Chapter-I

*Introduction, Review of Literature, Data and Methods*
Chapter One

“The solution of the tuberculosis problem is partly dependant on the removal of other evils and inequalities which constitute, no doubt, a more fundamental problem than does tuberculosis itself.” ~Quoted in Farmer, 1999.

1.1 Introduction
The greatest challenge facing the world is to combat and eradicate disparity or inequality. This disparity or inequality can be socioeconomic, regional, health or gender. A growing body of research demonstrates that the differences in health are not random; they are systematic and follow underlying hierarchies of social disadvantage (Braveman and Gruskin, 2003; Starfield, 2001; Karim et al., 2006). Social disadvantage also includes the social conditions where people live and powerfully influence their chances to be healthy. Indeed factors such as poverty, social exclusion, discrimination, poor housing, unhealthy early childhood conditions and low occupational status are important determinants of most of the diseases, deaths, and health inequalities between and within countries (WHO, 2004).

The association between poverty and ill-health are intertwined and has causality running in both directions (Wagstaff, 2002). It is also found at times that poor countries and poor people within a country suffer from a multiplicity of deprivations which translates to ill-health (Claeson et al., 2001; World Development Report, 2001) and are successively associated with substantial healthcare costs (Narayan et al., 2000). Concern about the links between ill-health and impoverishment have placed health at the center of development agencies’ poverty reduction targets and strategies (DFID, 1999) and has strengthened arguments for a substantial increase in health sector investment to improve access for the world’s poorest people to combat poverty as well as reduce disease burdens (WHO, 2002). Millennium Development Goals (goal 6, target 8) of rolling back of HIV/AIDS, tuberculosis (TB) and malaria are specific health targets, have been set to reduce the burden of disease. The specific indicators for addressing tuberculosis are to halve the prevalence and death rates associated with tuberculosis between 1990 and 2015 (Indicator 23), to detect 70 percent of
new smear positive TB cases arising annually and to successfully treat 85 percent of these cases by 2005 (Indicator 24).

1.1.1 Tuberculosis (TB)

Tuberculosis, widely known as TB, is a disease caused by infection with the bacterium called *Mycobacterium tuberculosis*. It is an ancient disease where in about 400 BC; the Greek physician Hippocrates described a disease thought to have been tuberculosis. It was then named as phthisis meaning “to waste away” a Greek word and then as consumption. Johann Schönlein coined the name tuberculosis in 1839 until then the responsible pathogen for the disease was not been discovered. Finally, Robert Koch identified *M. tuberculosis* in 1882. In 1890, Koch reported on the extraction of a bacterial protein from dead bacteria recovered from tuberculosis infections. The protein, which he detected, was tuberculin, which is an important means for detecting the presence of the bacteria.

The saga of tuberculosis control in India spans many decades. As in most nations, the initial anti-TB measures implemented in India was unplanned and *ad hoc* in nature, confined mainly to the establishment of hospitals and sanatoria. Attempts to tackle the problem of TB through organized efforts actually had their origin in the late 1930s. Agarwal, Vijay and Kumar *et al.* in 2005 have described the chronology of important landmarks in the history of TB control in three phases. The first phase was termed as ‘The Four Decades Prior to Tuberculosis Control Programs (prior to 1962)’. During this period, a number of TB dispensaries and societies launched campaign against TB to educate people about the cause and prevention from TB. Effective drugs against TB began to be available only during the time India got independence. In addition to mass BCG campaign started in 1951, 165 million vaccinated children were also administered tuberculin tests. It was for the first time in the history of India that messages related to health and prevention of disease was taken into the remotest part of the country. The BCG campaign also helped in raising awareness of the disease as a public health rather than a purely clinical problem, in the minds of the medical community. Another surprising reveal of this campaign was the high prevalence of TB infection in most parts of the country. The second phase is about 'three decades of the National Tuberculosis Program (1962-1992)' and the third phase is about the Revised National Tuberculosis Program from 1993 to present. The Revised National TB Control Program (RNTCP) was launched all over India in 1997, after extensive field-testing for technical and programmatic feasibility. Although the tuberculosis program has clearly covered a long way but the journey is still far from over.
1.1.2 Epidemiology of Tuberculosis

Quantitative information about the epidemiology of tuberculosis has been available only in the last half century. In India until April 2012, tuberculosis was not considered as national notifiable disease and hence, no routine health data been collected for estimating the disease state in the country.

Epidemiology of TB is also been considered as model of web of causation of disease where the agent, host, and environmental risk factors play their respective role. Traditionally, there have been three approaches to the epidemiology of tuberculosis, namely:

a. **The Etiologic Approach (analytic epidemiology):** mainly dealing with the risk factors associated with the agent – *M tuberculosis* i.e. an understanding of the exposure to risk factors which are leading to the TB infection.

b. **The Descriptive Approach:** dealing with the traditional incidence and prevalence of tubercular infection i.e. the frequency and distribution of the disease in a given community.

c. **The Predictive Approach:** dealing with what happens next – forecasting the tubercular epidemic i.e. the modelling and forecasting of the epidemic, based on observations from the past.

![Figure 1.1: A model for tuberculosis epidemiology, following the pathogenesis of tuberculosis. Source: American Thoracic Society, 1981.](image)

Above described model has been borrowed from American Thoracic Society where it was used in 1981 (Figure 1). According to this model, there are four steps in the absence of any intervention: exposure, infection, diseases, and death. As it is widely known that TB is an airborne disease and exposure to infectious case is a prerequisite for acquiring the infection. Exposure to TB bacilli is based on various factors like: number of incident infectious cases in
the community; the duration of their infectiousness; and number and nature of interactions between a case and contact per unit time of infectiousness etc. Relative concentrations of infectious droplets are necessary for transmission of infection. After transmission of the infection it remains in the body of an individual as latent infection and develops into disease only in the presence of risk factors like HIV infection, cigarette smoking, alcohol abuse, injection drug use and malnutrition, along with poor environmental (indoor air pollution, ventilation) or socioeconomic condition (crowding, urbanization, migration, poverty) (CTD, 2011). They adversely affect the immune system, and so could influence the tuberculosis disease incidence (Agrawal & Chauhan, 2005). Several other medical conditions are commonly associated with tuberculosis such as silicosis, where the risk has been shown to be 26 times higher to develop tuberculosis (Paul, 1961). It has also been found to be three times more in diabetics than in the general population (Opsahl et al., 1961), 10-15 times higher in patients with end stage renal failure and those with haemodialysis (Andrew et al., 1980; Belcon et al., 1982) and five times higher in male gastrectomy patients (Thorn et al., 1956). The presence of factors such as adequate ventilation or personal protective equipment like face masks worn by the infectious patients dramatically can reduce the possibility of the exposed person to be infected.

Tuberculosis may spontaneously remit if the disease is not treated. It will recur in a large proportion of cases and can lead to death. The risk of dying due to TB depends upon the site, type and severity of the disease as well as the timeliness and the initiation of appropriate treatment. According to current estimates TB mortality in India is 26/100,000 population in 2010 (WHO, 2011).

