Chapter-VII

Summary, Conclusions and Policy implications of the Study
Chapter Seven

7.1 Introduction

Tuberculosis continued to remain a major public health problem in India. It is a disease of poverty with several known social determinants (e.g. malnutrition, tobacco smoking and stigma) which are not adequately addressed in DOTS strategy. In most countries, TB services are integrated into mainstream national health systems. Weaknesses and inequities in health service delivery are therefore replicated in the delivery of TB services (Atun et al., 2010). In India, first National Tuberculosis Programme (NTP) failed because of low case detection and cure rates. Further, the Revised National Tuberculosis Control Program (RNTCP) reversed these trends in the public sector, with expanded access to improved diagnosis, short-course regimens and high cure rates. Despite of significant progress of TB programme, strains of drug-resistance TB, increasing cases of TB-HIV co-infection, adverse social and economic consequences indicate the need to relook the public health system in the country. Apart from new medical technologies for diagnosis, treatment and prevention, and extending the coverage of these interventions to the poorest (WHO, 2005), there is also a need to address the co-morbidities (such as human immunodeficiency virus and diabetes), substance use (such as alcohol and tobacco), and the social and economic conditions that determine both the course of the TB epidemic and exposure to these risk factors (Dye et al., 2009; CSDH, 2008).

Moreover, health professionals attribute the problem of recent drug-resistance tuberculosis in Mumbai to the unregulated private doctors who prescribe inappropriate drugs in slums (Loewenberg, 2012). Therefore, in order to gain long term achievements by RNTCP programme, there is need of proper management of quality of services provided by private practitioners and training.

Present study tries to unfold the process of treatment for tuberculosis among people living in slums of M-Ward, Mumbai, in presence of few social determinants of health like, poverty, discrimination, tobacco and alcohol use etc. The study tries to throw light on the pathways of treatment followed, delay in treatment, discriminations faced and its economic and health consequences on the individual.
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.

To address the above objectives, primary data has been collected from 367 patients residing in slums of M-ward, Mumbai. M-ward has been selected because of high density of slum population coupled with high incidence of tuberculosis cases. Only those registered patients in the age group of 17-54 at the time of registration, alive and not been transferred to any other places and resided in slums. Information about 877 patients is gathered for conducting the survey. Out of which only 367 cases are successfully traced and agreed for interview. High non-response is observed mainly due to wrong reporting of addresses and phone numbers, death and change in addresses of patients.

Furthermore, interview schedule used for data collection is broadly divided into five major sections. Section one covers the socioeconomic profile of individual, household information and their living condition. Second section deals with awareness about symptoms, modes of transmission and methods of prevention about Tuberculosis. Information related to HIV/AIDS is also covered in this section. Third sections dedicated to substance use and health hazards among patients. Substance use included information about tobacco, alcohol and drug use. Fourth section is about disease history, action taken and economic cost. Detail information about the treatment and incurred cost in sequence to each visit is asked in this section. This section also covered information about co-morbidity at the time of diagnosis of TB, prior to diagnosis and after diagnosis in three consecutive years are asked. Fifth section is about social experiences related to disease. Set of questions are asked describing the discriminations at family, community and health facility.

Thesis has been organised in seven chapters where summary of findings are presented in this chapter along with conclusions, policy implications and limitations of the study.
7.2 Summary of the Results
7.2.1 Profile, awareness and knowledge of TB and HIV

Household profile of the respondent studied for two subgroups of cases i.e. gender and morbidity status by background information of household members. Result reveals that mean household size of the patients is five across the subgroups. Further, to be noted that female patients’ household heads are relatively younger than male patients. More than one-fourth of male patients’ household heads and more than one-fifth of female patients’ household heads are not working at the time of the survey. Females belong marginally high from households with earlier episodes of TB than males. Moreover, economic status and median per day income of households do not vary by gender. Additionally, less than one-third of patients are head of their households where, more than half of males and about one-tenth of females is head of their households.

