

CHAPTER I

INTRODUCTION

1.1 Background of the Study

Tuberculosis (TB) is a major public health problem in the world, it was already declared as the global emergency by World Health Organization in 1993. In 2006, there were an estimated 14.4 million prevalent cases of TB in the world. There were an estimated 9.2 million new cases and 1.7 million deaths presented in the same year (WHO, 2008) In Nepal, about 45% of the total population is estimated to be infected with TB of which 60% are adult. Every year 40,000 people develop active TB, of whom 20,000 have infectious pulmonary diseases (HERD and MOHP 2011).

To control the TB problem WHO advocates the use of Directly Observed Treatment with a Short-Course drug regimen as part of the DOTS strategy (Dya et al. 1998) DOTS strategy as one of the most cost effective health interaction and recommends that effective TB treatment be a part of the essential clinical service package available in Primary Health Care. In Nepal, DOTS strategy has been implemented since 1996 (Subba et al, 2009).

Treatment by Directly Observed Treatment Short course (DOTS) has reduced the number of deaths. However, 5,000 - 7,000 people still die per year from TB (DoHS 2009/10).Through the Directly Observed Treatment Short-Course (DOTS) program has been operational in Nepal for more than a decade the burning of incident cases of TB is yet to register a significant fall (Panth et al, 2009).

The treatment process, treatment period and route of transmission of TB are key aspects that need to be manage properly. In order to improve the utilization of DOTS services public and private partnership has been taken as an important indicator (Tiwari, et. al. 2005). Defaulting from treatment result in persistent transmission of the tubercle bacilli within the community, increased morbidity and cost to TB control program. It can also lead to relapse and drug resistant TB (Bam et. al. 2005).

The government of Nepal, National Tuberculosis Centre developed a comprehensive National Strategy Plan (2010- 2015). The new strategy builds on the previous

national strategy and outlines enhanced and more focused commitment for tackling the TB epidemic consistent with new STOP TB strategy and Millennium Development Goals in line with the stop TB partnership target. The MGD has a target to control TB mortality rate 20 per 100,000 populations up to 2015.

1.2 Statement of the Problem

The rapid increasing of development in the health sector brings some innovative hope to cure the diseases and relief from pain. The possibilities in the health sector development increases day-to-day as lots of health organization, hospitals, educational institution as well as government and non- government agencies are involved in this sector. However, the parallel growing nature of health problems has new challenges that need to be tackling at a time. However, there are various programs and plans developed to manage the health situation but the people are not necessarily grasping its benefits due to social and cultural obstacles.

Tuberculosis is a socio- medical problem. High rate of people are infected by TB in developing countries. The SAARC region accounts more than the 29 percent of the global burden of Tuberculosis with 0.6 million death every year and two million new cases annually. Nepal by estimated number of case, is ranked at 27 globally (Subba et al, 2009).

In Nepal, by mid July 2011 a total of 4248 health institutions including 1192 treatment centers and 3126 sub treatment centers were offering DOTS provision of DOTS based TB control service (NTP 2010/ 11)

Directly Observation Treatment is one of the key components of the reducing TB strategy. DOT is, the patient should be directly observed as he or she swallows each dose of anti-TB treatment for at least the first two months to treatment by a train person. It is estimated that six out of 10 adults in Nepal are infected with TB (Bam et al 2005).

Relapse is another challenging part of TB. Nowadays many people become relapse cases after taking treatments under DOTS. Those who are confirmed culture positive during follow-up after cure are defined as a relapse (T. Yoshiyama et al) National

Tuberculosis Control Program Nepal (2010/11) reported 32,327 number of patient registered in different DOTS centers among them 2362 were relapse.

This study seeks to explore the perceived cause and consequences of TB relapse cases of Rupandehi District under the DOTS centers. In other word to explore the cause and consequences of TB relapse based on patents perceptions. Thus, this study has tried to find the answer of following research questions.

1. What are the perceived causes of tuberculosis?
2. How the previous TB experiences by the patients and what were mode of treatment?
3. What is the existing situation of relapse case?
4. What are the perceived causes of relapse?
5. What has been the consequence of relapse to individual and family?

1.3 Objective of the Study

The overall objective of the study is to analyze relapse cases of tuberculosis in Rupandehi district.

The Specific Objectives are as follows:

1. To identify the TB experiences and treatment practices perceived by TB affected persons.
2. To explore the perceived causes of relapse.
3. To analyze the consequences of relapse to the individual and family.

1.4 Significance of the Study

Tuberculosis is the commonest cause of death from infectious diseases. Seventy five percent of the mortality and morbidity due to the disease occurs in the age group of 15-45 years (NMJT 2003). The impact of tuberculosis is greatest on the poor; 99% of deaths and 95% of all cases occur in the developing world. The majority of people affected by TB are in the economically active age groups. Families and communities are loosing of their parents and their work force. Tuberculosis and poverty go hand in hand – people who get tuberculosis become poor (Smith, 1999)

A research in Nepal (HERD and MoHP 2011) stated that nearly one-fourth of family members (23%) of the people living with TB said that TB is a very serious disease while one-fifth of the members (20%) indicated the TB was somewhat of a serious disease. However more than two-fifth of family members responded that it is not a very serious diseases, and 14 percent of such members opined that they did not know how serious is the problem.

Modern anti-Tuberculosis drugs can cure most of the tuberculosis cases if proper doses are used for a sufficient period of time. However, in practice many cases are not cured (WHO 2005). The cure rate of tuberculosis in many developing countries is below the recommended target of WHO that is 85%. In present condition, official report show a 90% cure rate of tuberculosis in Nepal due to DOTS regime. However, there are many relapse patients still in Nepal. According to NTP, report (2009/10) there was total of 2,617 relapse clients reported in Nepal. The highest numbers of clients were present in Kathmandu district and second highest numbers of clients was Rupandehi district with a total of 122, consisting of 90 male and 32 female.

To the best of my knowledge, though many researches and studies have been conducted in tuberculosis the numbers of relapse cases are still unclear. In order to prevent clients from being relapsed it is really essential to prevent them on time (Atreya Indu 2009). In this research, I tried to identify the present condition of TB of relapse cases based on socio-cultural perspective and also tried to find out the cause and consequences of relapses. The finding of this research might be beneficial to practitioner, social scientist, community member, family members and other researcher who want to carry research in these sectors.

1.5 Organization of the Study

A total of eight chapters have been prepared for this dissertation. Chapter one introduces the research with its background of the study, statement of the problems, objectives of the study and its significance. In chapter two, I have presented some theoretical and empirical issues based on medical sociology and anthropology perspectives. I had reviewed some research literature of TB from nation to global context including some relapse literature, which helps to know about the condition of it. In the third chapter, I am dealing with the methodology that is used while carrying

the research. The fourth chapter deals with the general information of respondents according to their age, sex, ethnicity and TB types. The fifth chapter deals with the first objectives of the study by presenting some of data and information based on treatment experience and practices. The six chapter deals with the second objectives of research that is presenting perceived causal factor of TB relapse. Chapter seven deals with the third objective of the Study where I present information of consequences of TB relapse based on respondent perception and the last chapter eight includes a summary and conclusions.

CHAPTER II

LITERATURE REVIEW

Literature is main component of the research. It helps researcher or reader to know about root or epistemological part of the theory used in the research in order to give the shape of the study. In this chapter, I present some theoretical and empirical findings, which is related to medical sociology and anthropology. I have also included some research literature of TB, which is done at the national to global context including some relapse literature.

2.1. Theoretical Framework of the Study

At the previous, many medical researchers were conducting health research and they reported that health and health care system are totally belonging on biomedicine. Later many sociologists are interested to study on medicine and health sector issues. They claim that health and health care system are not only biological. According to Kleiman (1980): health care systems are socially and culturally constructed. They are forms of social reality. Social reality signifies the world of human interactions existing outside the individuals. It is the transactional world in which every-day life is enacted, in which social roles are defined and performed, and in which people negotiated with each other in established status relationship under a system of cultural rules. Social reality is constituted from and in term constitutes meanings, institutions and relationships, sanctioned by society. Social reality is constructed or created in the sense that certain meanings, social structural configurations and behaviors are sanctioned (or legitimated) while other are not.

Culture influences individual's medical knowledge. David Beine (2003) used cultural model concept on his research. He writes that cultural models are shared understandings about the way that are world works cultural models are mode up various biologically and cultural formed schemata that structure the meaning we associate with any experience. The application of culturally formed cognitive schemata produces a shared understanding of an event or phenomenon. He quoted (Shore 1996:315) that cultural model are better understood one kind of necessary resources by which people make meaning in their lives. From a cognitive point of

view, cultural models are salience-enhancing templates. They render certain kinds of experience perceptually significant and readily communicable within a community. But people may also have powerful experiences not directly predictable from any cultural model. And in the absence of a credible cultural model for making sense of a situation, individuals have the resources for schematizing their own models on the fly.

The movement of medical sociology towards greater closer connections with general sociology reflects the desire of a mature sub-discipline to expand its analytic capabilities and reinforce its potential. Changing social conditions associated with the transition in society from the postindustrial to the current late modern or postmodern period requires all of sociology to account for altered circumstances and formulate new concepts. This situation suggests that not only medical sociology connecting with general sociology, but that sociology is moving toward a closer affiliation with it – given the considerations of health increasingly evident in the everyday social lives of people and medical sociology’s capacity for explaining it. Under the current condition of social change, medical sociologists are making greater use of sociological theory because theory promotes the explanatory power of their empirical findings (Cockerham 2001).

Medicine continues to determine other social arenas the paradox of its possibility benevolence, its ability to save lives and its miraculous properties versus its capacity to support social inequalities to villains and victims and to entrench power differentials, becomes ever more evident. These contradictions are constantly operant when discussing the role played by medicine in society and has been particularly pertinent for women and other marginalized groups, to whose social position medicine has historically contributed. Medicine and culture tends to view non-western societies discourses and practices as socially constructed, but fails to recognize that the biomedical model dominant in western societies is equally a product of social relations (Deborah, 2003).

The sociological treatment of medical knowledge by sociologists of medicine themselves for long remained a stunned affair. Sociologist has still not produced a comprehensive and systematic analysis of most domains of medical knowledge, and core activities in the accomplishment of medical work. On the contrary, too much of the sociology of medical knowledge has been conducted at a high level of generality

and abstraction. There has been insufficient detailed empirical analysis of concrete example of medical knowledge in practice. There is now a small but rather muddled literature on the social character of medical knowledge, it is loosely grounded in contemporary sociologies of knowledge but uncertainly so. It is all too frequently couched in terms of rather ill focused appeals to constructivism realism materialism or whatever. There is a need for a careful appraisal of what is meant and what is possible within an adequate sociology of medical knowledge (Atkinsan 1995).

The Marxist tradition in the sociology of medicine specially attempts to link diseases to structural economic and political developments. Marxists argue that diseases and its treatment are the outcome of the capitalist economist system. The key text in the Marxist tradition is Friedrich Engels; *The Condition of the Working Class in England*. Engels argues that diseases are a direct outcome of capitalistic pursuit of profit at the expense of safety. By safety, he means not only industrial matters, but also housing conditions and food quality more generally. Engels drew together a wide range of materials in 'social medicine' and essentially laid the basis as sociology of health (Morgan 1995).