1.1.3 Tuberculosis Burden in India

India is one of the highest TB burden countries in the world, accounting for one fifth of the global incidence - an estimated 2.0 million cases annually, of which about 0.8 million are infectious new smear positive pulmonary TB cases (Central TB Division, 2008). India is 17th among 22 High Burden Countries in terms of TB incidence rate (WHO, 2010a). Tuberculosis continues to be a major public health problem in India affecting the most productive age group of 15 to 54. Nearly 40 percent of the Indian population is infected with the TB bacillus (CTD, 2009). Furthermore, the emergence of multi-drug resistant strains of tuberculosis is complicating treatment regimes, as well as posing a serious threat to the health of the public. One of the primary causes of multi-drug resistance is non-adherence
on the part of patients to medically prescribed drug regimes. It is estimated that 25 percent of all MDR-TB cases worldwide are in India alone (WHO, 2010b).

During a nationwide tuberculin survey in 2000–2003, higher rates of TB transmission were observed in urban than in rural areas. In urban areas, transmission was higher in slum areas (Chadha et al., 2005). As known, metropolitan cities in India have recently witnessed a higher population growth rate than other areas due to industrialization and in-migration, resulting in the rapid mushrooming of slums (Registrar General of India, 2001a, 2001b). Poor living condition, overcrowding and malnourishment which are prevalent in the slums means that people residing in slums are at greater risk of TB infection. The association between TB and poverty is also mediated by smoking, stress, social deprivation and poor social capital. The financial hardship caused by TB, particularly for the poor, is likely to deter many of them from seeking treatment (Needham et al., 2003). Further, deaths due to TB exceed the combined deaths from all other communicable diseases and account for 26 percent of all avoidable adult deaths. The most devastating impact of TB is death; without treatment, two-thirds of smear-positive cases die within five to eight years, with most dying within 18 months of being infected (Styblo and Rouillon, 1991). It is also the leading killer of women, causing more orphans than those produced by all causes of maternal mortality combined (Central TB Division, 2009). TB is not only the result but also the cause of poverty through loss of work, absence from school and payments for medical expenses. It also places an extraordinary burden on the families, communities and on government budgets. Besides loss of productivity, the cost of treating TB can also be significant. As estimated, the mean household spending on TB can account for as much as 8-20 percent of annual household income varying by region (Russell, 2004) and subsequently this burden has impact on children in the family. Each year, a significant proportion of children from families in India where the primary breadwinner has TB are forced to drop out of school or seek employment (Rajeswari, Balasubramanian et al., 1999). TB is a major barrier to economic development in account of direct healthcare costs and indirect economic costs.

1.1.3 Tuberculosis, HIV/AIDS and Multi-drug resistance: a tri-threat

Co-infection of TB with HIV and drug-resistant tuberculosis has threatened to complicate the tuberculosis situation in the country. As HIV continues to spread, warnings have been issued to disastrous AIDS and TB epidemics “new wave” countries of Eastern and Southern Africa, including India. India alone accounts for 20 percent of all new TB cases arising in the world each year (WHO, 2005). Simultaneously, all states and union territories in India have
reported HIV/AIDS cases and the six highly prevalent HIV states are prone to the epidemic of TB and HIV co-infection. Whereas, tuberculosis is the earliest opportunistic disease to develop among HIV positive people due to their weak immune system. Similarly, HIV infection is the most powerful risk factor for development of TB infection to TB disease among the persons infected with TB bacillus. In addition, the fact that TB shortens the survival of patients afflicted with HIV infection, accelerates the progression of HIV, and causes death in one third of people with AIDS worldwide (Vaidyanathan & Singh, 2003). HIV also curtails the effect of tuberculosis programs by lowering the life expectancy of those receiving the treatment.

Resistance to drugs is another major problem that has started striking the nation. Multi-drug resistance (MDR) is a stage of tuberculosis that occurs when a body develops resistance power against the first line drugs usually given for treatment. MDR-TB is important because patients with this type of drug resistance respond extremely poorly to the standard anti-TB treatment with first-line drugs. The treatment of MDR-TB is highly expensive and can bring the household/individual in debt. According to WHO (2010a), India had an estimated 64,000 multi-drug resistant (MDR-TB) cases out of 1.5 million RNTCP notified cases of pulmonary TB, the highest in the South East Asia region (WHO, 2011). These two problems have hindered the progress made so far in the diagnosis, treatment success, and control of tuberculosis.

1.2 Literature Review

1.2.1 Treatment seeking behavior of tuberculosis patients

Studies in several countries found that in most of the countries, despite of implementation of the National TB Program (NTP) with quality assured and subsidized TB diagnosis, many patients with symptoms of TB, including the very poor seek care from a wide variety of healthcare providers outside the network of NTP services, who often provide care of questionable quality at a high cost to patients (WHO, 2000; Uplekar et al., 2001b). Yamasaki-Nakagawa et al. (2001) found that women in Nepal were more likely than men to seek help from traditional healers first and longer patient delay among women was contributed by consultation with traditional healers and more frequent visits to healthcare providers before final consultation with the National Tuberculosis Programme. The scale of this is reflected in the findings from a study by Rahman (2000) in rural Bangladesh, where 86 percent of women received healthcare from non-qualified healthcare providers. Similarly, in a community-based study done by the National Tuberculosis Institute, Bangalore during
October 2003 to June 2005 on health-seeking behavior patterns of persons with pulmonary symptoms living in slums shows that only 50 percent of the persons with pulmonary TB had taken action for relief. Of these, three quarters had first approached private health facilities. Out of all cases interviewed with PTB (Pulmonary Tuberculosis) about 50 percent visited two health facilities before diagnosis and 87 percent visited two or more facilities before initiating treatment. A majority of persons with pulmonary symptoms and PTB cases had poor knowledge about TB, and most of those with pulmonary symptoms were not aware of the availability of free anti-tuberculosis services at government health facilities. A similar finding from many studies is that for some illnesses, people will choose traditional healers, village homeopaths or untrained allopathic doctors above formally trained practitioners or government health facilities (Rahman, 2000; Ahmed et al., 2001; Yamasaki-Nakagawa et al., 2001).

According to Fishbein and Ajzen (1975) adequate knowledge is needed to change people’s attitudes towards their behaviors; these attitudes can then influence the intention to perform certain behaviors, eventually leading to practice of the desired behaviors. Level of knowledge and awareness about TB has correlation with health care seeking and presentation of disease (Hoa et al., 2003; Enwuru et al., 2002). Different studies have shown different impacts of knowledge, ranging from no relationship (Liam et al., 1999; Hill et al., 2005) to a positive link (Johansson et al., 1999; Bam et al., 2006) on determining the tuberculosis care and health outcome.