Household profile across morbid groups reveals that household heads of patients suffered with only TB are younger than heads of co-morbid patients. Simultaneously, a higher proportion of heads are not working among co-morbid groups as compared to heads of only TB patients. Additionally, proportion of households with earlier episodes of TB is marginally high among co-morbid groups than households of only TB patients. Moreover, differentials in economic status of households exist across the morbid groups. About two-fifths of co-morbid households and less than one-third of only TB patients’ households are of low economic strata. Furthermore, majority of the households of patients suffered with only TB had single earning member while, households of co-morbid patients has two earning member. Additionally, average per day income of co-morbid households is less than households of only TB patients. A higher proportion of co-morbid patients headed their households than only TB patients. Living and sanitation condition of households demonstrated that a higher proportion of male and co-morbid patients’ households lived in overcrowded and poor environmental condition than female and patients suffered with only tuberculosis.

Socio-demographic profile of patients by gender suggests that females get tuberculosis at younger ages than males while male get TB in their middle ages. Result of marital status shows that a higher proportion of never married males reported TB than females and at the same time; a higher proportion of female, patients not in marital union get TB in comparison to males. Additionally, proportion of non-literate is higher among female than males. Large sections of males are working, and females are not working at the time of diagnosis.
Average age of patients is same for both the morbid groups. Further, higher proportion of co-morbid patients are non-literate and not in marital union category than only TB patients. Nevertheless, at the time of diagnosis, co-morbid patients are more into the work force than patients suffered with only TB. Across economic classes, middle class are marginally younger than poor and rich patients. Further, proportion of not in marital union is high among rich than middle and poor. At the same time, proportions of non-literate and primary educated patients are more among poor than middle and rich. Additionally, patients working at the time of diagnosis are more among poor than middle and rich.

Gender differentials reveals that newly diagnosed cases are more among female while old patients are more among male. Gender differentials for tuberculosis type show more pulmonary tuberculosis among males and more extra pulmonary tuberculosis among females. Further, males resulted with cured outcome more than females while treatment completed cases are more among female. Morbid groups did not show significant differentials in disease characteristics except HIV status where, HIV positive patients belonged to co-morbid group. Result across economic classes show that relapsed and defaulters are more among poor than middle and rich. Further, proportion of extra pulmonary tuberculosis cases increased with economic classes. Additionally, proportion of TB-HIV co-morbid patients is more among poor as compared to middle and rich economic class of patients. Poor resulted more with cured outcome but rich has completed their treatment more in comparison to their counterparts.

Awareness and knowledge about tuberculosis shows that males, only TB patients and rich are more aware about the symptoms of ‘cough for three weeks or more’. Similarly, males, patient suffered with only TB and middle class patient also has more accurate knowledge about modes of transmission of tuberculosis than their counterparts. Additionally, result suggests that males, co-morbid patients and rich have more correct knowledge about ways of prevention from spreading TB. Therefore, it is prominent that knowledge gap is wider among females, co-morbid patients and poor than their counterparts.

Result of knowledge about HIV/AIDS also suggested that females, co-morbid patients and poor has low awareness and knowledge about the place for HIV test than their counterparts. Gender differentials are significantly noted for comprehensive knowledge about HIV/AIDS where, male has higher knowledge about HIV/AIDS than females.
7.2.2 Pathways of treatment seeking process and factors affecting the delay in treatment

After knowing about the background profile of surveyed patients; it is important to look into the process of treatment for tuberculosis patients. This chapter describes the pathways and delay caused in the process of treatment. Result reveals that on average patients made two moves prior reaching to DOTS. Gender result shows that females made higher number of moves than males. Likewise, result of education status depicted that non-literate and primary educated patients went direct to DOTS more than other educational categories. At the same time, three and above number of moves are more taken by high school and above educated patients than low educational categories. Similarly, three and above moves is made more by co-morbid and rich as compared to their counterparts where, increases in number of moves with improvement in economic status are significant.

Utilization of pathways including informal sources increased with the number of moves for treatment. About one-fifth of patients believed in informal sources for their treatment. Multivariate results reveal that female is more likely to make a number of moves than male. Likewise, high school and above educated and rich patients are at higher risk to make a number of moves than non-literate and poor respectively. Simultaneously, patients belonged to household with no earlier episode of TB are less likely to make a number of moves for treatment than patients from a household with earlier episode of tuberculosis. Alcohol consumption and patient delay has been other risk factors for making a number of health care choices.