Cost and accessibility of the medical care is an important factor in influencing the choice of a tradition of medical care. In developing countries like Nepal, where the bulk of people live in poor economic conditions, the cost of specialist medical doctor, fees, pathological test and medicine are usually beyond their ordinary means. A large number of people living in the villages remains beyond the reach of this medical sector. When illnesses are minor, most people in Katmandu valley seek local healers or take over-the-counter; easily accessible and affordable medicines. Consequently, people often have to depend upon locally available medical facilities, which are within their geographical and economic reach. In such areas, locally available healers and their medications are within the economic means of people (Subedi 2003).

The above-mentioned paragraph indicates that medicine and health care issues are constructed from our society, which is the latest and important issue for sociological study. Tuberculosis is not out side this saying, as it is major problem of the world. Many research and published literature shows that people have describe and understand about disease and healing practices based on their local knowledge.,

believes system and their norms. So, this theory helps to understand, how social value and practices determine individuals perception of disease and illness.

2.2. Tuberculosis in World Context

TB is contagious disease like the common cold, it spreads through the air. Only people who are sick with TB in their lungs are infectious. When infectious people cough, sneeze, talk or spit, they propel TB germs known as bacilli, into the air. A person needs only to inhale a small of these to be infected. Left untreated, each person with active pulmonary positive TB will infect on average between 10 and 15 people every year. (WHO 2010).

Among five continents, Asia accounts for 55% of the global cases, Africa 31%, the other three continents account for a the relatively small fraction of the global cases. However, Africa is the second global burden continent; it has the highest incidence rate of TB per capita, 363 per 100,000 populations. The high incidence rate in the African region is partly explained by relatively high rate of HIV co-infection. HIV co-infection rates are higher in adult population: they are also estimated to be higher among new TB patients. India, China, Indonesia. South Africa and Nigeria rank first to fifth respectively in terms of absolute number of case (WHO 2008).

TB has become one of the major public health problems in South Asian countries. The South East Asia Region (of the WHO) account for nearly 38% of the world's tuberculosis cases, with 3 million new cases and nearly 750,000 deaths occurring annually. Among adults in this region, TB is the commonest cause of death from infections disease; 75% of the mortality and morbidity due to the disease occurs in the age group of 15-45 years. The scourge of HIV infection and the emergence of drug-resistance have further complicated the issue (Chaudhari and Thatte 2003).

Among the country in the South East Asia Region, Bangladesh has one of the highest burdens of TB in the world. Bangladesh introduced Directly Observed Treatment Short course (DOTS) in 1993. Despite enormous efforts to combat tuberculosis since, the country still ranks sixth among the 22 TB high burden countries. In 2001, the Bangladesh NTP estimated that 300,000 people or 0.25 % of the population become ill with TB with 7000 (0.05 % of the population) died of TB (Zafar et al 2010).

India has almost 30% of the global burden of TB; one person dies of the diseases every minute in the country. India has mounted the second largest DOTS programme in the world to control this disease. Even so 2 million people develop the diseases every year. (Chaudhari and Thattle 2003).

The estimates of the global burden of TB in 2009 are as follows: 9.4 million incident cases (range 8.5 million - 9.9 million). 14 million prevalent cases (range 12 million - 16 million) 1.3 million death cases among HIV- negative people (range 1.2 million – 1.5 million) and 0.38 million deaths among HIV positive people (range 0.32million - 0.45 million). Most cases were in the South Asia, South East Asia, and western pacific region (35%, 30% and 20% respectively). An estimated 11-13% of incident cases were HIV-positive; the African Region accounted for approximately 80% of such cases (WHO 2010).

Since South Africa adopted DOTS (the internationally recommended strategy TB control) in 1996, all districts have implemented the core DOTS components, although coverage varies widely within and among districts. Despite South Africa's investments in TB control, progress toward reaching program objectives has been slow: however new data suggest that for the first time in 2006, South Africa reached and supported the DOTS case detection target of 70 percent, further increased to 76 percent in 2007 (USAID 2010).

The interesting report on the top 12 countries of origin of foreign born persons with TB in the United States in 2009 were Mexico, Philippines, Vietnam, India, China, Haiti, Republic of Korea, Guatemala, Peru, El Salvador, Ethiopia and Honduras. Of the 6,854 TB cases reported in 2009 among foreign-born person, 40 % occurred among person in the Americas region and 30% occurred among person born in the western pacific region from 1993 to 2009, the proportion of reported case increased among persons born in the Eastern Mediterranean region from 3% in 1993 to 4.6 % in 2009. The Southeast Asia region: 6% in 1993 to 13% in 2009, and the African region: 2% in 1993 and 8% in 2009 (CDC, 2009).

In China, tuberculosis is the main cause of death among the infectious diseases among adult. Approximately 1.4 million people contract active tuberculosis each year and in 1990 alone about 36000 persons died from this disease in China. Globally TB

is positioned third as the major cause of disability and death among adults of between 15 years and 59 years. It is estimated that almost 33% of the population of the world is infected with the disease. In 1981, the government of China developed a national TB program in an attempt to reform the efforts in controlling the disease and to broaden the system for treatment and reporting. However, lack of enough financial support hampers the technical capacity and human resource of the program in a number of areas. Especially in provinces that are poor and those that lack proper infrastructure in primary family health care (AcademicWritingTips.org 2012).

In India about 80% of all qualified doctors, 75% of dispensaries 60% of hospitals and 75 % of the country's health expenditure are in the private sectors. Unfortunately, little information is available on patients with tuberculosis in private clinics and very few studies have investigated the tuberculosis management practices of private practitioners. The relative advantages of private practitioner are convenience of location and working hour's confidentiality, their personal report with patients and better treatment adherence among patients under their care, compared to patients under the Revised National Tuberculosis Control Program (RNTCP). However, these advantages are countered by the reluctance of doctors to use sputum examination for diagnosis, their disregard for recommended drug regimens, their virtual inaction with regard to treatment default, and their failure to keep even the minimum essential records. In addition, many patients cannot effort to pay for full course of treatment (NMJT 2003).

2.3 Tuberculosis in Nepalese Context

Tuberculosis is a major public health problem in Nepal. About 45 percent of the population is estimate to be infected with TB of which 60 percent are adults. Every year 40,000 patients develop active TB of whom 20,000 are infectious. These 20,000 are able to spread the diseases to others. Treatment by Directly Observed Treatment Short course (DOTS) has reduced the number of deaths. However, 5,000 - 7,000 people still die per year from TB (DoHS 2009/10).

National Health Policy Nepal (1991) has committed to strengthen the primary health care system and making effective health care services readily available at the local level and the second long term health plan (SLTHP 1997-2017) provided the broad

framework from which the 20 components of the Essential Health Care Services (EHCS) package were identified and the control of infectious diseases including tuberculosis singled out as priority elements. The National Strategic Plan (July 2010-July 2015) Nepal is focused on increasing case finding in Nepal, and hence to reach the goal to reduce the morbidity and transmission of TB until it is no longer a public health problem. The ultimate goal is to eliminate TB (less than 1 new sputum positive TB case per million population per year) from Nepal by 2050 (HERD and MoHP 2011).

The three years (2007-2010) in long-term plan included tuberculosis is under communicable diseases control program. The plan is: DOTS program coverage will be extended to all the 75 districts with the joint initiatives of the government, the private sector and people's participation will be mobilized to establish clinics and to search to stabilizing patient integrated and coordinated programs for HIV/AIDS and tuberculosis control.

DOTS have been successfully implemented throughout the country since April 2001. The NTP has coordinated with the public sectors, private sectors, local government bodies, I/NGOs, social workers, educational sectors and other sectors of the society in order to expand DOTS and sustain the present significant result achieved by NTP. By 16th July 2010 NTP has 1122 DOTS treatment centers with 3098 sub centers. (DoHS 2009/10).

Public private partnership efforts were further enhanced during the last years to enhance the involvement of the community in order to sustain the success of National TB control of Nepal. All the PHC in the country are providing NTP recommended DOTS service through designated centers. Orientation on DOTS to private practitioner industrial workers and pharmacists has resulted in increased referral of TB cases from the private sectors to the NTP. Some private nursing homes, polyclinics and industries have established DOTS centers. The NTP regularly conducts orientation and training for concerned health authorities within military, police, hospitals prisons, schools, public media, municipalities, village development committees and private pharmacists in order to improve collaboration for tuberculosis diagnosis and treatment facilities according to DOTS strategy.(NTP 2010)

There are a variety of social aspect and relations some broadly speaking cultural and others linked to hierarchy in the health system into which the DOTS program falls. Both health workers and patients relations to the implementation of this program were varied. But the research experience suggests that given the right conditions and supervisory support, most of the staff would work out appropriate strategies for dealing with the vexed question of adherence to treatment. This requires a different relationship, however, with the staff and an understanding of how the rigid requirement of a research agenda linked to the health service can feed counter productively (from the perspective of patient support) in to already existing social hierarchies (Harper 2005)

2.4 Relapse Cases of TB

A relapse case can be considered as a most significant issue while treating the medicine dependent clients. In general medical terms, "relapse" means an uncontrolled return to drug use, who tent to recognize the seriousness of their addiction, even those who have gained mastery over their treatment default in remaining abstinent. In case of TB "relapse" means re-occur the disease after cured

There are varieties of reasons why patents fail to take their medication. The symptoms of tuberculosis (TB) commonly resolve within a few week of starting TB treatment and many patients then lose motivation to continue taking their medication. Regular follow up is important to check on compliance and to identity any problems patients are having with their medicine. Patients need to be told of the important of taking their tablets regularly, and the importance of completing treatment because of the risk of relapse or drug-resistance developing otherwise. (wikipedi.org 2012)

The primary analysis dealt with positive culture after completion of tuberculosis treatment. In this content, Laboratories cross-contamination was defined as the occurrence of a single positive culture in a patient who had converted to culture negative, whose subsequent genotype did not match that of the original isolate and who lacked any clinical or radiographic evidence of recurrence tuberculosis. Relapse was defined as the occurrences of a positive culture after both documented culture conversion and treatment completion in a patient with symptoms of recurrent tuberculosis, whose original and subsequent isolates had matching genotypes.

Reinfection was defined as the occurrence of non-matching genotype of original and subsequent isolates in patients which clinical course consistent with failure or relapse. (AGRCM 2004)

Recurrent tuberculosis (TB) after treatment can reflect exogenous re-infection or relapse. Investigators who followed a cohort of South African gold-mine workers who had been treated for TB in 1995 to determine whether recurrent TB in this population was caused by relapse or reinfection and to assess risk factors for each workers with non-multi drug-resistant, culture – confirmed TB who had been effectively treated for minimum of 6 months were examined at 3 and 6 months after treatment then annually and when ever unwell (Watch 2011).

In 2009/10 there were 15,569 TB patients registered in Nepal Tuberculosis center. Among them 2617 were registered as relapse patients. According to NTP report, there is different result in the five regional areas. In the eastern region there are 3,144 new TB patients are registered, among them 394 were relapse. In the central region, there were 5,924 new patients registered, among them 1,006 were relapse. In the same way, in the western region 2,807 new patients are registered, among them 547 were relapse. In the mid western region 2154 patient were registered among them 423 were relapse. Moreover, in far western region 1480 new patient were registered among them 247 were relapse case. This data shows that at the policy level there are severe challenges of TB treatment.

CHAPTER III

METHODOLOGY

The main components of the methodology in this research has been divided in following topic: rational of the site selection, sample size, nature and sources of data, sampling procedure and tools used for data collection and processing. To illustrate the research work all the information has been illustrated in direct and indirect narrative form.