1.2.2 Delay and adherence to treatment of tuberculosis

Delay in diagnosis, which is an important factor for treatment of any diseases, can affect disease prognosis at the individual level and enhance transmission of TB within the community. This delay can occur at different stages. One is patient delay - the time interval between the onset of symptoms and patients’ first visit to a medical facility is often the biggest cause of delay. Factors contributing to this include distance to services, cost of care, and perceived poor attitudes of health workers and lack of knowledge about TB treatment. Research in Tanzania found that many people with TB adopt other approaches including visits to chemists, herbalists, hospitals and prayer houses before consulting a DOTS facility (Okeinor et al., 2007). Studies have also reported several factors which are associated with longer patient delays, including older age, education below nine years, lower family income, alcoholism and lack of knowledge about tuberculosis (Sherman et al., 1999; Wandwalo & Morkve, 2000; Rajeswari et al., 2002).
Another is the health service delay - the time interval between the first consultation and diagnosis can be caused by health workers who have low awareness of TB, particularly those working outside the primary level government clinics such as unqualified vendors and traditional practitioners. Even within government run facilities delay can occur, when staffs are poorly trained and only limited diagnostic facilities are available. Muniyandi (2004) concluded from his study in Tiruvallur district of Tamil Nadu that the average number of days delayed from onset of symptoms to diagnosis of TB was three times more in non-DOTS area (107 days) as compared to DOTS area (30 days). Additionally, proportion of patients who completed treatment successfully was significantly higher in DOTS area (75 percent) as compared to that of patients in non-DOTS area (61 percent).

Poor patient adherence to the treatment regimen is a major cause of treatment failure and the emergence of drug-resistant TB. Earlier research reports that travel expenses, travelling to treatment centres, male sex, poor patient information and communication, alcoholism and homelessness are the major determinants of non adherence to anti-TB treatment (Naing et al., 2001; O'Boyle et al., 2002; Comolet et al., 1998; Liam et al., 1999; Brudney et al., 1991). Patient adherence to the standard anti-TB therapy in developing countries has been estimated to be as low as 40 percent (Dye et al., 1999). A study in Mumbai found that around 16 percent of pulmonary TB patients receiving DOTS were non-adherent to anti-TB therapy. The study also found besides smoking, travel related factors such as distance and time are major determinants of non adherence to anti-TB drugs among newly diagnosed patients. Smoking and alcohol consumption during the treatment period are major risk factors for non adherence among residual other group of patients (Bagchi et al., 2010). In a prospective cohort study of Bangkok, Okanurak et al. (2008) found that among patients, females had a higher success rate of treatment than males and patients with regular incomes had twice the likelihood of success than the unemployed. Additionally, patients with high knowledge levels were more likely to complete treatment (OR = 2.0, 95 percent CI 1.2–3.4), while those with adverse effects were less likely to adhere (OR = 0.6, 95 percent CI 0.4–0.9).

1.2.3 Economic burden of tuberculosis treatment

Scoones (1998) defined economic burden as the expenditure on seeking treatment (direct cost), production and income losses (indirect cost), related coping strategies and their consequences on the household livelihood in terms of indicators such as the number of workers and working days, asset portfolios, income and food consumption levels.
In developing countries, high out-of-pocket payments, an absence of risk-pooling mechanisms in health financing systems and high levels of poverty can result in catastrophic healthcare expenditure (Xu et al., 2003). Costly healthcare also deters people from using health services thereby generating prolonged or worsened health problems (Gilson, 1998; Russell, 2004). Certain household characteristics, such as households headed by an elderly or disabled person, families with a low income and those who have a member with chronic disease are at risk for catastrophic expenditure (Water et al., 2004).

Economically poor and vulnerable groups are at greater risk of infection with mycobacterium tuberculosis compared to the general population. Overcrowding, substandard of living or working condition, poor nutrition, interrelated disease (such as HIV/AIDS and diabetes), and migration from (or to) are high risk factors for development of TB (WHO, 2005; Spence et al., 1993). It was also found from a study in Tamil Nadu that 75 percent of urban and 67 percent of rural TB patients’ households were in debt after TB diagnosis and treatment and the average amount borrowed was US $ 59 (Rajeswari et al., 2002).

Studies have classified healthcare payments above 10 percent of income as ‘catastrophic’ for households, assuming that above this threshold payment are likely to cause cuts to food consumption, debt and impoverishment (Prescott, 1999; Ranson, 2002). A more refined indicator of capacity to pay, changes the income denominator to that remaining after basic consumption needs have been met (WHO, 2000). A health expenditure burden greater than 40 or 50 percent of capacity to pay is assumed to be ‘catastrophic’ for households (WHO, 2000; Wagstaff and van Doorslaer, 2003; Xu et al., 2003). In a cross sectional survey done in Sri Lanka showed that majority (90 percent) of household incurred a low burden of direct illness costs because of access to free public healthcare used especially for regular treatment of chronic illness and inpatient care. However, the finding also revealed a gap in the protection offered by public health services, with a large minority (10 percent) experiencing a direct cost burden above 10 percent of monthly income and households from poorest quartile experienced higher cost burden than better-off groups (Russell, 2001).

In 2004, Russell also found that in a resource-poor setting, illness imposes high and the regressive cost burden on patients and their families. Direct and indirect costs of illness of malaria were less than 10 percent of household income, but catastrophic when combined with the costs of other illness and the costs of TB and HIV/AIDS (more than 10 percent of the household income). The mean expenditure before registration in Directly Observed Treatment (DOT) center was Rs. 3385.5 irrespective of all socioeconomic classes reported in
a study from Delhi (Ray et al., 2005). Studies also highlight the association between patient’s delay and an increased economic burden and mortality attributed to tuberculosis (Long, 1999; Raj et al., 2002). Sometimes, it is even argued by researchers that perception of illness severity is strongly associated with healthcare seeking and household income up to certain threshold levels, above which its effect stabilizes (Taffa and Chepngeno, 2005).

1.2.4 Gender and tuberculosis

Gender is a powerful social determinant of health that interacts with other variables such as, age, family structure, income, education and social support, and with a variety of behavioral factors (WHO, 2004). Globally, significant excess cases of men over women are reported with TB each year including India (Khatri, 1999; Tuberculosis Research Centre, 2001; WHO, 2001 and 2003) and among those who receive treatment; women generally tend to comply better and are less likely to die of the disease (Yannai et al., 1998; Karim et al., 2008).

In many low-income countries, women often have a lower social position and poorer access to economic resources, education and information than men. These gender differences influence both health risks among women and care seeking behavior (Paolisso and Lislie, 1995). In some developing countries, women cannot decide themselves to seek healthcare, but the decision is often made by the husband or senior members of the family. As a result of their subordinate roles in the family, they depend on men or older women for expenses and mobility in the event of illness and disease. Untimely access to healthcare is also a result of restrictions on women’s mobility and seclusion of women in the household (Okojie, 1994). Furthermore, due to lack of information, women themselves may not recognize the early symptoms of diseases. All these factors may lead to poorer health status and poorer access to healthcare services among women, and therefore, women may receive less adequate healthcare than men (Key, 1987).

