were earning below 15000 and most of them were living in a rent. The majority of the respondents infected with the disease were female and majority of the respondents were found to be single. The study also highlight that majority of the respondents infected with the disease were found to be Buddhist by religion.

The field data concerning the level of awareness and perception regarding the disease among the respondents reveals that majority of the respondents were aware or had knowledge regarding mode of transmission and mode of prevention and almost all the respondent were aware of the common symptoms of tuberculosis. However many of the respondents had their own perception regarding the mode of transmission and prevention of tuberculosis like sitting on the hot stool of other person as mode of transmission and limiting interaction with infected person as mode of prevention. The research also throws light on the respondent's perception of the disease as a curse and majority of the respondents considered the disease to be hereditary. The research also shows contradictory assumption regarding cause of tuberculosis, lack of intake of non- vegetarian diet is cause for high incidence of Tuberculosis among the Hindus and on the contrary high incidence of Tuberculosis among the Bhutia is due to intake of non-vegetarian diet. However this perception is very subjective which reveals the respondents being bias towards their own religion. The study has also revealed the misconception and myths surrounding the cause and spread of tuberculosis. Respondents hold beliefs that tuberculosis was acquired because of respondent's indulgence in smoking and drinking alcohol which is socially not acceptable. This shows the lack of knowledge and awareness among the respondents regarding the disease which can lead to failure in receiving appropriate treatment.

Based on the empirical observation and field data concerning the help seeking pattern prevalent among the respondents, the basic findings is that the traditional healers were given much preference. The reasons given by the respondents for seeking help from the healers was stigma attached to the disease; inexpensive way of treatment; parent's decision; reservation of seats in the health centre; long period of course; and doubt in the modern methods of treatment. Gender bias was observed in seeking help from the healers as majority of the

respondents seeking help from the healers were found to be female. The study reveals majority of respondents seeking help from the healers when the health of the person became critical. The study also highlights various other methods of treatment employed by the respondents. Consumption of monkeys and fox meat and beef soup was considered to be a medicine for Tuberculosis infected persons, even though this could not cure the disease but still people carried on this methods as this seems to be passed unto them from their past generations. This shows the respondents delay in seeking proper help which ultimately results in deteriorating the health of the disease infected individuals, spreading the disease and leading to an increase in number of Multiple Drug Resistance Tuberculosis and Total Drug Resistance Tuberculosis.

Analysis of the field data concerning the impact of disease on the economic status of the infected persons shows that tuberculosis does have financial burden on the individuals the study shows that the family expenditure of the respondents being affected due to the disease. Despite the free DOTS course, the disease had financial burden on the individuals affecting their lives as respondents had to make expense in buying nutritious food and giving taxi fare to reach health centre. This shows that being infected with the disease cost heavily on the respondent's financial status which might be one of the reasons for the default or relapse cases.

Regarding the objective of comprehending the impact of stigma and its influences in the interactions of the TB infected individuals and others; the study has revealed that tuberculosis is highly stigmatizing disease as almost all the respondents has experienced being stigmatized due to the disease. It was observed that stigma associated with acted as a hindrance in disclosing the disease. Being infected with the disease was debilitating for the females involving divorce and broken engagements. This shows that the burden of stigma due to the disease was found to be present more among the females than the male. Because of the stigma surrounding the disease the interaction with other in Goffman term normal or non-stigmatized people was also limited. This reveals that stigma related to tuberculosis does influence the interaction which can be considered as creating inferiority feeling among the infected individuals. The study also throws light on the consequences of stigma affecting the help seeking behaviours among the respondents. The research also reveals that respondents isolated themselves so that others will not be infected. The case study of the respondents reveals the problems they faced after being diagnosed with the disease. Education of the

respondents was affected and even one of the respondents had to give up her job due to the disease. This shows that the stigma linked to the disease affected the lives of the people resulting in many social problems. Stigma was also seen as hindrance in adherence to treatment and due to fear of being stigmatized persons often delay in seeking help leading to an increase in number of TB incidence. As regards to the objective of exploring the gender differential in treatment process, the study shows the gender bias in treatment of the disease. Majority of female seek their help from the traditional healers for treating the disease due to fear of being stigmatized. The field data also reveals that the burden of disease was high among the female. The majority of the respondent infected with the disease was also female as per the data collected from the field. The nature of stigma surroundings the disease also affected the gender roles.

Despite the role of public policy in controlling the disease, tuberculosis is seen as a major health threat. The above discussed all the variables are responsible for delay in the initiation of treatment, default or failure; and relapse resulting in number of MDR and TDR TB and also deaths case due to the disease. Hence the study highlights the need to endeavour into multi- dimensional aspects of the disease and a further research with larger sample size may produce more precise and insight into the social meanings and implications of tuberculosis which could be helpful in making people aware about the disease and in curbing the problems faced due to the disease. Based on the research observation and the findings some suggestions have been given below:

**Suggestions:**

- Counselling should be given to the patients so that they will not be depressed due to the disease
- MDR TB patients and XDR TB patients should be kept separately as it was observed or found during the research that both the patients staying together makes the environment more unhealthy.
- Awareness programme should be organised twice or thrice in a year focusing more on those areas where TB incidence is high, it should not be organised only on world TB day
- While organizing the programme the issue related to stigma, myths and health seeking pattern should be taken into consideration

- Allocation of beds to the patients should not be reserved as it was observed that patients having to wait for the beds for two days outside the centre as this could lead to patients negligence towards the health centre and seek alternative help which often leads to spread of disease and increase in number of MDR TB and XDR TB
- Both the medical practitioners and traditional healers should work in coordination to fight TB.