3.1 Rational of the Site Selection

All of the district of Nepal has DOTS services to reduce mortality and morbidity rate of people suffering from tuberculosis. According to NTP 2011, at the district level the District Health Officer is responsible for the planning and implementation of NTP activities within the district. All 75 districts also have dedicated full time District TB Leprosy Officers in place. Within a district, the basic unit of management for diagnosis and treatment are district hospital and the primary health care center. Direct Observed Treatment is available at Health Post, Sub health post and other health institution within a district.

Rupandehi district has been purposively selected as the study area. Rupandehi district is situated in the western part of Nepal. This area is also called middle south part of Nepal. There are two municipalities and 69 VDCs and the population account for 886,706 (2011 census). Rupandehi is a multi ethnic and multicultural district. The Nepal national tuberculosis center (NTP 2010) shows that second highest TB relapse patient registered in Rupandehi district. According to annual case finding report 1,344 patients are registered for treatment in Rupandehi among them 122 are relapse and 13 are treatment failures.

In Rupandehi there are 15 DOTS centers and more than 30 sub centers providing the services. Every DOTS center has one lab for biological test. However, sub DOTS centers have no such facility. They only distribute medicine for patient. That is why; every patient is registered in a DOTS center but taking medicine from nearer sub DOTS center.

3.2 Research Design

This study was based on descriptive and exploratory types of research design. The researcher carefully tried to record all the interview and observation events from the study area and describe them as faithfully as possible. In addition, this study was exploratory, because it tries to explore about present situation, social cause and consequences of TB relapse patient.

3.3 Nature and Sources of Data

In this study, the researcher included both primary and secondary source of data. The primary data was collected through field study using interview method. Interview was main tools to collect the information whereas observation was done at side. The secondary data was obtained from DOTS center and other related sources.

3.4 Sample size and Sampling Technique

This study is based on TB relapse patient in Rupandehi district. The sampling has been taken purposively. Therefore, different backgrounds people were included as a respondent like age, sex and ethnicity. In the study, there are only 38 TB patients participated of which 20 were relapses and 18 were new. The required information was collected through interview. I spent minimum 1.5 to 2.0 hour for each interview. The patients were interviewed at DOTS centers.

3.5 Field Experience and Data Collection Technique

In the field, I visited nine DOTS center and two-sub center during the research period. I had hoped to visit all of DOTS center but the distance of some DOTS center made me unable to do so. In addition, some DOTS staff was not doing friendly behavior, as they did not want to manage time for me. One Health post and one hospital did not give good response and they did not to give permission to visit patient. More than three times, I went to these DOTS centers but no good response was seen. However, other DOTS centers heartily welcomed me and provided patient information and cooperate for my interview.

In the field, I found most of the patient were not following DOTS rule. Patients were not regularly come for receiving the medicine in the center. So I was facing challenges to meet the patient in proper time. I found only Devdaha DOTS center were giving medicine daily under the observation. Other centers were distributing medicine based on negotiation between health person and patient. Only a few patients were using mask though every center has a strategy to distribute mask for TB patient.

Similarly I found some respondents who were already suffered TB in previous time and at the present time too, thus they were relapses but they were taking cat I medicine and not cat II treatment. However, at the relapse case most of them were taking cat II medicine according to DOTS regime. I found that there were weak investigations and medical person giving medicine blindly.

TB patients were the main information source of my research. As information based on key informants are important for any research. In this study, I have focused mainly interview and observation technique to collect the required data.

3.5.1 Interview

Interviews were done to collect sufficient information of TB relapse. In this study, 38 respondents participated in interviews. The researcher had used some questions to understand TB treatment practices, causes of relapse and its consequences. Personal, social, cultural, economical and other factors were learnt through this method.

3.5.2 Observation

Observation as a tool has been used to comprehend the life style and situation of respondent as there were differences between the saying and doing practices of individual. At that time, doing observation is useful tools to get actual information. In this research, I got some chance to observe relation between patient and health person, behave to each other and other practices, which were contrary medicine rule and norms. For example, I found some patient were taking alcohol in my interview periods who were relapse patient and medicating on anti-TB drugs. Alcohol should be avoid by TB patient.

Ethical Consideration

As far as my research is concerned, I have not observed any medical experiments and biological tests. I draw all the lab reports through the health person and I am seriously concerned with research ethic. In this research, I used respondent as a code because I want to save their personal respect. I have not focused on any sensitive issues and not to force anybody to speak at interview period. I took interview separately and all of interviews were taken in the hospital coming period but I did not take interview in the hospital office. I was managing every interview in natural and open environment and there were no any other disturbance.

5.7 Limitation of the Study

Every study has its own limitation and more than one particular person bonding in certain time, perspective and sources cannot possible to study whole aspect. So, there is some limitation in any research and this research is no exception either. The limitations of the research area are as follow:

1. This study was limited to selected DOTS center in Rupandehi districts. So the findings of the study can not be generalized for other setting.
2. The research was studied only Tuberculosis relapse cases.

CHAPTER IV

GENERAL INFORMATION OF THE RESPONDENT

The government of Nepal, National Tuberculosis Center has developed a comprehensive National strategy based on the previous national plan (2010 – 2015). The New Strategy builds on the previous national strategy and outlines enhanced and more focused commitment for tackling the TB epidemic, consistent with new STOP TB strategy and Millennium Development Goals in line with the Stop TB Partnership targets (NTC 2010). At national and global level, many programs were launched to reduce worldwide TB problem. Stop TB program, Public Private Partnership, DOTS policy etc are playing the crucial role for control of the diseases. These types of program enhance the accessible of medicine and treatment center and it decreases the mortality rate caused by disease, which are holding the strong position in our community. It is clear that TB is not only a result of biological factors but influence by social and cultural factors too. Here, I am trying to analyze TB disease with the respect of social and cultural aspect.

In this research, I tried to obtain all the information from respondents who were medicating TB drugs under the DOTS centers in Rupandehi district. In doing so, I draw treatment information of respondent from patient treatment cards with the help of DOTS center and latter on I interviewed with them. All interviews were conducted with in-depth purposes, which last for two hour. This chapter present general information of the respondent based on age, sex, ethnicity and TB types.

4.1 Demographic Characteristic of Respondent

Demographic characteristics of patients were gathered to gain information of patients in order to measure the level of experience and treatment practices happened in their life. Thus, I tried to divide the respondents categories based on general indicator such as age, sex, ethnicity and TB types etc.

4.1.1 Age and Sex Composition

Age and sex are important variable for analyzing the information about respondent roles and social position. In any society, there might be creation of stratification and hierarchy based on age and sex. Social responsibility, economic accessibility, individual rights, and work divisions are also divided based on these two types of variables. Thus, health-seeking behavior of any individual can't be explained without the influence of age and gender role.

In this study, the respondents were selected purposively. The age of respondent was above 15 years for interview. Therefore, fifteen to seventy-one year's age patients participated in the research. From the entire respondent, most of patients were in the 59-64 (26.31/) age groups and minimum respondent were in the 65-74 age group (7.89).

Table 1 Age and Sex Composition

S.N.	Age In Year	Male	Percent	Female	Percent	Total	Percent
1	15-24	2	5.26	3	7.89	5	13.15
2	25-34	6	15.78	3	7.89	9	23.68
3	35-44	5	13.15	2	5.28	7	18.42
4	45-54	2	5.26	2	5.28	4	10.52
5	55-64	9	23.68	1	2.63	10	26.31
6	65-74	2	5.28	1	2.63	3	7.89
Total		26	68.40	12	31.60	38	100

Source: Field survey 2012

New and relapse cases of patients were participated. For new cases, eighteen patients participated in interview and for the case of relapse, 20 patients participated. In this research, majority of respondent were male i.e 26 male and only 12 patients were female.

4.1.2 Respondent by Ethnicity

As no anthropological/linguistic survey has been carried out in Nepal to date to note the various ethnic/caste groups, their distribution and population size, the exact number of ethnic/caste groups and their population size is somewhat imprecise in Nepal even today. In this kind of uncertain situation, the CBS has remained the single most important reliable source in providing the national- level information on caste/ethnicity and their various socioeconomic characteristics (Dahal 2005). Here I am discussing the major 12 ethnic/caste group of Rupandehi district according to census survey 2001. The total population of Rupandehi was only 708419. Following table shows the respondent proportion of various ethnic groups.

Table No. 2 Distribution of Ethnic/Caste Population of Respondent in Rupandehi

S.N	Ethnic/Caste	Population	Percent	No of Patient (Respondent)	Percent
1	Hill Brahmin	107643	15.19	4	10.52
2	Chhetri	41164	5.81	5	13.15
3	Shrestha	15767	2.22	5	13.15
4	Gurung	19793	2.79	2	5.26
5	Magar	62248	8.78	11	28.94
6	Kami	14974	2.11	2	5.26
7	Damai	7562	1.06	1	2.63
8	Tharu	74888	10.57	2	5.26
9	Yadhav	54486	7.69	1	2.63
10	Harijen	27697	3.90	3	7.89
11	Koiri	7803	1.10	1	2.63
12	Thakur	5396	0.76	1	2.63
Total		439421	62.52%	38	100%

Source: 1. National census survey 2001. 2. Field survey 2012

The table 2 includes 62.52% of population from total. These groups are major ethnic or caste group of Rupandehi district. Hill Brahmin are holding high rate (15.19%) from the total population of the district. In my research, high rate of respondent were belonging from Magar (28.94%). It may be the cause that Magar peoples follow own

type of cultural practices and their food habit is different from Brahmin. The respondents were selected purposively. There was no significant relationship between high rate of population and high rate of respondent. In Rupandehi, Census Survey 2001 counted only 42 Ethnic/caste group. Table no. 02 shows that only 12 ethnic/caste group were holding majority of population (62.52%) in this district.

4.2 Respondent by TB Types

Medical science defines two main types of TB, one is pulmonary TB and the other is extra pulmonary TB. Pulmonary TB has also two types which are pulmonary positive TB (sputum smear positive TB) and pulmonary Negative TB (sputum smear negative TB). They have a different character but caused by the same bacteria.

Pulmonary tuberculosis is a contagious infectious disease with chronic evolution, caused by Koch bacillus (*Mycobacterium tuberculosis*) and which may affect all body organs, especially lungs. Any person can be infected with tuberculosis, regardless of social status and financial situation. Most exposed: people who are in constant contact with people with contagious pulmonary tuberculosis, people with low immunity caused by malnutrition and bad living conditions, HIV infected people, active smokers, people who drink alcohol and take drugs, children who are not vaccinated against tuberculosis. The main symptoms of pulmonary tuberculosis are cough with sputum for more than three weeks, fever for a week without an obvious cause, chills, pain in the chest, haemoptysis (sputum with blood in coughing), sudden drop in weight, loss of appetite, constant fatigue, excessive sweating, especially at night. (www.tuberculosisissymptoms.com 2012)

Extra pulmonary tuberculosis is a form of tuberculosis that affects other organs than lungs like liver, kidney, lymph node. There also can be peritonitis, pericarditis and spinal tuberculosis. Extra pulmonary tuberculosis affects people with weak immune system, diabetes, HIV, or malnourished people, very young children or elderly, those undergoing prolonged treatment with chemotherapy or cortisone. Among the most common forms of extra pulmonary tuberculosis are node tuberculosis, osteo-articular, renal and skin tuberculosis. Meningitis may accompany pulmonary tuberculosis or be an independent disease. Commonly it occurs in children between one and five years and affects the elderly people too. (www.tuberculosisissymptoms.com 2012)

According to DHO report (2010) of Rupandehi, 56.92% of the respondents were suffering from pulmonary positive TB and 24.26% of the patients were pulmonary negative. There were 15.48% of the respondent sufferings from extra pulmonary TB.