Gender inequality also has severe consequences on public health where compared to men, women experience longer delays at various stages of clinical process of help seeking for TB. Patient’s mean and median delays were longer than the health system delay. Older age women are strongly associated with total delay i.e. total diagnostic delay and patient’s delay (Karim et al., 2007). Unemployed and homeless women experience longer delays in seeking care resulting in increased suffering and expenses and higher risk of community transmission (Jose and Ramon-Pardo, 2008). As a disease of poverty, the social implications of TB are heightened among women living and working in resource poor settings, such as those found
in urban slum settlements in Mumbai. Delays in seeking help that arise from gender disparities to access and entitlements to care have been demonstrated to play a significant role in Maharashtra (Vlassoff et al., 2000). However, in India greater use of the private health sector has been reported by women in the age group of 15 to 24 years, indicating a tendency to avoid public health services among the women of marriageable age (George et al., 1997).

1.2.5 Stigma and Discrimination related to Tuberculosis

Illness and chronic disease create multiple burdens for patients, including the necessity to deal with pain, suffering, reduced quality of life, premature mortality, financial costs and familial emotional trauma. Tuberculosis (TB) is a classic example of a disease with both medical and social dimensions, characterized by its close relation to poor socioeconomic conditions. Stigma in tuberculosis patients is usually of two types (Scambler, 1998) – one i.e. a fear of the patient about other’s behavior to him and a sense of inferiority due to the development of tuberculosis i.e. perceived stigma; and other due to actual discrimination or been actually avoided by the people since the patient has now tuberculosis i.e. enacted stigma. The patient often tries to hide his/her disease from others due to stigma resulting in further delay in diagnosis and treatment and thus increase the chances of transmission to a healthy community.

In India the stigma of TB is still rampant and is an important factor which not only delays the initiation of treatment but is also a major factor in hindrance to adherence to treatment. Stigma associated with TB adds to the burden of disease for both men and women particularly if they are of marriageable age (Uplekar et al., 2001). A study done at tuberculosis research center, Chennai in 2004 reported that both men and women TB patients aged less than 45 years registered under RNTCP felt equally inhibited discussing their treatment with friends and family (Balasubramanian et al., 2004). In a study by Jaggarajamma et al. (2008), among both male and female TB patients enrolled under Revised National TB Control Programme, perceived stigma was more than enacted stigma in the context of personal, family, community and work place interactions. Uplekar et al. (2001a) also reported that parents of the young women don’t want to reveal their daughter’s illness or don’t want to send them to DOTS due to difficulties that may arise in marrying them. In India, it is estimated that 100,000 women lose their status as mothers and wives because of the social stigma of TB, and death of women due to TB than all causes of maternal mortality combined (Central TB Division, 2009).
The word stigma and discrimination are often used interchangeably, and this can lead to confusion. Perception of stigma by people or by the stigmatized person him/herself leads to discrimination; and therefore the stigma becomes important because of the way it causes discrimination. Much of such discrimination may be self-discrimination (Health and Development Network, 2004), where an individual feels unworthy or guilty, leading to a lack of self-worth and depression and abnormal behavior such as self-isolation, avoidance behavior and introversion (Health and Development Network, 2006).

Enacted stigma demonstrated through discrimination and prejudice, resulting in social isolation and job loss (Khan et al., 2000; Liefooghe et al., 1997; Nair et al., 1997) while perceived stigma includes such feelings as loneliness and self-blame (Fife and Wright, 2000). These consequences can negatively influence decisions to seek treatment and adhere to prescribed medication regimens (Ahsan et al., 2004; Auer et al., 2000; Rosen et al., 2000).

Discrimination against the person suffering from TB and HIV is also a problem which people face and find it difficult to continue or seek the treatment. A study conducted in Thailand to assess social stigma, knowledge and belief about TB-HIV co-infected patients. Out of 769 enrolled, 500 (65 percent) reported high TB stigma, 177 (23 percent) low TB knowledge and 379 (49 percent) low HIV knowledge. Patients with low TB knowledge were more likely to have a severe TB disease (Jittimanee et al., 2009). Findings from few studies also reveal that the majority of male and female HIV-TB co-morbid patients reported experiencing more discrimination once others came to know about their TB medication (Ngamvithayapong et al., 2000; Okeibunor et al., 2007). AIDS stigma has led some TB patients to delay seeking healthcare or not to seek care at all (Barnhoorn and Van Der Geest, 1997). Married women from western India had expressed fear of rejection from husbands and harassment by in-laws due to the disease (Uplekar and Regan, 1996; Nair et al., 1997). This is likely in agreement with the estimates made in India that every year 1,00,000 women are rejected by their family members on account of their illness (Central TB Division, 2006).

Stigma and discrimination against people diseased with tuberculosis can occur in diverse settings like within a family, at the workplace, at healthcare facilities, or within the community. Stigma often prevents people from seeking health care attention, which constitutes a direct public health threat to the community. Even though, patients attend treatment, social disapproval of their family or community members decreases compliance with treatment (World Economic Forum, 2008) and proper adherence is critical to avoid the
development of multi-drug resistant Tuberculosis (MDR- Tuberculosis). Such attitudes also obstruct health care providers in delivering effective treatment.

1.3 Need for the study

Treatment seeking behavior of patients has always remained an important research agenda, but in-depth analysis of the process of seeking treatment, factors influencing it and its consequences on health outcomes has rarely been investigated. Since treatment seeking is a critical bridge between the health problem and the outcome, it becomes very important to unfold its dynamics. Generally, in India a majority of patients with illness seek treatment and among them many spend a great deal of time and money in visiting a number of healthcare providers, from home remedies, expert general practitioners and general hospitals to practitioners of indigenous medicines or even quacks. As a result, such practices can result with delay in initiation of effective treatment and entail high economic burden for those who are poor. This kind of delay in treatment can be harmful for people suffering from diseases like tuberculosis in terms of adverse effect on health outcomes and to the people in their close contact as they are more likely to transmit the infection from one person to another. Sometimes, the choice of ineffective or less effective sources of medicine may actually force the vulnerable groups such as those living in slums to discontinue treatment much before the illness is cured.

The fundamental tool for prevention and control of TB lies in early case detection, rapid diagnosis and initiation of treatment under Directly Observed Treatment Short-course (DOTS) clinic. As DOTS is a widely accepted standardized comprehensive strategy, endorsed by the WHO, which combines microscopy services to detect TB, regular uninterrupted supply of anti-TB drugs, and direct observation of the treatment for at least an initial intensive phase of treatment. Thus, diagnosis of all TB cases rapidly and treating them until they are cured is the best way to prevent the development of drug resistance along with pulmonary tuberculosis.

Tuberculosis has been found to be one of the major causes of death among people living with HIV/AIDS (Central TB Division 2009). People suffering from TB-HIV co-morbidity has different health outcomes and likely to delay in treatment due to fear of disclosure of the disease and discrimination from family and community. Thus, it becomes important to understand the factors affecting the treatment seeking processes and pathways chosen by the TB patients before initiation of treatment under DOTS i.e. from the first realization of
symptom to the initiation of treatment under DOTS and its influence on health outcomes and economic cost. Urban slum-dwellers, who are at higher risk of developing TB and other related diseases, are also likely to face all the three problems i.e. adverse health outcome, high treatment cost and discrimination. Thus, current research tries to explore the health seeking behaviour of slum dwellers that has special needs to be addressed. This study is expected to help in strengthening support and care system of the tuberculosis program and addressing TB cases.