Result of pathways reveals that most favourable pathway of treatment among patients is to approach private allopathic doctor and then a government facility and then finally to DOTS; which is more chosen by females than males. Pathway of direct move to DOTS is more chosen by males than females. Similarly, other mixed facility pathway (includes longer pathways with no definite pattern) has more been used by females than males. Furthermore, pathway of informal sources to a government facility and then to DOTS has more been followed by patients suffered with only TB than co-morbid group. Simultaneously, co-morbid patients have chosen pathways involving three and more healthcare providers for treatment more than only TB patients. Selection of pathways by economic classes reveals that poor chose direct move to DOTS more than middle and wealthy patients. At the same time, rich patient chose other mixed pathways more than middle and poor patients. Moreover, non-literate and primary educated patients directly went to DOTS than high
educated patients. Further, other mixed pathway has more been followed by high school and above educated patients followed by non-literate, middle and then primary educated patients. Average delay in treatment is lowest for the pathway of direct move to DOTS while longest for other mixed pathways to reach DOTS (more than two months). Pathways with private allopathic doctor increased the average health system delay.

Furthermore, it is important to study the factors associated with delays among both the gender. Factors affecting patient delay among male reveals that chances to delay longer decreases with an increase in family size. Simultaneously, number of symptoms experienced by men increases their chances to delay longer for consultation with any healthcare provider. Risk factors among females suggest that risk to delay long in consulting any health care provider is higher among middle age group of women (25-34 age group and 35-44 age group) than younger women (18-24 age groups). At the same time, chances to delay longer by Muslim women are less than Hindu women. Additionally, increase in the number of moves for treatment increased the chances to delay longer to consult any healthcare provider.

Moreover, factors associated with the health system delay depict that a female has a higher risk to delay longer while visiting healthcare facilities than males. Further, Buddhist and other religious groups are more at risk to delay longer in visiting health services than Hindu. Similarly, middle and rich patients have higher chances to delay longer to reach DOTS in comparison to poor. Patients suffered with extra pulmonary tuberculosis found to make shorter health system delay to reach DOTS than pulmonary TB patients. Nonetheless, across pathways, the chance to delay longer is higher for those who reached DOTS after a visit to single allopathic doctor or after visits to one private allopathic doctor and a government facility doctor or through other mixed pathways. Further, number of moves for treatment also increased the chances of the health system delay. Thus, it is clear that number of providers selected for treatment has strong relationship with patient and health system delay.

7.2.3 Consequences of treatment seeking pathways on health outcome

After pathways and delay in treatment, it is important to look into its implication on health condition. Therefore, this chapter deals with treatment seeking pathways and its relations with health outcome of patients. Bi-variate result shows gender, religion, caste, tuberculosis type and patient type has a significant association with the treatment outcome of the patient.
However, females, Muslims, other backward classes, extra pulmonary TB, and newly diagnosed patients have resulted more with positive health outcome than their counterparts.

Out of all, pathway of private allopathic doctor to a government facility and then to DOTS has highest cured cases in comparison to other pathways, followed by the pathway of moving to DOTS after visiting private allopathic doctor. However, defaulters are more among other mixed facility pathway followed by the pathway of moving to DOTS after visiting private allopathic doctor and government facility. Result suggests that defaulters are higher for the pathways with government facility. This implies that government facilities need to strengthen to overcome defaulters.

Result reveals that average health system delay among failure and default cases are longer as compared to cured and treatment completed cases. Adherence to treatment is one of the major factors to determine the success in treatment outcome; therefore, it is important to look the adherence among patients. Result shows that female, Muslims, other backward class and patient suffered with only TB has been adherent to treatment than their counterparts. Additionally, consumer of tobacco and alcohol after diagnosis of TB has been non-adherent to treatment more than their non-consumers. It is clear that increase in number of moves decreases the adherence among patients. Simultaneously, patients with an unsuccessful outcome have been non-adherent to treatment more than those with a successful outcome. Further, gender differential in reasons for non-adherence reveals that ‘no improvement in health condition’ as a leading cause of non-adherence, which has more been reported by females than males. Second most common reason reported is ‘busy with household work or job’, which has also reported more by females than males.