Table 3 Distribution of TB Types According to DHO Report

S.N	TB Type	Patient	percent
1	Pulmonary Positive	765	56.92
2	Pulmonary Negative	326	24.26
3	Extra-Pulmonary	208	15.48
4	Others	45	3.34
Total		1344	100

Source: DHO Report 2012

In the field, I found the patients having no clear ideas about different types of TB and its symptom. They take all type of TB medicine at a same time. In the research sample showed that 81.21 percent of respondent were pulmonary positive and 7.89% were pulmonary negative. Only 10.52% were extra pulmonary cases.

Table 4 Distribution of TB Types of Respondent

S.N.	TB Types	Number	percent
1	Pulmonary Positive	31	81.21
2	Pulmonary Negative	3	7.89
3	Extra Pulmonary	4	10.52
Total		38	100

Source: Field survey 2012

The above data shows that registered pulmonary TB has large proportion of population and other type has low proportion. It means high percent of TB people has possibility transfer germ for other because pulmonary TB has risky to transmit.

CHAPTER V

TB EXPERIENCES AND TREATMENT PRACTICES

Patients have different TB experience and treatment practices as it can be determine on their medical accessibility and knowledge. They have different diagnosis experience and medication practices. They have their own experiences about the first response of TB. Directly Observed Treatment Short-Course (DOTS) based on hospital practices and socio cultural based of patient practices play a dualistic role for seeking the treatment for patients. Economics condition and distance of hospital also affect the treatment practices of patients.

5.1 Diagnosis and Medication

Knowledge plays vital role for health seeking behavior. The study shows misconception and that a low level of recognizing TB is very traditional. The respondent has low level of awareness about sickness and disease. Many respondents were unknown about TB disease, as they did not go hospital in time. However, when they felt illness then started to take medicine from the private medical hall without examination.

I found that only a few patients started to take medicine within a month after feeling illness. High rate of respondents spent more time to know about the type of their diseases eiter it was TB or any other. Those who were unknown and uneducated about TB practices started to taking medicine from private medical hall whereas other got medicine over the counter. Therefore, there is a mutual relation between diagnosis and medication system, which affects by social and cultural aspects.

Table 5 Delay in Health Seeking at Health Facility

S.N.	Time Duration	Number	Percent
1	Within one month	9	23.68
2	Two to three month	11	28.94
3	Four to six month	10	26.32
4	7 to one year	7	18.42
5	Above one year	1	2.64

	Total	38	100
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Source: Field survey 2012

The causes of late diagnosis was not only determined by the patient's perception of medicine but also due to socio/cultural practices. Here are some of the cases of respondents who were facing above situation and being late to examine the disease. 55 years, male, Janajati, relapse patient, code no. 33, was already taking medicine of paralysis, diabetes and blood pressure. On those medication periods, he didn't leave his alcoholic habit. Eight year ago, he suffered from TB. After cured he didn't leave his alcoholic habit. Every evening, he always used to take alcohol and not to give priority for his food. Now, he is again feeling very weakness along with chest pain. At first, he had taken medicine from clinic without check up. While he used medicine he was felt relief then after end of the medicine the symptoms occurred again. Similarly, he took Jadibuti medicine and used Jharphuk but the problem was not gone. After six month of symptoms, he went Bhim Hospital for checkup then identify that the disease was TB.

Not only code no. 33 faced that situation. He is not a single example of this cause, other 29 Respondent were faced this situation. 49 years, male, Janajati, relapse patient, code no. 35, learnt about his disease after 5 month of first symptoms. At first, he has taken home based medicine prepared by his family members, and after he went to a nearer clinic to treatment of his problem but health person gave medicine without examining the disease. After five month, he went to Bhim hospital for treatment and then found out that his disease was TB. Professionally he was a lawyer and used to take his food in the hotel because of workload. He didn't have alcoholic habit but only used to take Khaini (tobacco). After ten years he is a relapse case, he is again taking anti-TB medicine.

Code no, 33 and 35 were not of a poor economic background but they were bad health seeking behavior. 61 years, male, Janajati, Indian retired army, code no. 37, had suffered from pulmonary positive TB. After six month of first symptoms, he went to check up his disease in Bhim Hospital. At the previous TB period, he was in the job. Now he was not thinking about the symptoms of disease was TB. He was facing unexpected result that TB was infected to him. Now he is driving a truck. He was

very busy when symptoms were occurring. Therefore, he I came late to hospital for checkup of his health.

This information shows patient spent long time without taking actual medicine. All the above respondents were Janajati background socially and they were going to hospital for treatment. When a person suffering from TB and not taking actual medicine then, there is more possibility of transferring others. Therefore, the risk of TB disease still exists without identifying the proper types of diseases at a time.

5.2 Response and Reaction When Known

TB is a disease, which has different social definitions. Community member believed that it is a deadly disease which occurs due to result of sinful act or bad deed in previous life. The disease of TB is also called Khapate, Kalorog and Maharog. At previous time, it was deadly disease but now when a person take medicine regularly it is easily cured. People have not sufficient information about the disease. Though, TB is a major public health problem in the world but some respondent known about TB only after they suffer from it. Therefore, their response and reaction were different when they knew it was TB.

Table 6 Response and Reaction of Respondent when they knew

S.N	Reaction	Number	Percent
1	Surprise and normally Accept	16	42.10
2	No surprise	15	39.41
3	Surprise and hardly Accept	4	10.52
4	Being faint	3	7.89
Total		38	100

Source: Field survey 2012

In the research, some respondent were no shocked when they knew they suffered from TB disease. It may be of two reasons, either they had sufficient information about TB or they were unknown and took it as a normal disease. On the other hand, some patients were shocked when knew that they were infected from the TB disease.

60 years, male, janajati, relapse patient, code no. 28, said that he was in Panjab (India) when for the first time he suffered from TB. At that time, he had suffered from continuous fever and cough. One day the blood was seen in his cough. He was very afraid and went to hospital with his brother. The doctor was unsuccessful to find out the disease and gave him medicine for malaria. Few days later when his disease was not recovered, he went to hospital again. At that period, the doctor declares that his disease was TB. He was very surprised. He thought that he was going to die soon but the doctor successfully treated and after long medication, he had recovered. Now 30 years later he was again suffering from TB.

Some respondent thought that TB is the cause due to taking of Rakshi, Churot and Surti. They thought TB is a normal for them who were taking those things but some respondent never took those things but suffered from TB. 40 years, male, Janajati, code no. 22, was very surprised when he knew his disease was TB. He knew that it will happened to those people who were taking Rakshi, Churot and Surti but he had suffered from this disease though he has not habit of those things. This was out of his imagination. 71 years, male, Dalit, relapse, code no. 26 was very surprised when he knew his disease was TB. He was very afraid. He felt that he was going to die soon but health person successfully treated him. This was his happy moment as at that time many people were dying by TB and now he had suffering from TB and taking anti-TB medicine.

Table 6 shows only 16 respondents were not shocked when they knew the disease was TB. The other entire respondents shocked when they knew they were suffering from TB. Some respondent accepted it normally but some respondent hardly accepted because they thought TB was not for them and some had fainted (three respondent) when they knew the disease was TB. This information shows that most of the respondent had no insights about TB and they surprised when they knew. It means there was lack of awareness about cause, prevention and education of the disease.

5.3 Medication System and Challenge

Directly observed Therapy Short-course (DOTS) policy includes five essential elements, namely: political commitment to increasing resources and including tuberculosis (TB) control as an activity integral to national health system; good,

widely available sputum microscopy services so that the disease can be correctly identified; standardized short-course chemotherapy, including the direct observation of treatment; uninterrupted supply of drug; and finally, recording and reporting system (WHO 2002). The directly observation of treatment is a challenging part of system. Patient must visit DOTS daily to take medicine but lack of economic access, job, study, weakness and age factors make problems to visit daily. DOTS centers have its own rules to distribute medicine for patient thus reality is different than its policy. Some patients used to visit daily, some used to visit weekly and some patients used to come after ten days or above.

Table 7 Time duration to come DOTS center for medicine

S.N.	Time	Number	Percent
1	Daily	5	13.15
2	Weakly	27	71.07
3	10days or above	6	15.78
Total		38	100

Source: Field survey 2012

In the research, I found that only five patients were coming daily to receive medicine in DOTS center though one of the most essential parts of DOTS policy is patient most attend daily to take medicine. However, 33 out of 38 respondents were not following this rule.

Here I want to include some response of the respondents, which is about their medicine receiving practices. 24 year's, female, code no. 26, who just finished her CMA course from LITES institution and she was participated her OJT (On the Job Training) course in Butwal Anchal Hospital. She builds a good relation with health personnel and staffs as she was familiar with this center. Therefore, the health person gives her medicine for 15 days. She only comes to receive medicine twice a month.

Code no. 26, is health background educated people as she has knowledge about TB and its impacts. 50 year's, female, code no. 18, was suffering from pulmonary positive TB. She was seriously ill and went to many other hospitals but her disease was not cured. After Seven month of illness, she went Bhim hospital Bhairahawa

then she started to take anti -TB medicine. At the previous, she used to come in between 2/3 days in a week but now she left to come in the hospital. Her daughter-in-law had receiving medicine for her every Sunday. 27 years, female, code no16, have same experience. She said, *"In the beginning of first two month, I used to come thrice a week but now I came either once a week or thrice a month.* 60 years, relapse patient, code no.28, said that he was medicating from mission hospital Palpa (another district) at the previous period. The distance of hospital was so far from his permanent residence so he took medicine for one month but on this occasion, he was receiving medicine from nearer health post once a week.

Therefore, policy and practices of DOTS are different. Neither health person following this rule nor TB patient wants to understand the policy. These two (health person and patient) are doing their practices according to their perceived understanding.

5.4 Monetary Expenses

When a person suffers from TB, she\ he might be weak or jobless. If economic status were low, it would be difficult to manage. There is saying that TB is a disease of poor. Balance diet must be maintained for medication period. Patient must spend money. Nevertheless, many patients had problem to manage travel expenses for coming and going to treatment center. DOTS program provide free medicine but many patient were walking long distance to receive medicine because of economic and other problem. At this situation, there is a problem for the maintenance of a balanced diet

Table 8 Monetary expenses when come to DOTS center for medicine

S.N.	Monetary expansion when come to DOTS center for receive medicine	Number	Percent
1	Under 50 -100	16	42.16
2	Above 100-200	2	5.26
3	Above 200-300	-	-
4	Above 300-400	1	2.64
5	Above 400-500	2	5.28
6	No expenses	17	44.74
Total		38	100

Source

e: Field survey 2012

Medicine of TB is available free of cost for those people who are suffering from TB disease. In this research, I found a majority of respondent spent money indirectly for receiving the medicine. It was found that twenty-one respondents spent money for travel (to coming DOTS center and going fee). If people follow the DOTS rule and coming daily, it is difficult to maintain their travel cost because most of the respondents were poor economics background. If fifty rupees cost per a day a patient and patient follows DOTS rule and come to daily treatment it will go 1500 per a month for travel, which is high cost for the patient. 35 years, female, code no. 14, was coming from India, spend 500 per week for travel. Every month she lost 2000 rupees for medicine (travel). Sometime she only came here to receive medicine and some time her husband came to pick up medicine. When both come for check up and receive medicine, at that period they spent about 1000 rupees per day. 55 years', male, relapse, code no. 33, had a problem to walk because of paralysis. He always hired taxi to go Bhim hospital Bhairahawa from Sunauli. He spent 400 Rs. per week.