**Research Questions**

Few research questions emerging from the review of the literature are:

- What makes people choose different sources of treatment for tuberculosis (TB)?
- Does selection of types of healthcare providers for treatment has implications on health outcomes?
- What causes delay in initiation of treatment for tuberculosis and does it has any effect on health outcomes?
- Does preference of a particular pathway for treatment have implications on economic cost?
- Does gender have an influence on discrimination faced due to tuberculosis and health outcome?

**1.4 Objectives of the study**

In view of the above discussion, the broad objective of the study is to unfold the underlying processes of treatment seeking for tuberculosis among people living in slums of M-ward, Mumbai. The specific objectives of the study are:

1. To identify the patterns of treatment seeking among registered TB patients under DOTS and its implication on health outcomes.
2. To examine the factors responsible for delay in initiation of treatment and further its effect on health outcome.
3. To study the association between patterns of selection of treatment sources and the economic cost.
4. To study the linkages between gender, discrimination faced due to tuberculosis and health outcome.
1.5 Theoretical background of health seeking behavior (HSB)

Researchers and Health practitioners for long have been interested in what facilitates the use of health services, and what influences people to behave differently in relation to their health. There are two dominant approaches: the development of ‘pathways models’ of HSB, which tend to describe a series of steps an individual take; and studies of ‘determinants’ of behavior, highlighting the factors influencing that journey (Bedri, 2001). Conceptualization of Health Seeking Behavior as a 'sequence of remedial actions' was inadequate to justify the health inequalities because mere provision of medical services does not change the practices.

The second body of research stated that there are psychological factors which prevent them from making ‘healthy choices’ in either their lifestyle behaviors or their use of medical care and treatment. A number of ‘social cognition models’ have been developed in this tradition to predict possible behavior patterns (Conner and Norman, 1996a). These are based on a mixture of demographic, social, emotional and cognitive factors, perceived symptoms, access to care and personality (Conner and Norman, 1996b). A number of genres of such model exist, one of the most widely applied is the ‘health belief model’ (Hochbaum, 1958; Becker et al., 1977; Sheeran and Abraham, 1996). However, health belief models have been criticized for portraying individuals as social economic decision-makers, and applications to major contemporary health issues, such as sexual behavior, have failed to offer any real insights (Sheeran and Abraham, 1996). A second genre of model is linked to the general assumption that those who believe they have control over their health are more likely to engage in health-promoting behaviors (Norman and Bennett, 1996). The ‘health locus of control’ construct is therefore utilized to assess the relationship between an individual’s actions and experience from previous outcomes. The most popular of these is the ‘multidimensional health locus of control measure’ (Wallston, 1992). However, this approach to social cognition models has been criticized for taking too narrow an approach to health and insufficiently explaining the amount of variance (Norman and Bennett 1996).

Uplekar and colleagues developed a stepwise barrier framework that suggests ways of considering gender differentials from occurrence to help seeking, diagnosis, treatment and outcome (Uplekar et al., 2001a). In the present study framework is developed to study the stepwise progression from infection to diseases and ultimately the health outcome. On the same line, modified framework for the present study has been prepared. The stages have been borrowed from Uplekar’s given framework and further detail conceptualization has been done based on present study; like type of services used under utilization of services being
discussed and resulting delay and economic burden which also has an impact on treatment outcome of patients.

**Stages of framework adapted from Uplekar (2001a)**

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<th>Stage 2</th>
<th>Stage 3</th>
<th>Stage 4</th>
<th>Stage 5</th>
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<td>Occurrence of symptom and acknowledgement</td>
<td>Treatment seeking</td>
<td>Utilization of Health services</td>
<td>Diagnosis, initiation of treatment and adherence</td>
<td>Treatment Outcome</td>
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![Diagram showing stages of framework](image)

**Figure 1.2: Conceptual framework for the present study**

Present framework has been divided into five stages of treatment starting with exposure to risk factors which leads to infection and the occurrence of symptoms. Once symptoms are acknowledged by the individual, then he/she either seeks treatment from any healthcare providers or do not seek treatment. The present study focuses on only those patients who sought treatment for their symptoms. Choice of provider for consultation arises next, which can be from government facility doctors, private allopathic doctor, government facility doctor, ayurvedic doctor, homeopathic doctor, religious healers or quacks. The individual is rational in choosing any of these sources for treatment therefore it is important to study these choices in detail. Many times patients directly go to DOTS after identification of
symptoms of their own which is possible only when the individual is knowledge enough about the risk factors and symptoms. It is also an ultimate indicator of successful tuberculosis program running in the area. Often patients reach DOTS after visiting several healthcare providers which incur longer health system delay and high economic cost which also affects treatment outcome of an individual. Existing stigma and discrimination against the disease always operate during a period of suffering and has its negative impact on individual’s treatment seeking behavior.

1.6 Sampling design

1.6.1 Selection of study area

In the present study Mumbai has been purposefully selected as a study area for conducting the study. The rationale behind selecting it is due to the growing number of population and mushrooming of slums in the city. Mumbai, the capital of Maharashtra and financial capital of India is often described by the stark disparity of gleaming skyscrapers side by side with humble jhapatpattis (slum like settlements), is just a reflection of the large scale economic inequalities in the state which has its direct impact on the health status of people. Census 2001 shows that around 56 percent of population in Mumbai is consisting of slum population. As per UN-HABITAT (2006-07) slum is defined as a group of individual living under the same roof in an urban area who lack one or more of the following:

1. Durable housing of a permanent nature that protects against extreme climate conditions.
2. Sufficient living space which means not more than three people sharing the same room.
3. Easy access to safe water in sufficient amounts at an affordable price.
4. Access to adequate sanitation in the form of a private or public toilet shared by a reasonable number of people.
5. Security of tenure that prevents forced evictions.

1.6.2 Selection of wards

The Maharashtra state government gives ward wise information (referred as Tuberculosis Unit) for tuberculosis case detection in its quarterly performance report under RNTCP (Revised National Tuberculosis Program). Mumbai is divided into six zones and zones are comprised of wards. Further, bigger wards are either divided into two, three or four parts named as south-north or east-west.
Table 1.1: Ward wise information of the total population, percentage of slum population, the number of TB detected cases and a number of DOTS centres in Greater Mumbai.