Success rate for treatment across gender and morbid groups by characteristics show that female and patient suffered with only TB resulted more with a successful outcome than their counterparts. Among males, success rate show a significant difference for work status where, working male resulted more with a successful outcome than not working. Likewise, newly diagnosed male patients resulted more with a successful outcome than retreated cases. Among female, success rate across tuberculosis type shows a significant difference where extra pulmonary tuberculosis patient resulted more with a successful outcome as compared to pulmonary cases. Similarly, success rate among only TB patients significantly declined with the increase in ages. Success rate among only TB patients also shows result similar for tuberculosis as of female where, extra pulmonary TB patients succeeded more with a positive outcome than pulmonary patients. Further, among the co-morbid group, only patient type
has significant difference in success rate; where, newly diagnosed cases resulted more with a successful outcome than retreated cases (old cases).

Multivariate result for determinants of a successful outcome shows that females are more likely to result with positive health outcome than male. However, not working patients have a low chance to result with successful health outcome as compared to working patients. Low knowledge gap about tuberculosis at the time of survey and adherence to treatment among patients is likely to result with successful treatment outcome. Further, longer health system delay to reach DOTS is less likely to result with successful treatment outcome for patients. Determinants by gender shows male in middle ages (35-44 age group) are less likely to result with a successful outcome than younger ones (18-24 age group). Simultaneously, not working and retreated cases (old patient) are less likely to be successful than their comparative groups. At the same time, experience of a number of symptoms by male reduces their chances of a successful outcome. Alcohol consumption shows contradictory result among males where, non consumers of alcohol resulted less with a successful outcome than alcoholic patients. This merely indicates that alcohol consumption is not showing negative impact on the treatment outcome of patients. Adherence to treatment significantly influence successful outcome among male, but result needs to be tested with much bigger sample before generalization.

Moreover, among female, Muslims women are more likely to result with a successful outcome than Hindu. Low knowledge gap about tuberculosis among women influences the success of treatment outcome. Similarly, adherence to treatment also increases the chances of a successful outcome among women. Patient delay is showing negative result where, increase in delay increases the likelihood for a successful outcome. This shows that patient delay among women has no negative impact on positive health outcome of patients. Nonetheless, delay in the health system likely to decrease the chances of a successful outcome among women. Experiences of discrimination by women increase the chances of the unsuccessful outcome, discussed in chapter six. This reflects that gender, discrimination faced and health outcome are inter related to each other.

7.2.4 Economic cost of tuberculosis treatment

Present chapter attempts to study the association of pathways and delay in treatment and the incurred economic cost. Economic burden has been one of the barriers for Tuberculosis patients in seeking treatment. Therefore, it is important to look into the incurred cost of
treatment for surveyed patients. Result reveals that the direct cost of hospitalization is fourteen folds, and indirect cost is three folds higher as of cost incurred for non-hospitalized patients. Direct cost of hospitalization is high for males and indirect cost for females. Nevertheless, indirect cost of hospitalization for poor has been forty times higher as compared to middle and rich. Further, direct cost of treatment for non-hospitalized cases is higher for females, co-morbid and middle economic class of patients as compared to their counterparts. On the other side, non-hospitalized males, co-morbid patients and poor paid high indirect cost for treatment than their counterparts. Higher indirect cost burden on poor is largely because of wage losses during hospitalization and treatment; as most of the slum population works on daily wage where, there is no provision of paid leaves.

Among non-hospitalized cases, direct and indirect cost of treatment is highest for the pathway of reaching DOTS after visiting two allopathic doctors. Involvement of more health care providers undoubtedly increases the duration and cost of treatment, but consultation of private allopathic doctors notably increased the direct cost. Further, other mixed pathways incurred higher direct and indirect cost of treatment as compared to identified pathways. Hospitalized cases also show a similar result as non-hospitalized cases where, other mixed pathway resulted with higher direct and indirect cost of treatment as compared to identified pathways. Duration of treatment among non-hospitalized cases is longest for those who reached DOTS after visiting two private allopathic doctors and a government facility (i.e. 286 days). Cost of treatment for economic classes according to pathways shows that for poor, irrespective of hospitalization, identified pathways incurred low price than other mixed pathways.