The given information shows that the government of Nepal provides that the medicine of TB is free but at the same time, patients have expenses because of travel cost and many others problems. Therefore, the researcher presents the data, which is very remarkable to proof its cost indirectly. It is not only decrease economic condition of patient but also force of their medicine pick up.

CHAPTER VI

SOCIAL AND CULTURAL FACTOR OF THE RELAPSE

There are many causative factors that make a patient relapse of their health suffered by TB. Communication, knowledge, concept, patient perception of medicine, health seeking behavior, awareness, economics condition, maintenance of nutrition are main socio-cultural factors of relapse. In this chapter, I have described the perceived causative factors of relapse and information gap between service provider and receiver.

6.1 Gap of Communication between Receiver and Provider

Tuberculosis causes an enormous burden of disease and death around the world. In the context of south Asia, it is a major public health problem. Nepal is also not far from this scenario. In this research, the data shows that there is a wide gap between receiver and provider, which is an important cause of rising TB problem. It gives challenges for those launching programs that had been taking ambition to reduce the TB problems.

The removal or cure of any disease or illness requires a very good relationship between doctor and patient. Here, provider is a health personal who gives the medicine for those people who is suffering from TB and receiver is patient who is

suffering from TB who visits hospital to take medicine. This research helps to find the gaps between patient and health person. Patient do not raise any questions to a doctor about their cause of diseases nor health personnel are interested to listen to the patients feeling.

“In this hospital, when I came to checkup my health, health personnel did not say anything to me. They gave medicine and I took it home”. (55 years, female, illiterate Madeshi, code no. 12)

“At that time I was very weak. I went Bhim hospital with my son for physical check-up. Health personnel tested my cough, blood and took my X-ray but he had not said anything to me about my disease and its cause”. (65 years, male, illiterate, Dalit, code no. 10)

They were illiterate people who were living normally in their house but they did not know about the cause of their own disease. They couldn't ask any questions to health person and health person also did not said about the cause of the disease. Code no. 18, 50 years, Janajati, Female, shared the same experience about the causative factors of TB. Previously, when she was not suffering from TB, she did not know about sign and symptoms but now when she is suffering from TB they are also unknown. And she has not actual and sufficient information about TB. She did not raise any question about it and health person also did not say anything. She said *'health person told nothing important, they examine me, give medicine and told to take medicine regularly.* 30 years, Dalit, Madeshi, male, code no.8, which has a poor economic condition that's likely why, he was suffering from TB two times but he was no knowledge about the cause of it. According to him, *health person told that the illness was the cause of TB but he did not said about the other cause of this disease.*

Most of people living with TB are, still unaware about the main causative agent of TB (HERD and MoHP 2010) even literate people also not established good communication and they did not talk about disease to each other. It shows the weakness of knowledge. If they did not discuss about the causative factor, it would be difficult to reduce the TB problem. In this research some respondent, who were literate, were well concerned about TB but they had not discuss with health person about this disease. Health person also did not say anything about the cause of TB.

“Well, they didn't said any think to me but when I was reading, my teacher used to teach that it may transfer as it is communicable disease and also because of weakness”. (24year's, female, health person, literate, Chhetri, code no. 26,)

“Health person have not said anything about the cause of disease”. (15year’s, male, student, Brahmin, code no. 06,)

“I don’t remember anything about TB. When I was student, I had studied about it but forget. Now as I am suffering from this disease then I myself know about it. Health person didn’t say anything about TB”. (24 year’s female, player, Janajati Code no. 4)

According to them, there were some gaps and problems to understanding each other. Patients are not interested to know about disease as well as health persons are not making aware to them. There is hierarchy between TB patient and medicine professional which guided by society. TB patients are treated as lower level or status people where as medical personnel treated as a higher status people. This type of hierarchy creates the communication gap between them. Therefore, TB patients are treated as a lower level people either s/he is educated or not. Nevertheless, some patients had taken little information through health personnel during treatment period.

“In the hospital when I came for the blood test the health, personnel told me that it is a communicable disease. It transmits from one person to another”. (27 years, female, Janajati, code no 16)

“At the first treatment period the health person suggests me to avoid alcohol and cigarette but they didn’t say to me about the cause of my disease”. (32 years, male, Madeshi, code no. 02,)

“Yes, the doctor asks me at private clinic when after finished first diagnosis. He says that it is a contagious disease. It also become occur those person who have habit of alcohol and cigarette”. (25 years, male, Brahmin, code no. 01)

According to above statement, patients do not clearly knew the cause of their own disease. They develop their knowledge based on their local context, which may differ from medicine law and practices. There is no doubt, every people had guided by the traditional knowledge, which is carried by generation to generation. In the research, some respondent gives unclear answer about the causative factor of TB. Neither did they take any interests to understand about it nor health person provide any sufficient information. It may influential for a relapse.

6.2 Long Medication Period and Patient Irritation

Generally, TB patient must be taking medicine for six month. When a person misses to take medicine, according to the DOTS regimes duration of medication is extension.

Normally, patients must be regular and conscious about health and medicine. Consciousness determines to save their life and health. In the case of TB, there is no any choice to take medicines less than six month. If patient is diagnosis as a relapse, s/he must takes injection first two months regularly. This period is a difficult for the patient. While patient used medicine, his/ her health condition will improve than it is a temptation to leave medicine. After some days of medication patient will feel full strength and felt irritation to take continuously and think not necessary to take medicine.

In this research, some patients were facing that type of situation. They left medicine because thinking of cured but the disease was repeated.

“In between previous medication time, I missed to take medicine for two or three time and at the end of medication period, I left at least one week due to my academic examination. I was full strength and medicine made me very lazy and sleepy. Therefore, I left to take. This may be the cause of re-infection”. (24 years male, Brahmin, code 03)

“Yes, at the previous time I missed medicine because I was fully cured and also I lost my treatment card. I through health person may be angry with me because of my treatment card. At that time I had taken medicine for five month”. (59 years male, Chhetri code no. 05)

Thus, above statements show that there is something problems in DOTS. In the long medication period patient must stay in a particular area but they were facing social barrier. The long keep in touch situation between patient and health person made irritation for patient. It slowly pushes patients for the leaving medicine. Such as, 45 years, relapse, male, Janajati, code no.7 had economically poor background. He was a sweeper, belonged on Siddhertha Municipal in Bhairahawa. He left medicine because of economic problem. He had a problem to maintain basic needs for his family and children. He left his medicine two times during the period of six month. Though his record was registered in Bhim hospital Bhairahawa but I meet him in TB patient hostel in Lumbini Zonal hospital Butwal. He said me that if he took rest and he left his dusty work, it would be difficult to manage his life. Therefore, he wants to finished medicine and wants to return to his work soon. 60 years male Janajati patient, code no 28, has taking medicine continuously in this occasion. Before he is taking medicine, he was in India. The course of medication was 18 months but he left

his medicine before two month. He thought that his disease had gone because of using long medication. So, he left to use his medicine without final examination.

There were some patients, who were receiving medicine continuously but they have no knowledge about how long time they should take it. Neither health person said it nor do they know by other. They do not dare to ask any questions to the health person. Even education and awareness had not played effective role between literature and illiterate, upper caste and lower caste, poor and rich. They had same kind of knowledge and practices about TB. Most of the patient did not know why the medication period is long.

“I have to take medicine for six months I knew it when I suffered from TB we have take medicine for a long period, but why this period is long. I have no idea about it”. (55years, female, illiterate, Madeshi, code no. 12)

“It’s been three months that I have started to take medicine. I don’t know the medicating period of TB when doctor will advise me to stop the medicine I will stop taking medicine I think it is a big disease so, the medicating period is so long”. (50 years female, illiterate Janajati, code no.18.)

“I have to take medicine for six month. I though as TB is communicable disease, so its medicine course is short, but I was wrong I have to take medicine for six month, I have no idea why the medicine period is so long”. (27 years, female, literate, Janajati, code no. 16)

As a patient of risky disease, it is important to know about why the medication period is long? Why they should take medicines regularly? What happened if we miss or left? This type of orientation is important for patient. But I found majority of respondent had no knowledge about disease, medicine and its duration.

6.3 Knowledge and Concept of Disease

Knowledge is the important factor which enhances the motivations in patients' medicine choice and practices. This research shows that patients have own perception about sickness and they ascribe to it according to their family knowledge. They have own way treatment practices. When a person had suffered from any diseases, firstly

he or she started to take home based medicine. It is cultural cause, because people have developed their own concept about disease and medicine based on their cultural practice. This might be the reason of lately going hospital. In the context of TB disease, a person who is late going to hospital has possibility to become weaker. Many patients who was ill because of TB but they were not thinking about it and surprised when knew it was TB.

“I was surprise. I was being faint when I knew my disease was TB. After that, I managed myself”. (65 years, male, Madeshi, code no. 10)

“I was surprised and I was afraid of this disease. I felt I was going to die. But they have successfully treated me. This was my happy movement because many people was dying by TB”. (male, 71 years, relapse, Dalit code no. 26)

“I was surprised when I knew I was suffering from TB. I heard that TB is a disease which occurs to those persons who take alcohol, cigarette and other but I haven’t take these things”. (25 years, male, Brahmin, code no. 01)

Kleiman(1980) describes about three sector of health care in his book *‘patients and healers in the context of culture’*. These three sectors are folk sector, popular sector and professional sector. In our context DOTS regimes corresponds to the professional sector. Many patients who were near the hospital were late for DOTS treatment because firstly, they practice folk and popular then lately come to the hospitals.

At first, they started to take medicine from private medical hall without examination but some patients reach in hospital but health person did not give actual medicine for the patient and this situation help to become weaker. TB is a high-risk contagious disease so, it is necessary to treat from the very beginning. If it is late, the close contact of a patient is very sensitive and more possibility to transmit other persons. I found many of them were not doing separate behavior and they were very close with family members and with their small children. They were sleeping with them in the medicating period. Many patients didn’t know about what to do or not? Which things to use or avoid?

“Nobody has done bad behavior towards me. When I was suffered first time there was some change on sleeping arrangement but now no change in sleeping arrangement because we are living in a small house and there is no much space and separate palace to sleep. Therefore, we have to sleep together. I have children, I need to play with them and I am close with my children. I also regularly visit my friends and relatives” (30 years, male, relapse, Madeshi, code no. 08).

“I don’t know anybody who was negatively treated me. I do not take other impure food because I am lama (spiritual healer.) Children also near with me. My wife and I always sleep in one bed”. (71 years, male, relapse, Dalit, code no 26)

Patients were confused because some accept TB as a contagious disease and some did not accept. They have their own perspective about it and they analyzed based on their experiences about knowledge.

“Someone says me, it can transfer when we sneeze and cough but I don’t trust it. I am not transforming other in my family and neighbor” (45 female, Janajati, code no. 24).