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Zone 1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A-ward</td>
<td>2,10,847</td>
<td>28.88</td>
<td>1666</td>
<td>23</td>
</tr>
<tr>
<td>B-ward</td>
<td>1,40,335</td>
<td>13.33</td>
<td>14</td>
<td></td>
</tr>
<tr>
<td>C-ward</td>
<td>2,03,220</td>
<td>No slum</td>
<td></td>
<td>24</td>
</tr>
<tr>
<td>D-ward</td>
<td>3,82,841</td>
<td>9.95</td>
<td>673</td>
<td>21</td>
</tr>
<tr>
<td>E-ward</td>
<td>4,40,335</td>
<td>11.86</td>
<td>1263</td>
<td>22</td>
</tr>
<tr>
<td>Zone 2</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>F/S-ward</td>
<td>3,96,122</td>
<td>35.76</td>
<td>4891</td>
<td>73</td>
</tr>
<tr>
<td>F/N-ward</td>
<td>5,24,393</td>
<td>58.07</td>
<td>1723</td>
<td>31</td>
</tr>
<tr>
<td>G/S-ward</td>
<td>4,57,931</td>
<td>33.08</td>
<td>939</td>
<td>29</td>
</tr>
<tr>
<td>G/N-ward</td>
<td>5,82,007</td>
<td>55.82</td>
<td>1723</td>
<td>80</td>
</tr>
<tr>
<td>Zone 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>H/E-ward</td>
<td>5,80,835</td>
<td>78.79</td>
<td>1587</td>
<td>90</td>
</tr>
<tr>
<td>H/W-ward</td>
<td>3,37,391</td>
<td>41.06</td>
<td>757</td>
<td>20</td>
</tr>
<tr>
<td>K/E-ward</td>
<td>8,10,002</td>
<td>58.30</td>
<td>1479</td>
<td>23</td>
</tr>
<tr>
<td>K/W-ward</td>
<td>7,00,680</td>
<td>45.11</td>
<td>1104</td>
<td>21</td>
</tr>
<tr>
<td>Zone 4</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>P/S-ward</td>
<td>4,37,849</td>
<td>48.10</td>
<td>956</td>
<td>17</td>
</tr>
<tr>
<td>P/N-ward</td>
<td>7,98,775</td>
<td>63.65</td>
<td>1797</td>
<td>26</td>
</tr>
<tr>
<td>R/S-ward</td>
<td>5,89,887</td>
<td>58.07</td>
<td>1115</td>
<td>28</td>
</tr>
<tr>
<td>R/C-ward</td>
<td>5,13,077</td>
<td>33.75</td>
<td>535</td>
<td>24</td>
</tr>
<tr>
<td>R/N-ward</td>
<td>3,63,827</td>
<td>46.63</td>
<td>546</td>
<td>30</td>
</tr>
<tr>
<td>Zone 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>L-ward</td>
<td>7,78,218</td>
<td>84.68</td>
<td>1652</td>
<td>24</td>
</tr>
<tr>
<td>M/E-ward</td>
<td>6,74,850</td>
<td>77.55</td>
<td>3263</td>
<td>42</td>
</tr>
<tr>
<td>M/W-ward</td>
<td>4,14,050</td>
<td>68.48</td>
<td>1186</td>
<td>35</td>
</tr>
<tr>
<td>Zone 6</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>N-ward</td>
<td>6,19,556</td>
<td>70.21</td>
<td>1162</td>
<td>16</td>
</tr>
<tr>
<td>S-ward</td>
<td>6,91,227</td>
<td>85.83</td>
<td>1489</td>
<td>43</td>
</tr>
<tr>
<td>T-ward</td>
<td>3,30,195</td>
<td>35.21</td>
<td>598</td>
<td>13</td>
</tr>
<tr>
<td>Greater Mumbai</td>
<td>11,97,8450</td>
<td>54.06</td>
<td>32125</td>
<td>769</td>
</tr>
</tbody>
</table>

Source: Census 2001, Town directory has been used for population and slum population; RNTCP Status report 2009 (1st quarter) has been used for number of TB cases and RNTCP DOTS directory for number of DOTS centres in respective wards.

Table 1.1 shows the ward wise information total population, the proportion of slum population, number of identified TB cases and numbers of DOTS centers/providers operating in the wards. Figure 1.3 clearly shows that number of tuberculosis cases detected is highest in F/south ward (4891) and M/east ward (3263) in the year 2008. Since the focus of the study is on slum population therefore, the proportion of slum dwellers in the wards is the second criteria of selection. At the same time, census 2001 gives us privilege to get the proportion of slum population in these wards. The proportions of slum population in F/South ward are 36 percent and 78 percent in M/east ward (Figure 1.4). Therefore, M/east ward is preferred over F/south ward. Further, it is also observed that M/west ward also has
a greater proportion of slum population (69 percent), sharing boundaries with M/east ward (Figure 1.4) and 1186 cases detected in 2008. Thus, both M/east and M/west ward is selected for the study. As RNTCP do not cover the whole population in these wards so tuberculosis detected cases cannot be generalized for the complete wards. Around 42 DOTS centers/providers/NGO in M/east and 35 in the M/west ward are operating under RNTCP (DOTS directory of Mumbai).

1.6.3 Community profile of slums in M-ward

In order to understand the situation of slums in M/east and M/west ward, information is also compiled for slum population in these two wards from census 2001. Table 1.2 gives the overall view of the slum population with available information. Number of households in slums is more in M/east ward than M/west ward. Overall sex ratio (female per 1000 males) in the slums is found to be 790 females per 1000 males in M/west ward and 785 females per 1000 males in M/east ward of Mumbai. Proportion of scheduled caste population is higher in the M/west (16 percent) as compared to M/east ward (7 percent). People living in slums of the M/west ward are more literate (72 percent) than M/east ward (30 percent). The working population is also more in M/west ward than M/east ward. A number of
community toilets and tap points for protected water supply are much higher in M/eastward than M/west ward slums.

Table 1.2: Characteristics of slums in the M/East and M/West wards of Mumbai, Census- 2001

<table>
<thead>
<tr>
<th>Characteristics of slum in the wards</th>
<th>M/East</th>
<th>M/West</th>
</tr>
</thead>
<tbody>
<tr>
<td>No. of households</td>
<td>1,00,519</td>
<td>57,934</td>
</tr>
<tr>
<td>Sex ratio (female per 1000 males)</td>
<td>785</td>
<td>790</td>
</tr>
<tr>
<td>Percentage of Scheduled Caste population</td>
<td>6.92</td>
<td>15.83</td>
</tr>
<tr>
<td>Percentage of Scheduled Tribe population</td>
<td>0.69</td>
<td>0.67</td>
</tr>
<tr>
<td>Percentage literate</td>
<td>29.52</td>
<td>71.46</td>
</tr>
<tr>
<td>Percentage of working population</td>
<td>32.64</td>
<td>37.23</td>
</tr>
<tr>
<td>Number of community toilets</td>
<td>6141</td>
<td>1862</td>
</tr>
<tr>
<td>No. of tap points for protected water supply</td>
<td>4167</td>
<td>338</td>
</tr>
<tr>
<td>Percentage of household with electricity connection</td>
<td>86.07</td>
<td>n.a.</td>
</tr>
</tbody>
</table>

Source: Census 2001 town directory has been used for information of slums in the wards.

n.a: Not available

1.7 Data

In the absence of population based survey on tuberculosis and availability of limited information from RNTCP (Revised National Tuberculosis Program) on registered patients, primary data collection became important for the study. Prior approval has been taken from RNTCP for conducting the survey among registered TB patients under DOTS in these two wards.