Average duration of treatment for identified pathways has been shorter than other mixed pathways and relatively longer for hospitalized cases across all the subgroups of patients. Health system delay and total delay have a significant association with direct cost of treatment across the subgroups. Direct cost of treatment is much higher for those who delay more than two weeks in visiting several healthcare providers and relatively high for females, co-morbid and middle class patients. Likewise, patients with more than two weeks of delay spend more direct cost of treatment than those who delayed less than two weeks. Nevertheless, average indirect cost of treatment has been higher for less than two weeks of patient delay among males, females, only TB patients and middle economic classes otherwise; it has been higher for more than two weeks of the health system and total delay.
Looking into the differentials in costs, it is important to study the burden of these costs on the economic condition of patients’ households. Therefore, economic burden of tuberculosis treatment expenditure measured out of monthly household income. Result reveals that burden of indirect cost has been more on households than the direct cost of treatment; which has been significantly higher for male patients than female. Additionally, it has also been observed that about one-third of poor spent more than 10 percent and six percent of them spent more than 40 percent of their monthly household income on treatment of tuberculosis.

As expected, the economic burden increases with a number of moves, but patient with no move has to pay highest indirect cost which significantly declines with an increase in number of moves. This shows that though RNTCP has taken efforts to make drugs freely available for patients but failed to control indirect costs attached with the treatment. More than one-fourth of patients have spent above ten percent of their monthly household income on treatment. Further, with an increase in number of moves for treatment share of indirect cost of treatment decreases and direct cost of treatment increases. Ultimately, patients with no move are vulnerable to catastrophic situation due to indirect cost of treatment for tuberculosis. This is mainly because direct move made by poor, and lower educated patients who have less economic resources to meet their treatment expenses.

Multivariate result supports the bi-variate finding that female patients’ households are less risky to be impoverished than male. Further, patients in the age group of 25-34 and 45 and above are two times more risky to be impoverished than 18-24 age groups of patients. Buddhist/other and other backward class groups are less likely to be impoverished than their comparative groups. Similarly, patients with primary education and from rich economic class are less likely to be impoverished than non-literate and poor respectively. Further, patients from a large family sizes have a low risk to be impoverished due to treatment of tuberculosis. Two pathways recorded low chances of impoverishment; one is to reach DOTS from a government facility and another is after visiting a private allopathic doctor and a government facility. Moreover, hospitalization increases the chances of impoverishment to 14 folds. Likewise, health system delay has also been a major risk factor for impoverishment of households because of tuberculosis treatment.
7.2.5 Discrimination faced by people suffered from tuberculosis

This chapter deals with the stigma and discrimination attached to a disease like tuberculosis which not only influence individual but also their health outcome. Disclosure is the resultant of existing stigma in the community, and it can occur in any setting. Thus, in the present study discrimination at three places i.e. at family, community and health facility has been explored.

Bi-variate results of the present study reveal that more females, and patients suffered with only tuberculosis did not reveal their tuberculosis status to anyone. Further, women have more confidants within the family in comparison to males for sharing their disease condition while males have confidants outside the family. Secrecy is more maintained by patients suffered with TB as they disclose to only spouse more as compared to co-morbid patients. This implies that stigma has more influence on women and only TB patients in comparison to their counterparts.

Types of discriminations are self-impose, perceived or enacted where, level of self-imposed discrimination is highest followed by enacted and perceived discrimination. Result of self-imposed discrimination shows that most of the patients try to keep oneself away from other family members out of the fear of spreading the infection. Patients in the age group of 35-44 experienced more all types of discriminations i.e. self-imposed, perceived and enacted in comparison to other age groups. About one-fifth of patients faced discrimination by one or other members around them due to tuberculosis suffering. Further, co-morbid patients experience more enacted discrimination than patients suffered with only TB. This indicates that along with tuberculosis, suffering with other diseases increases the chances of vulnerability towards discrimination.