“I don’t believe it but people say it is a contagious it can transmit to other. I think my disease is not a contagious. Nobody suffered from me” (29 years, female, Janjati, code no. 11).

Some people focus that the disease was the cause of genealogical and it occurs the cause of their heredity. The belief is that TB is not curable disease and it has more possibility to occur in any time.

“I think, this disease occurred to me because of my mother as she was already infected. I think it might be transfer by heredity”. (25 years, male, literate, Brahmin code no. 01)

“My mother had suffered from this disease. When I was five years, she died. As well, my maternal side aunty had also suffered from it. I think it may be the genealogical”. (24 years, male literate, Brahmin, code no.03)

According to above data, people have lack of actual knowledge about disease. Their analysis is based on their own experience and knowledge, which comes from their

society. There are many confusion and they have not actual knowledge about TB even they are relapse cases. It is clear that the people who have less appropriate knowledge and practices on disease, that's why they face many problems. Therefore, it may possibility to increasing TB problem and becoming relapse.

6.4 Awareness and Its Dysfunctional Role

Generally, awareness has played a positive role but some time it gives negative reactions. Education is an important tool of awareness but visually education does not give proper effect because it's wrong implementation play dysfunctional role. In the health and health care issues, awareness is important and compulsory things. If a person aware about his health status, s/he has less possibility suffer from any disease. It helps to give simple and preventive knowledge for the people. However some time it plays dysfunctional role. It means understanding between knowledge provider and receiver can give the negative meaning. In this research, some patients describe that his/her disease is not a contagious disease, in the of a non communication wind of TB

"People say TB is a contagious disease but I don't think so because the doctor says my disease is not communicable". (27 years, female, Janajati, suffered from P-TB, code no.16)

"I don't belief it but people say it is a contagious it can transfer other, but doctor said me my disease is not a contagious. Nobody con suffer from me". (29 years, female Janjati, suffered from EP-TB, code no. 11,)

30 years, male, Dalit, Madeshi, code no. 02, is a relapse patient who knows TB is a contagious disease but he was not trust about it because he was infected from TB two times. He raises Question that *"TB is a communicable disease but how would I know that I transferred this disease to other?"* Moreover, his family member doesn't think he is a contagious. They think TB can possibility to happen everyone. Code no. 13, 60 years, female, Madeshi, woman has same experience about it. In her family members, she was only one person who had suffered from TB and in her community nobody were suffering from this disease. She knows TB is a contagious disease but she didn't think so as all family members are living together in one house but not any

other family members have suffered from this disease. Her family members did not say that she is a contagious expect her daughter-in-law.

Some patient said that pulmonary positive (P+) TB only transfer to other and pulmonary negative (P-) and extra pulmonary (EP-) is not transmittable. This concept is because of lack of awareness. All of the TB has some possibility to transmit for other. P+TB however have more possibility to transmit then P- and EP TB. However, EP respondents are facing challenge for diagnosis and health professional have little knowledge about its reaction. Ramakanth (2008) state that extra-Pulmonary TB is TB of any other part of body except lungs (TB in lungs is referred to as pulmonary TB) for public health reasons, governments want to find all cause of pulmonary TB as they are spreading TB through cough (infection) but causes of Extra-pulmonary TB don't spread TB by coughing and is not easy to transmit. It means P- and EP TB is not easily transmitted but can Possibly convert to P- and P+ TB.

Some patient say that during the medication period, it has no possibility to transmit, but it is not a reality. At the medication period, it has also possibility to transfer; it has also chance to become failure, default, and continuous relapse. The TB germ is still there, when we started to take medicine. However, patient says that when they were starting to take anti-TB medicine and thought that it has no possibility to transmit. Therefore, they start to sleep together, start to do hard work and share foods and pots.

In this research majority of respondent perceived TB differently. Among them, aware people are doing separate and clean behavior. At the period of diagnosis, health person give some knowledge about TB. 28 years, female, Janajati, code no. 15, was suffering TB from six months. Now, her medication is running last month. After her checke up, health personnel said that this disease was contagious and can be transfer. It might be the cause of alcohol, smoking and tobacco. Her beliefs that the disease is contagious and in the beginning of the treatment, she used to wear mask. 25 years, male, Brahmin, code no. 01, has same experiences about TB. The doctor find out his disease in private clinic and now he is taking medicine from government hospital. Doctor told him that it is contagious disease and it occur to those people who have the habit of using alcohol and cigarette.

Various social, cultural and economic factors help to understand about disease and its effects. These factors may be the cause of TB. Carelessness of health, economic conditions of family, balance diet, medicine facility, and belief in traditional healing practices are the dominant factors of TB. However, awareness about TB may play vital role until and unless the condition of patient is normal.

6.5 Economic Condition and Nutrition Management Problem

The statement 'tuberculosis is a disease of poverty' means poor people who have economic problem could not managed balance diet that's why they are infected by TB. Literature shows that more TB patients are living in Asia and Africa than America and Europe. In Nepal, estimated to about 45% of total population is infected with TB (HERD, MOHP). A high rate of TB is a cause of poverty. In this research the majority of respondents were lower and middle class of economic statuses. They had problem to manage food so after suffering; they had no normal eating behavior as previous. Many respondents were doing hard work during medication period same as before. Medicine is free because of DOTS policy but some patients spend more money (5000 to 40,000) in diagnosis period. It was difficulties maintenance balance diet because they already spent money and become jobless. If patient has difficult to maintain diet, it wills a greater possibility for a return of the disease.

24 years, male, Brahmin, code no. 01 said *'I am a middle class people. In village my father, mother and sister are living. They are working in agriculture but totally traditional so they are dependent on my job'*.

59 years, Chhetri, female, code no. 05 said *'I am a very poor. I have no any land and property. I am liveing here on hotel. I ride rickshaw, which was given by Boss. I must pay him its rent'*

60 years, Madeshi, female, code no. 13 said *'we are middle class people. We don't have any land and property. We depend on my husband job. Our economic source is my husband's job.'*

42 years, male, Janajati code no. 17 said *'I am lower class family. I must do work for survival because there is no other way to survive. My families are also hoping me. Now, I am coming here to finish my work'*.

A person who has responsibility to manage family, it is difficult because s/he becomes weaker because of disease. In this condition, patients faced difficulties to give time and money to improve their health. There raises question that if people facing above situation how can they properly maintain nutrition food? Some respondent said that their current economic standard is changed because of TB.

'There are some changes. I left my job. We have problem to manage our family, because of poverty'. (21 years, female, Dalit, code no. 19)

'My economic condition has change because of suffering TB. I used to manage for my daily expenses from coaching fee but now I am dependent on my parents'. (24 years, national players of Janajati background, code no. 04)

'There is very much change after suffered from this disease, I was very weak. Therefore, I have to leave my work. My economic source was stopped. There were very much difficulties'. (30 years, male, Madeshi, code no. 08)

The economic status of the family directly affects people's health seeking behaviors. As long as the economic status of the family is strong, s/he will be able to feed nutritious foods. If the economic condition is strong, they would easily have access to get medical treatment but who have a problem to manage basic food then how can it be possibility to take balance diet. Therefore, it is one of the vital factors responsibilities for better health of individual and family. At this condition patient are unsuccessful to maintain his diet system. It may increase the possibility to become a relapse case.

6.6 Health-Seeking Behavior and Repeating the Disease

Health-seeking behavior is the important factor of relapse. People must improve their food habit in the medication period. A person's other habit such as alcohol, cigarette, tobacco can influences to develop TB and repeating again. In this research 78 percent of relapse respondent used to take alcohol, cigarette and tobacco after finished

previous medication period. Some respondent had taken alcohol during previous medication. They had own practice about foods and other habitual things and they follow themselves in which is necessary to avoid and which is not, when it takes and leaves. Some patients had taken alcohol in their cultural function (festival). Some of them avoid this habit during medication period and started to take after recovered. Only 22 percent of relapse respondent didn't have harmful habit but they had bad health seeking behaviors. They didn't take proper food in time and did not take care of their health. Somebody left medicine without completed dose and somebody give emphasis only his job.

56 years, male, relapse, code no. 21, had accepted that the cause of TB is his behavior. He always used to drink alcohol and he did not give priority to take food. Now he avoids those things like, Rakshi, Churot and Surti and also left his Job. According to him, his habit might be the cause of repeating TB. He also thought that it would be transfer by other. Similarly, 59 years, male, Chhetri, code no. 05, have similar response about lifestyle behavior. He has no family and house. He takes his food when he feels hungry. He has not regulation for food and uses cigarettes, alcohol and tobacco. Now he left his habit. He thinks that his habit might be the cause of becoming sick.

Some respondent said that the disease was the cause of their bad health seeking behavior.

Yes, I didn't care my health and my food habit. I had taken useless and harmful thing (Rakshi, Churot and Surti) which was the cause of TB .(67 year, female, Janajati, code no. 23,)

Yes, it may be the cause of my careless of my health and disease. I gave more emphasis to my work. I used to take alcohol and I careless to take medicine, I used to it when I get. (21 years, female, Dalit, code no. 19)

I spend a lot of time to earn money. I didn't give more time for my health; I took my food late and little. So that it had happened to me. (71 years, male, Dalit, code no. 26)

Following this statement, there is important to change personal behavior while suffering from any disease. The health person has advice that when a person infected from risky or communicable disease s/he must be separate from any function and cultural program. But they rather follow their cultural and family rule than their medicine rule. If people's health condition is vulnerable, at that time taking avoidable things has possibility to return TB.

6.7 Hiding the Disease and Transformation Possibility

In this research, the respondents had not participated in any social awareness programs about TB. They didn't exchange information and experience on a community level. Self-stigmatization is also creating huge gap between community and individual. Majority of respondent would not share about his/her disease with others. They wanted to hide their disease. Some patients wanted to keep it secret and they hide their treatment card in pocket when coming to treatment center. Even educated members feel discrimination that's why they want to hide the problem. Some respondents who were out of household and didn't give information about their own disease in his/her house members. They did normal behavior in neighbors and others.

45 years, Janajati, female, code no. 24 were not talking about this disease in her community (neighbor) but when she was very thin and weak then they asked her why are you thin? What happened and so on? Now health condition was improved. Therefore, community members take her normally. Her neighbor didn't know about her disease.

29 years, female, code no.11 has suffering from EP TB and she only knows about EP TB when she suffered. Therefore, she didn't talk about her disease with her community but she heard that TB is a contagious disease and it can transfer to other.

59 years, male, code no. 05, had two times suffering from TB but he doesn't know it is a contagious or not. He was not talking about TB with his friends or others. Therefore, he didn't know the perceptions of friends and community member about his disease.

In the research, I found through observation above 85% of the respondent do not use mask but only small number of patient used it when coming to receive medicine in the hospital because of fear of health professional. In the community, they didn't use mask. They behave normally although they were contagious and there might be a chance of transmission to other.

6.8 Belief and Understanding

Patient have their own beliefs and understanding about illness and its cause. So, they analyzed it according to their own perspective. We can found there was a large gap between belief and biological understanding of the disease. Patients understand different casual factor of their own disease, which play the role for their health.