Selection of respondents: For selection of respondents following criteria has been taken into consideration while listing of patients from RNTCP record registers.

- Only those patients are taken who are in between the age group of 17-54 at the time of registration assuming that they must be in the age group 18-55 at the time of interview.
- Complete addresses of only those patients are taken who have been registered during March 2009 to September 2009 because permission was given only for this period.
- Patients who have either died or been transferred out are not taken into account.
- Patient residing in the non slum area are also not taken into the selection criteria.

Pre-coded, pre-tested and structured schedule is used for data collection. Information is collected from the patients themselves in their households. Due to change in addresses, wrong addresses, dead cases found at the time of the survey, a high non response was observed during the field work. Therefore, the study had to restrict only to patients with
correct addresses and successfully identified for interviews. Thus the total sample size stood up to 367.

1.8 Ethical issues

To conduct the survey and address the issues of interest possible ethical procedures had been followed. Like, proper permission from the Revised National Tuberculosis Programme has been taken to interview the patients and use the details only for research purpose. Further, before conducting the interview, patients were explained about the purpose of study and then interview was conducted after their consent for the interview. Additionally, purpose of visits was not disclosed to community people in order to keep the patient’s diseases history as secret.

1.9 Contents of interview schedule

Interview schedule is divided into five sections where necessary information is collected to fulfil the proposed objectives. Sections of the schedule are discussed below.

Section one: Socioeconomic Background

Socioeconomic section has been divided into two parts i.e. household details and personal details. In household detail information is collected about household amenities and household members’ age, sex, work status, income and whether member has suffered from TB in their life time. Personal details include patients’ age, religion, caste, marital status, education and three consecutive years’ work history i.e. prior to diagnosis of TB, year of diagnosis and after diagnosis of TB (2008-2010).

Section two: Knowledge about HIV/AIDS and tuberculosis

Detail information is collected about respondent’s comprehensive knowledge about HIV/AIDS and tuberculosis in this section. Knowledge about HIV/AIDS is collected through their awareness about the disease, source of information, conception and misconceptions about HIV/AIDS. Along with this, place for HIV testing and time since they have been tested for HIV is also asked. In order to assess knowledge of tuberculosis, patients are asked about their awareness about symptoms of TB, modes of transmission and ways of prevention. Information is also collected about their knowledge related to treatment under DOTS, minimum prescribed duration for treatment and side effects of doses.
Section three: Substance use and health hazards

This section is about respondent’s substance use and any other member in the family. Information about use of three types of substance is collected i.e. tobacco, alcohol and any kind of drugs. Tobacco use included both smokeless and smoked tobacco. Drug use included ganja, charas, brown sugar or cocaine. Detail information is collected only for respondents and not for all substance abusers in the family; like age at initiation, frequency of use before, during and after diagnosis of tuberculosis. Only current substance use is asked for members.

Section four: Disease history, action taken and economic cost

In this section, co-morbidity history of the patients for consecutive three years is asked i.e. prior to the year of TB diagnosis, year of diagnosis and post the year of diagnosis. Up to five co-morbid disease’s information is collected. Consecutively, information on treatment taken and cost incurred on these diseases are also asked. Patients are also asked about the symptoms they experienced prior to diagnosis of tuberculosis, time taken to visit any healthcare provider since realization of symptom, number of visits made to different providers, and number of days spent with each provider and monetary loss during each visits. Additionally, information about prime care taker and their wage losses are also taken into consideration.

Section five: Social experiences

Information is collected about discrimination faced due to TB, its disclosure and reasons for not disclosing the disease. Patients are asked about discrimination faced from family members, community people, at work place and health posts. Same set of questions are also asked for HIV from those who have been suffering from both TB and HIV.

1.10 Field experience and data collection

Entire period of data collection was a herculean and challenging task for researcher. It is felt so because point from getting permission from RNTCP government officials to the identification of the patient's household from the recorded address and conduct interview of tuberculosis patients registered under the DOTS program was a difficult and quite time consuming. It almost took seven months to get permission from the RNTCP office to get approval for the study. Further, it took one month to list the patients’ address and disease status from the official registers of those who were registered since April 2009 to September
2009. Information was not provided for the patients other than the above mentioned period because records were not maintained beyond this period. After listing the information of 877 patients, researcher’s next challenge was to make household visit to the recorded patients according to given address. With the help of one investigator researcher has conducted entire field work. Study could not follow any sampling procedure and all patients identified with the mentioned address were included in the study and interviewed.

1.11 Conceptualization of used terminologies

Delay: It is measured as time gap between realization of any symptom that needs attention for treatment and consulting any healthcare provider is termed as patient delay and time gap between contacting first healthcare provider to reaching DOTS is termed as health system delay. In the present study DOTS has been considered as gold standard for treatment of tuberculosis.

Health Outcome: It has been measured as per RNTCP categorisation of treatment outcome. RNTCP defines treatment outcomes as cured, treatment completed, dead, failure, default and transferred out.

Cured: Initially sputum smear-positive patient who has completed treatment and had negative sputum smears on two occasions one out of which is at the end of treatment.

Treatment completed: A patient who completed treatment but did not meet the criteria for cure or failure. In other words, sputum smear-positive or smear-negative TB patients who have received full course of treatment and has not been smear-positive during or at the end of treatment. This definition applies to pulmonary smear-positive and smear-negative and extra pulmonary patients.

Dead: A patient who died during the course of treatment regardless of causes. These cases are not taken in to consideration for present study.

Failure: A patient who was initially smear-positive and remained smear-positive at five months or more after starting treatment. Failure also includes a patient who was treated with category III (New cases who are pulmonary smear negative, not seriously ill or extra pulmonary, not seriously ill) regimen but who becomes smear positive during treatment.

Default: A patient whose treatment was interrupted for two consecutive months or more.
Transferred out: A patient who has been transferred to another tuberculosis unit/district and treatment outcome of those patients are not known is termed as transferred out cases. These cases are not taken into the study.

Successful/unsuccessful treatment outcome: Successful outcome has been described as those who either been cured or completed the treatment and unsuccessful as those who are failure or defaulters. This classification is used as per World Health Organisation.

Economic Cost: It is measured in terms of direct and indirect cost of treatment. Further, direct cost is measured as money spent on treatment with each type of provider consulted which includes amount spent on fees, medicines, diagnostic tests, hospital charges if been hospitalised, special food, and any other extra charges which is not been covered but related to procedure of treatment. Whist, indirect cost has been measured as travel cost; expenses occurred on care taker, wages loss of respondent due to illness and loss of caregiver’s productive labour cost due to illness of respondent. Only one prime care taker has been taken into consideration.

Economic Burden: Economic burden is defined as share of monthly treatment cost beyond 10 percent of monthly household income. Economic burden is also used as impoverishment of household due to treatment cost beyond 10 percent of monthly household income.

Social discrimination: This is measured by change in behaviour experienced by patients from family, friends, relatives, neighbours and at work place due to tuberculosis. Invitations to attend social functions and festivals post disclosure of disease is considered as act of discrimination by community.