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### Questionnaire for patients

1. Name:
2. Sex:
3. Age:
4. Occupation:
5. Education:
6. Income:
7. Marital status:
8. Religion:
9. Housing conditions:
10. Which type of TB were/are you suffering from?
  - a) Pulmonary Tuberculosis
  - b) Extra Pulmonary-Tuberculosis
  - c) No Idea
10. Why do you think you are suffering from the disease?
11. Do you think that being infected with TB would affect your chances of getting married?  
If yes in what ways
12. What was your first reaction when you came to know about your disease?
13. What was your spouse' first reaction when he/she came to know about the disease?
14. Who disclosed/how you came to know about your disease?
  - a) Parents
  - b) Doctors
  - c) Relatives
  - d) Other
  
16. Which of the following places did you visit for confirmation/verification about your disease?
  - a) Medical shop / drug retailer (MS/DR)
  - b) Govt. Primary Health Care Centre (PHCC)
  - c) Govt. Hospital (GH)
  - d) Private Hospital (PH)
  - e) Private Clinic of a registered medical doctor (PC)

- f) Traditional healer (TH)
- g) Private health worker (PHW)
- i) Village level health worker (VLHW)
- j) Others ..... (Please specify exactly)

15. Which of the following places do you trust more to cure the disease at better efficiency rate? And why/

- a) Medical shop / drug retailer (MS/DR)
- b) Govt. Primary Health Care Centre (PHCC)
- c) Govt. Hospital (GH)
- d) Private Hospital (PH)
- e) Private Clinic of a registered medical doctor (PC)
- f) Traditional healer (TH)
- g) Private health worker (PHW)
- i) Village level health worker (VLHW)
- j) Others ..... (Please specify exactly)

16. Have you discussed you health condition with the other family members?

- a) Yes b) No

If no why

18. Does your neighbours know about your disease?

- a) Yes b) No

If yes were there any changes in their behaviours. Y/N

If no then why

19. Does your working colleagues know about your disease? Y/N Why

20. Does your friends know about your disease? Y/N Why

21. Are / were you in the same job even after being diagnosed with the disease? Y/N Why

22. Was any kind of social ceremony/ campaigning held in your locality regarding the disease? Y/N

23. Did / do you go for routine check up? Y/N

24. Where did you go for routine check up?

- a) DOTS Centre
- b) Self Medication
- c) Primary Health Centre (PHC)

d) Private clinics

25. Do you feel excluded after being infected with tuberculosis?

a) Yes b) No

If yes in what ways are you excluded

26. Have you incur any debt for seeking the treatment.

a) Yes b) No. If yes then how much and why did you have to incur debts

27. What is your relation with your friends after being infected with the disease?

A) Close, b) not close, c) any other specify. Why

28. Has being infected with the disease affected your social life?

a) Yes b) No

If then in what ways and why

29. Mode of transportation used when assessing the treatment.

a) Walking b) motor vehicles c) car d) any other specify

30. How long does it take you to go and collect your drugs on each visit?

### **Questionnaire for representative of the patient**

1. What was your first reaction when you came to know about your relatives' disease?

a) Shocked

b) Serious

c) Normal

d) No reaction

2. Who gave you the first information about his/her disease?

a) Family member

b) Through other people

c) Patients themselves

d) Relatives

3. Does your near one being infected with the disease affect your social life?

a) Yes b) No

If yes then in what ways

4. How has the community reacted after him/her being infected with the disease?

5. Why do you think that the community members are reacting in this manner?

6. What is your perception regarding the disease?

- a) Curable
- b) Hereditary
- c) Not curable
- d) Curse/ punishment of past deeds

Why do you think so?

7. Who accompanies the infected to the hospital?

- a) Mother
- b) Father
- c) No one
- d) Brother/ Sisters

8. Do you have a separate room for the patients?

- a) Yes
- b) No

Why?

9. Have you kept a separate toilet for the patients?

- a) Yes
- b) No

Why?

10. How did you come to know that the patient was suffering from TB?

11. Where did you first seek the help from when the patients was suffering from the disease?

- a) Traditional healers
- b) Doctors
- c) Self medication
- d) Any other specify

Why

12. Does being infected with the disease affect the education of the children in your family?

- a) Yes
- b) No

How and Why

13. Did you find any changes in the behaviours of the patients after being infected with the disease?

- a) Yes
- b) No

If yes why do you think such change has occurred in the behaviour?

14. Were you able to disclose patient's disease to your relatives at first?

- A) Yes
- b) No

Why

15. Did you disclose the illness to your neighbour?

a) Yes b) No

Why

16. Do you think that having a TB patient in the house has affected your relation with others?

If yes in what ways?

17. Have you heard of RNTCP?

a) Yes b) No

If yes then is the treatment going under the RNTCP regime?

a) Yes b) No

If yes then what do you think of RNTCP?

18. What was the result of treatment from RNTCP.

a) Positive b) negative

19. Did any of your family member has being or is infected with the disease before.

a) Yes b) No

If yes how many

19. Do you take precautions while talking with the patients?

a) Yes b) No

20. Do you cook food separately for the patients?

a) Yes b) No

IF yes why

21. Do you also have separate utensils for the patient? Why

22. Does the person being affected by the disease affect your family expenditure?

a) Yes b) No

If yes then in what way does it affect the expenditure?

23. Were you concerned about your status when you knew about the disease in your family?

a) Yes b) No

If yes then in what ways and why?

24. Do you know about the DOTS treatment?

25. How do you make sure that the patient takes his/her medicine regularly?

Who gives the medicine?