According to them, their own type of understanding about the cause of having TB. At first majority of respondent didn't think their illness may be the cause of TB. 60 years, female, Janajati, code no. 13, has different belief about her disease. In research, she said, *"My illness had started before one year. In the beginning, I had no idea about my disease. There was continuous fever and coughing. I went many medicals. When I used to take medicine, my illness begins to start"*. She was feeling that the cause of TB is medicine. When he started to take medicine for illness, it made TB. Similarly, code no. 24, 45 years, Janajati has different opinion about his disease. She said, *"Before one year, I was not feeling well. One day, when I was cutting grass the water started to rain. I had no umbrella and there was no shelter. I got wet then my heart become weak. Fever was started to come with continuous khoki. This was the cause of my disease"*.

Above two respondent define the cause of TB in own way although both causes are different then medicine perspective. This is the different between perception of people's and medical rules

Some respondent define a cause according to own understanding which is near the medical definition. 56 years male, Janajati, code no. 21, said, *"in my opinion, my disease was the cause of alcoholic habit (Rakshi Khane Bani) I used to take alcohol a lot. I was spending money in vatti and dispute started in house. Now I left this habit. I think the cause of my disease was not only of alcohol but also may have been*

transmitted by other. 71 years, male, Dalit, code no. 26, said, 'in my opinion previous TB was the cause of relapse. It was to remain the previous TB in the corner of my body; otherwise, it may be the cause of my occupation. I spend more time to my work and careless my food time'. 27 years, male, Chhetri, code no. 25, said, "I think, cold, dust, steam fume, pollution, hotel foods friend's impure food (Jutho Khana) etc. may be the cause of my disease'. 57 years, male, Brahmin, code no. 27, said, 'In my opinion, at the past I was very fat and suffered from diabetes, I started to control my diet. Then I was feeling weak and body pain. This may be the cause of this disease'.

Belief and understanding, two variables, are dependent on individual's social/cultural practices. So that, different types of patients express will be seen the same disease differently. Some understandings of causative factors are near the medical science and some are totally near the traditional cultural aspect.

CHAPTER VII

SOCIAL CHALLENGES AND CONSEQUENCES OF RELAPSE

It is clear that when anybody is suffering from a long disease like TB, they have to pass through many social barriers and challenges. In the research, I found Patient had faced many difficulties due to TB like family and society makes discrimination behavior, economic condition was going to poor, back from family decision power, and other unfair situations were facing there.

7.1 Stigma and Discrimination

Stigma is a very abstract subject and difficult to measure about the level of it. In the health and health care issues, there are many social stigmas, which directly affected person's health seeking behaviour and medicine perception. According to Brakel (2005) stigma affects people psychologically. It often lowers self-esteem and can cause or aggravate psychiatric morbidity. Both enacted and perceived stigma restricts social participation in a wide range of areas. He further says – stigma has many components. Stigmatizing attributes in a community play a major role but are not the only source of stigma. Other important sources are the media, health and social services, the educational system and legislation. Stigma should be assessed from the community perspective as well as the perspective of the affected persons and their family.

Discrimination is signifies an unfair relationship, which helps to create social hierarchy. Stigma and discrimination are interconnected elements. It is difficulties to define separately. Sushil et al (2007) says that two forms of discrimination one is direct and other is indirect. Direct discrimination occurs when a person is treated less favorably, on the grounds of their disease then others are or would be treated in the same and similar circumstances. Indirect discrimination occurs when a requirement or condition is such that a considerably smaller proportion of people with the disease can comply with it and it cannot be shown to be justifiable other than on health ground.

In this research, I found some patients facing the problem of deep stigma and discrimination. 35 years, Dalit, women, code no. 14, who have a pulmonary TB, have facing many stigma and discrimination by her father-in-law and mother-in-law. After medicating, she is feeling good but they say that she has suffering TB and going to die soon. So she is facing mentally torched by her family members.

15 years teenage boy and studying at secondary level student, code no. 06, has extra pulmonary and pulmonary positive TB. He is not facing any stigma and discrimination in household but his friend treat him negatively when he is in the school. He does not want to miss classes. Therefore, he is going regularly but there is not a same behaviour as previous. His sitting bench is separate from the other students because of disease. Therefore, he is felling uneasy in school.

60 year's woman, code no. 13, is normal feeling from neighbors and villagers. However, in house, her sister-in-law discriminates and she does not come near to her. She tries to keep far her children from grandmother but they (children) come to near and sit with her. 21 years young, female, Dalit, code no. 19, who had suffered by this disease first time when she was seventeen. At that time, she was doing housework job in Pokhara. When house owner knows about the symptoms of TB, they send her to Butwal (in her house). She missed her job. Now when the symptoms occur again community members treat her negatively.

In the case of TB, there is still stigma and discrimination in the society even it is a curable disease and low possibility to transmit to other during the patients medicating period. TB patients are discriminated by the society not on the basis of gender, caste and age but on the basis of perceptions against TB. Here are some patients who have same experience while treatment.

'Yes someone discriminate me. One time, I was going to checkup my disease in the hospital. I was very hungry and I had no money. There was a man whose house was nearer the hospital; I requested for some food, I also said about my disease. He took his house and gave some food on banana leaf. He and his wife treated me dishonorably. I didn't accept that food. (27 years, Chheri, male, relapse, code no.25)

Somebody little bit treated me negatively, mainly my neighbors. When this disease started to suffered me, I left my job and other activities. They ask me why you left the job. Why you are living in the house? (24 years, male, Brahmin, Code no. 03)

I found majority of respondent did not want to share the discrimination faced by them but actually, they were facing many types of discrimination silently. Many respondents wanted to hide the disease in their community; they did, as they were normal because if community member know about the disease they may face social stigma and discrimination. Therefore, they hide it.

7.2 Difficulties to Improve Economics Condition

There is a direct relation between economic condition and TB disease. In this research many patient spent a lot of money during diagnosis period. If patient's economics status is poor, it is difficult to manage and maintenance. During medication period patients need to maintain their diet and transportation fee. TB is called a disease of poverty. I found most of people were economically poor. They were working only for survival. Only few patients have good economics condition. If anyone is economically poor and infected by TB then economics conditions is started to become poorer because they are going to be jobless and workless. If economic condition is poor, it is difficulties to maintain the same economic condition as previous.

In many cases, poverty is considered the leading risk factor or determinant for such disease and in some cases the disease themselves are identified as barriers to economic development. Poverty is in many cases the single dominating factor in higher rate of prevalence of these diseases. Poor hygiene, ignorance in health related education, non-availability of safe drinking water, inadequate nutrition and indoor pollution are factors exacerbated by poverty. ([www. Wikipedia.org](http://www.Wikipedia.org))

21 years, married female, code no. 19, has difficulties to maintain her daily needs because of relapse. Now, she is living in bank of Tinau River in Sukumbasi Basti. She has not any property and land and now she is jobless. Therefore, she feels that she is going to be poor and weak because of TB. She already left her job and depend on husband's small job, because of difficult facing to manage recent family life.

A young boy of 27, code no. 25 left his job due to a relapse. At first, he spent around 50,000 above rupees for diagnosis. At the very beginning, he was himself helping his family economically but now he has no job. He is depending upon family but there is no bigger economic resource.

32 years, Janajati, young man, code no. 29, had returned from Saudi Arab because of illness. He started to checkup his health in Kathmandu and spent money a lot. At first, the doctor did not found his disease and gave him other medicine. Again, he went to hospital and then clearly seen that it was TB. He spent a lot of money because of illness when he was in Saudi Arab and lastly he left his foreign job. Now a day his economics condition is going down.

Weak nutrition or lack of balance diet is determining cause of person's economic condition. The respondents give information that their economic condition are going to poor because they left work (job) and unsuccessful to continue it. If economics is going to worse, it is difficult to improve health -wise.

7.3 Self-Barrier on Social Activities

In every community, we can see there is a launching of many social activities. All members are participating and they have their own responsibility to conduct these activities but unhealthy people because of TB couldn't participate in any social activities because they are suffering from disease and feeling weak. Therefore, patients are themselves feel stigma and do not to participate any community programs and other socials activities.

Patients develop their belief based on their knowledge. So, patients themselves avoid to participated any programs. Patients generally isolate themselves from friends, family members and children because of fear of transmitting the disease.

59 years, male, relapse, code no. 38, was not afraid when the disease repeated again because he knew and take it normally. But, he was not participated in social programs. He didn't think about TB is a communicable disease but people say it is contagious. At home, he has behaved differently. He sleeps in different room and

different eating behaviour than other family member. He did not want to tell about this disease to others.

62 years, male, relapse, code no. 36, was again suffering from TB. He thought TB is a contagious disease. Nobody of his community member was suffered from this disease. Therefore, he didn't talk about TB with them. He did not know anybody treat negatively. He was living separately. He has own bed and nobody come near him because of fear of transmitting.

56 years, male, Janajati, code no. 21, is suffering from TB. He takes it normally now but previously he faced some challenges. People said TB is a deadly disease and he was going to die soon but he successfully recovered. Now situation is change. Medicine is available everywhere. He has not experience about others negative behavior or attitude from his family and society. He did not take and give impure (jutho) food. He has separate behavior in house. But he thinks people can talk about his disease behind him. At first when he knows about the disease, he felt shy but now taking it normally.

A young educated Brahmin, code no. 03, left his job because of TB. He did not help his father's business and givup his aboard study plan. He reduces to meet his friend. Somebody had little bit treated negatively. People ask him why you are in the house. Why you left the job etc. but his family is educated so they do not say anything and do not behave differently. Now he is doing care his food habit.

Most of the patients have faced different types of social stigma and self-barrier of their choice then previous. Many respondents did not want to express about his illness and they were hiding their disease in community. During interview period they did not interested to give answer openly. All of the TB patients are facing verious types of stigma but most of patient did not show any type of change and taking it normally.

67 years, female, relapse, code no. 23, has different experiences. There are no any changes in her life because of relapse. Nobody has found treating her negatively. She was sleeping separately but she take food with her family as same as before. She has

a little child who is sleeping with her in the same bed. She participated in other social works.

32 year's, male, Madeshi, code no. 02, have a similar experience. Family members treated him good. They support him. Therefore, he was not treated different behavior previous and present. That's why; he eats and sleeps with family members.

This is one of the consequences of TB, which created the distance between previous normal life and present suffering life. In normal life, there is no any barrier and stigma but TB, created many barriers and challenges. It shows that disease not only coming alone but also bringing social and other challenges.

7.4 Avoid and Back to Desire

Every respondent have different understanding about what is necessary to take and what to avoid in the case of TB. It means different respondents have different meanings about their feeding habits and other lifestyle arrangement. It depends on their cultural norms and values. Culture influences the disease and illness are depends according to cultural knowledge and practices although; it may be the disease and illness or may be any habitual cause. According to Kleinman (1980) – illness is a response to an imagined, perceived or even desired disease. We also can think of illness behavior as if it were mimicked consciously or unconsciously. Clearly, disease comes down to a position of the conceptual modes used to label to those problems. In the same way, in my research I found TB related conception is near this concept.

Among those interviewed the majority of relapse respondents' left alcoholic habit but occasionally they started then again. It means it is difficult to suppress their desire due to disease therefore, they return to use those things which medicine rules defines to be avoided.

32 years, male relapse, code no. 29, had an alcoholic habit at previous but he left this habit when TB is appeared again. After using medicine he cured but he again started to take alcohol. As a result, he become relapse and again left his alcoholic habit. Avoiding and taking is continuously running in his life. He is a person having Janajati background identity called 'Matawali'. It means alcohol is a culturally acceptable

food for those (Matawali) people. Maximum Janajati people like Magar, Gurung, Tharu, Shrestha etc have an alcoholic experience and they use alcohol as compulsory rituals objects. Other respondents then Janajati also included alcohol as a "cultural food"

59 years, male, Chhetri, Rikshaw driver, code no. 05, had take cigarette, tobacco and alcohol before previous suffering TB. When he stoped his medication then again started to take all of those avoided things. Now he is in relapse and avoiding it.