1.12 Construction of variables

Household variables

Age of household head: It has been taken as per age reported by patient about head of the household which has been further categorised into four categories for easy understanding.

Number of rooms in the household: It is recorded from total number of rooms in the household (including kitchen) as reported by respondent. Only two categories are made as large proportions of respondent are staying in one room house.

Number of earning member in the household: It has been calculated from the household member information where work status of each household member is asked.
Household with earlier experience of TB: Information is also collected from each member about any earlier experience of TB. Household which has any member who had experienced TB in their life time are recorded as household with experience of TB.

Wealth Index: This variable has been constructed using household amenities. It has been used as indicator for economic status of respondent throughout the dissertation. Index has been constructed using set of 17 variables. Principal component analysis (PCA) is used with the help of SPSS 16.0. First four components explained around 65 percent of variation and first component is used for the construction of index which alone explained 24 percent variation. Items used in the index are given in appendix of the thesis.

TB knowledge Index: Knowledge index has been constructed as per response on 11 items related to tuberculosis. Those who knows

- Symptoms of cough for three weeks or more sometimes with blood streaked sputum is a symptom of TB,
- Correct mode of transmission and has no other misconception about spreading of tuberculosis,
- Covering mouth and nose while coughing or sneezing can prevent others from getting the infection,
- Tuberculosis can be cured,
- Minimum duration of tuberculosis doses under DOTS is of six, nine or twelve months,
- That a person can die from TB if he/she does not take their medicines regularly,
- That a person should continue taking medicines even though they develop side effects during TB treatment,
- That person should not stop taking TB drugs even after feeling better,
- That after migrating to other place one can continue their treatment at the place of destination,
- That TB is not a genetically transferable disease and
- That people suffering from HIV has chances of getting TB and vice a viz. are coded as one and zero otherwise.

Summative scale has been used to make TB knowledge index which has reliability score of 0.51. Based on median value of index, categories have been classified as ‘low’ for below median values and ‘high’ for median and above value of index.
Comprehensive knowledge of HIV: It has been calculated as per definition used in NFHS-3. Those who said people can reduce their chances of getting HIV/AIDS by having just one uninfected partner, people cannot get HIV/AIDS from mosquito bites, consistent use of condom reduces the chances of getting infection, AIDS do not spread by sharing food and healthy looking person can also have HIV/AIDS is categorised as having comprehensive knowledge of HIV/AIDS.

Discrimination Index: It is based on 18 items summative scores which have reliability score of 0.86. Items of discrimination are measured at family, community and health facility level. Set of items are borrowed from ‘HIV/AIDS related stigma and discrimination knowledge about quantifying stigma in developing countries’ (USAID, 2006). Index is based on overall enacted discrimination faced within family, in the community and at health facility. Items of the index are given in appendix of the thesis.

Individual variables

Age: It is calculated from month and year of birth asked from respondent. If they did not remember the month and year of birth then it is taken from listing record with adjustment of one year.

Marital Status: Question is directly asked to respondents about their marital status and, widowed/widower and separated/disserted/divorced are grouped into ‘not in marital union’ category along with never married. Currently married category is kept as separate segment.

Religion: Major three religion categories has emerged in the sample i.e. Hindu, Muslim and Buddhist. Those not falling in these categories are coded as other. Therefore, four major categories are narrowed down under religion.

Caste: It has been categorised into three categories i.e. scheduled caste/scheduled tribe, other backward classes and non-scheduled caste/scheduled tribe/other backward classes. Scheduled caste and scheduled tribe has been coded under single code as number of cases is less in scheduled tribe category.

Education: It has been computed from completed years of schooling. Those who reported that they do not know to read write or sign are grouped into non-literate group. Respondent with one to five years of schooling are labelled as primary. Next, six to eight years of schooling as middle and nine and above as high school and above.
**Tuberculosis type:** There are two kind of TB which is widely occurring in the population one is pulmonary and other one is extra pulmonary. Information about the type of TB is collected directly from RNTCP records. Pulmonary TB is communicable in nature while extra-pulmonary is non-communicable.

**Type of patient:** This information is also collected from record. There are six categories of patient in the type of patient i.e. new, relapsed, transferred in, failure, and treatment after default and other. No cases have been observed with transferred in status therefore it has not been mentioned. Therefore, sample contains only five categories.

**Work Status:** Work status has been taken as patients working at the time of diagnosis of TB which has been categorised as working and not working. This is done mainly because state of not working is likely to be more among patients at the time of interview especially due to those who did not go back to their work as a result of long duration of suffering from tuberculosis.

**Co-morbid:** It is constructed from the information where respondents reports about suffering from other diseases. All those who have been ill with any other diseases during the year of diagnosis of TB i.e. 2009 is categorised as co-morbid cases. Only major ailments are taken into consideration (other than cough, cold and body aches).

**Number of moves:** It is the number of healthcare providers consulted for treatment of tuberculosis.

**Patient delay:** It is based on number of days taken by patients to consult any healthcare provider after recognition of problem. It has been used as two categories i.e. like less than two weeks (14 days) and more than two weeks at some places, otherwise used in continuous form either as number of days or number of weeks.

**Health system delay:** It is the time spent while visiting different healthcare providers prior reaching to DOTS. Number of days spent in visiting different healthcare providers is summed up to get health system delay. Further, it has been used in two categories like earlier i.e. less than two weeks (14 days) and more than two weeks otherwise in continuous form. Two weeks cut-off has been chosen because it is universally declared cut-off point for identification of symptom of TB under guidelines of DOTS; those with more than two weeks of persistence of cough could be a case of TB and cough is most common symptom experienced by patients of tuberculosis.
1.13 Organization of thesis

Chapter 1: Introduction, Review of Literature, Need, Objective, Data and Methods

Chapter 2: Profile, Awareness and Knowledge of TB and HIV among Surveyed Tuberculosis Patients

Chapter 3: Pathways of Treatment Seeking and Factors Affecting the Delay in Treatment.

Chapter 4: Consequences of Treatment Seeking Pathways on Health Outcome

Chapter 5: Economic Cost of Tuberculosis Treatment

Chapter 6: Discrimination Faced by People suffering from Tuberculosis

Chapter 7: Summary, Conclusion, Policy implications and Limitations of the study.

Appendix: Variables used in the construction of indices, Interview schedule used for the study.

1.14 Analysis plan

Study is completely based on quantitative information. Pre-coded data has been entered using CS Pro 4.0 and further converted into SPSS 16.0 and STATA 12.0 format for analysis. Univariate, bi-variate and multivariate techniques are used to address the objectives of the study. Chi-square and fisher's exact test has been used to study the association between two variable of interest. Krushkal-wallis test has been used to study the differences in median value when two and more categories of independent variable are studied. Further, binary logistic regression model has been used to study the determinants for dichotomous dependent variable. Poisson and negative binomial regression is used to study the risk factors when dependent variable is count in nature. Poisson model is used when dependent variable is normally distributed and negative binomial is used in case of heavily dispersed data.

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