67 years, female, relapse, code no. 23, had habit of smoking cigar and chewing tobacco. Sometimes she used to take alcohol. Ten years ago, she suffered from TB. After that, her health was good and she again started to take avoidable things. After relapse, she stopped to take those things.

21 years, Dalit, female, relapse, code no. 19, a similar experiences. At the previous, she used to take alcohol. Now she was suffered by TB though she left her habit but after stopping medicine she started to take alcohol little again. Now, after relapse, she is taking anti-TB medicine and left her alcoholic habit.

Sometime medical rules force to avoid alcohol and other such things, which are harmful for human body, but cultural norms force to adopt those things. This is not a holistic cause of relapse but it may prolong TB or increase the chance of a relapse.

7.5 Loss of Decision Making Power

When anybody is feeling sickness obviously, s/he is losing immune power. They are not only losing their immune but also losing their decision making power as a family member or community member. They cannot act as an active member of a community. Therefore, the disease not only makes people's health condition weak but also going far from the family and society. As a TB patient, they are feeling more weak physically. In research, I found some patients who lost main decision-making powers during and after after suffering TB disease.

50 years, female, code no. 18, said that at a previous time she managed her family and her house. She was a head of her house. Now the situation is change, she is very week and staying on the bed and her daughter-in-law manages and handles the things.

45 years, female, code no. 24, was middle class economically. At home, she was leading all of the things but before one year, she was very weak because of TB. Now she left her family work and her daughter in law manages her family. Now she is in the city (Bhairahawa) care with her son and daughter-in-law.

50 years, Chhetri, male, code no. 34, had faced same experiences as above. He said, *'it is change somehow as I lost my job because of this disease. If my wife had not a job then today we had to stay in the street begging for money as a beggar. I used to work in spice factory. No I am fully dependent on my wife'*.

When a person is physically weak, s/he also lost their family, social and other power, which they had gained in their previous healthy life. In normal life, every individual is playing many roles in the society. If his/her normal life is changed due to disease, the social role of the person changes. The researcher found that respondents positions is lost because of disease.

CHAPTER VIII

SUMMARY AND CONCLUSION

8.1 Summary

Tuberculosis is a major public health problem in Nepal. An estimated about 45 percent of the population are infected with TB among them 60 percent are adults, who are main manpower of the country. Every year 40000 patients are contract TB among them 20000 have infectious diseases. These 20000 infectious people are able to spread the disease to others. Since 1996, DOTS program entered Nepal. The result of this program is good but there are various aspects to be improved. With medication of DOTS, there are still a relapse and default problems.

This study is based on social and cultural aspect of TB patients who were taking treatment in the Rupandehi district at different DOTS centers. The major focus of the study is relapses of TB, its perceived causes and consequences. Three major types of TB are presented in the research. They are pulmonary positive, pulmonary negative and extra pulmonary TB. Among them the high rate of respondent (81.21%) were suffering from pulmonary positive TB. The cause of high rate of such TB is due to a high rate of infection. Nowadays, varies TB program are launched in the society by different government and non-government agency but the heavy rate of infection is hardly less. There are some reasons behind this cause. Economic conditions and nutrition maintenance problem, awareness, knowledge and concept, health seeking behavior, long medication practices, different belief system on medicine practices and social and self-stigma are the dominant factor of TB problem.

In the research I found that those the people who suffered from TB delayed going to hospital for treatment. More than 26.31 percent of respondent goes hospital to taken treatment after four to six month from suffering and more than 18 percent patients go to hospital to get treatment after seven month to one years. This is also one of the national conditions of TB. According to DOTS policy, patient must take the medicine daily under the observation of a health professional. In this case the condition is behind the policy of DOTS. More than 71.05 percent respondent comes to take medicine for 7 days and 13.15 percent respondent come to take medicine more than

10 days. Only 13 percent of the respondents of the research had taking medicines on the observation of DOTS.

Among the respondent, the belief of TB is different in different people. Before the diagnosis, only 42 percent of the respondents accepted the diagnosis whereas the rest didn't and some accepted that they are suffering from TB. Among it, the seven percent respondent were fainted when they knew it was TB. Long duration of medication period is also the cause of re-infection or relapse. More than 38 percent relapse respondents leave the medication during the period. When a person suffering from TB the health person convey that TB is a normal disease and easily cured when take medicine normally. So, when patient understand that it is normal diseases then they disorder their health behavior so the disease again occurs. Nutrition diet is another cause of TB relapse. As we know, in Nepal many people are under poverty so they do not take proper food for the health. But TB patient most take nutrition diet when taking medicine. When a person unsuccessful to maintain diet they will be weak and there might be the relapse.

The respondents were facing many stigma and discriminations in the society. As people suffering from TB, they are hated by the society and friends. People of the society are thinking that TB is a transmittable disease and there is possibility of transmission. So, patient feel nervous and didn't like to come out from home and not want to be out in the society. Reoccurring TB makes a patient's economics condition very weak. Patient has difficult to maintenance medicine and food, which is the cause of low immune power in their body. When patient cured the disease and back to normal life, it is good but his/her economic condition was worse and must pay credit or spend money. It is difficult to improve economic life again. When first time suffer from the disease patients avoid their smoking and drinking habits like Rakshi, Churot and Surti and such harmful things but after cured again suffering from same disease because started to use those thing again.

These are the consequences of TB relapse. After relapse, the patients become economically week, socially stigmatized, loss to decision power in the family and other so many problems and challenges occur in their life.

8.2 Conclusion

There are two line practices in our society about understanding of TB disease and its treatment. One is followed by health person in the norms of medicine rule and another is followed by patient which comes through cultural base of the society. These two practices are the root causes of relapse.

The patients of TB come from cultural practices, which come through the society. The victims identify every disease in their own way. They do not want to change their thought easily towards the disease. They follow the medicine rules when the emergency case of disease appears. After feeling some relief, they start to follow same previous life style. On the other side, health person who have a responsible for the treatment of TB patient does not want to know the cultural practices of patients and give the medicine on base of the medicine rule.

These two practices show the present condition of TB relapse. As long as there is not understanding between medicine practices and cultural practices, the burning problem of TB will be existing in the society.

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Treatment information

- 1) Name of patient :
- 2) Age:
- 3) Registration Date (year and month)
- 4) Registration number:
- 5) Registration category: (New, Relapse, treatment failure, defaulter, transfer in other)
- 6) Treatment start date:
- 7) Treatment Outcomes: (Cured, Completed, Failure, Died, Defaulted, Transferred out, other)
- 8) Treatment Stop date (year and month) :

Demographic information

1 General Introduction

Name:

Sex:

Address:

Age:

2 Education

- | | |
|----------------------------|---------------------------|
| a) Primary | b) Secondary |
| c) Higher Secondary Higher | d) Above higher secondary |

3 Ethnic Group

- | | |
|------------|-------------------------|
| a) Brahmin | b) Chhetri |
| c) Magar | d) Others (Specify....) |

4 Type of Family

- | | |
|------------|----------|
| a) Nuclear | b) Joint |
|------------|----------|

5) Marital status

- | | |
|------------|--------------|
| a) Married | b) Unmarried |
|------------|--------------|

6) Occupation

- | | | |
|---------------|----------------|-------------------------|
| a) House wife | b) Agriculture | |
| c) Job holder | d) Business | e) others (specify....) |

INTERVIEW QUESTIONS

General Question

1. When and how did your illness start?
2. When and how did you learn that it was TB?
3. Was it a surprise and what was your reaction?
4. How long after the first symptoms before you were started on anti-TB treatment?
5. How did you end up on anti-TB treatment?
6. How long between the end of the previous treatment and the relapse registration?
7. After care treatment, which were the signs of something becoming amiss.
8. Which practical actions for the illness were taken before anti-TB treatment?
9. Others in your family/household with this illness before or after you?

Treatment experiences

10. When you came for your medicines did you usually come alone?
11. How much of the day was spent to pick up the medicines?
12. Approximately what was the total monetary expenses, including costs for the coming and going to the treatment center?
13. How often did you miss coming for the medicines and why?
14. What other treatment did you have parallel to the anti-TB treatment?
15. Did you face any problem from service provider at the previous treatment?
16. Have you faced any situational challenges in previous treatment time for missed?

Causes of TB

17. Has health personnel spoken to you about the cause of the disease, if yes, what is the cause according to him?
18. According to your own belief what was the cause of TB?

19. At home, what do people around you think about the cause/s of TB?
20. At home, what do people around you think about the cause/causes for your relapse.
21. What according to your own opinion caused your relapse?
22. Could you have done anything to avoid having a relapse?
23. At the end of the previous treatment did you suspect that perhaps the disease was not gone? If so - why
24. Your health-seeking behavior after again becoming sick? Please, in some detail!

The consequences of relapse

25. How did you react learning that again it was TB?
26. How you experience the present treatments?
27. Do you believe that you are contagious - that you can give the disease to others?
28. Do members of your family or others around you think that you are contagious?
29. Are there people in your community who think that TB is a deadly disease?
30. Are you afraid that you will not be cured?
31. What has changed in your life because of the relapse?
32. Are you participate any social program?
33. Who decide about your treatment?
34. Have any change in the household because of disease?
35. How is you economics status before you got sick?
36. Your present health status?

APPENDIX: 3**Relapse Respondent Information**

SN	Age	Ethnicity	TB Type	Regd No	Code No
1	59	Janajati	P +	2	38
2	57	Brahmin	P +	43	27
3	27	Chhetri	P +	104	25
4	56	Janajati	P +	13	21
5	32	Janajati	P +	23	29
6	40	Janajati	P +	----	7
7	30	Madesi D.	P +	80	8
8	55	Janajati	P +	23	33
9	67	Janajati	P +	47	23
10	71	Dalit	P +	26	26
11	21	Dalit	P +	---	19
12	24	Brahmin	EP	28	3
13	61	Janajati	P +	97	37
14	49	Janajati	P +	14	35
15	40	Janajati	P +	13	22
16	59	Chhetri	P +	53	5
17	62	Janajati	P +	6	36
18	60	Janajati	P +	73	28
19	44	Janajati	P +	40	31
20	42	Janajati	P +	42	17

APPENDIX: 4**Information of New TB Patient**

SN	Age	Ethnicity	TB type	Regd No	Code No
1	27	Janajati	p-	25	16
2	24	Janajati	P +	7	4
3	45	Janajati	P +	5	24
4	40	Madeshi D.	P +	25	30
5	35	Madeshi D.	P +	14	14
6	65	Madeshi D.	P +	16	10
7	28	Janajati	EP	135	32
8	25	Brahmin	P -	158	1
9	50	janajati	P +	29	18
10	24	Chhetri	P +	99	20
11	32	Madeshi D.	P +	26	2
12	55	Madeshi	P +	10	12
13	50	Janajati	P +	95	34
14	38	Janajati	P -	55	15
15	28	Madeshi	P +	21	9
16	15	Brahmin	P +/ EP	31	6
17	60	Janajati	P +	32	13
18	29	Janajati	EP	46	11