Moreover, patients experienced family and community level discrimination more than health facility discrimination. Patients below 35 years of age experienced more community level discriminations, whereas patients above 35 years experienced more of family level discrimination. Females experienced higher discrimination at family and community than males while males experienced high discrimination at health facilities than females. Simultaneously, poor experienced more family level discrimination than its counterparts while middle class patients faced community level discrimination more than poor and rich. Additionally, rich experienced more health facility discrimination than poor and middle class
patients. Further, co-morbid and pulmonary TB patients experienced more discrimination at all the settings than their counterparts.

Most common form of enacted discrimination faced within the family of ‘not sharing utensils with the patient’ is more experienced by females than males. Second common form of discrimination faced by patients is ‘verbal abuse’ which, females and co-morbid patients experienced more than their comparative groups. Further, most common form of community level discrimination faced by patients ‘been gossiped about their disease status’ also experienced more by females and co-morbid patients than their counterparts. Second common form of discrimination faced at community setting is ‘less visits by friends, relatives and neighbours’ also experienced more by female and co-morbid patients.

However, perceived and enacted discriminations have a strong association with the health system and total delay in treatment. Result reveals that those who perceived and faced discrimination also delayed significantly longer in visiting health services than those who did not experience such discriminations. Similarly, these discriminations have been also significantly associated with the number of moves made for treatment where, those who experienced these discriminations made higher number of moves than those who did not experience. That means discrimination in its perception or actual form makes patient prone towards delay and higher number of moves for treatment.

Discrimination has also been found significantly associated with treatment outcome of patients. Patients who discriminate themselves from other family members found to result more with a successful outcome than those who did not discriminate. This is mostly because of their precautionary measures towards their health. On the other side, those who perceive to be discriminated and face enacted discriminations have resulted less with a successful outcome than those who did not experience these discriminations. This indicates that perceived and enacted discrimination significantly affect health outcome of patients.

Further, number of family level discriminations faced by subgroups of patient shows that female and co-morbid patients experience a number of discriminations than their counterparts. Single form of discrimination is experienced more by females and co-morbid patients whereas; two forms of family level discrimination are more faced by male and patient suffered with only TB but three and more forms are also experienced more by females and co-morbid patients. On the other side, single form of community level discrimination faced by males and co-morbid patients whereas; two forms of discrimination
are more faced by females and co-morbid patients. Further, three and more forms are more experienced by females and patients suffered with TB than their counterparts.

However, across age groups, 35-44 age groups of patients faced a number of discriminations than other age groups. Likewise, females experienced significantly higher number of discriminations than males. At the same time, non-literates and poor experienced more three and above forms of discriminations than their counterparts. Similarly, pulmonary and co-morbid TB patients experienced more of three and above forms of discriminations than their counterparts.

Multivariate result depicts that 25-34 age group and 35-44 age groups of patients has a higher risk to face a number of discriminations than 18-24 age group when controlled for all the variants. Female patients face higher discrimination than males. Buddhist/others experienced more discrimination as compared to Hindus. Likewise, important to note that other backward classes and non-scheduled caste/tribe/other backward classes experienced higher discriminations than scheduled caste and scheduled tribes. This indicates that discrimination against tuberculosis is not prevalent among scheduled castes and scheduled tribes, in fact more common among other caste groups. On other side, poor patients face more number of discriminations compared to other economic classes. Alcohol consumers are more discriminated than their comparative group. More number of moves for treatment also increases the risk for number of discriminations faced.

Discrimination faced has also been studied for both the gender. Risk factors for the number of discrimination among males show that Buddhists/other religious group, middle economic classes and males with extra pulmonary tuberculosis are less likely to face a number of discriminations than Hindus, poor and pulmonary tuberculosis males. Non-alcoholic males are less likely to face a number of discriminations than alcoholic patients. This is probably because alcohol consumption is a matter of social taboo in the society. Number of moves for treatment increases the risk to face number of discriminations.

At the same time among female, 25-34 and 35-44 age group of patients have higher risk to face more number of discrimination than 18-24 age group. Buddhists/other religious group women have a higher risk to face a number of discriminations than Hindus. At the same time, non-scheduled caste/tribe/other backward class and other backward class patients are also at higher risk to face a number of discriminations than scheduled castes/scheduled tribes. Education shows a negative relationship with discrimination among women where
primary, and middle educated patients faced a number of discriminations than non-literate. Similarly, women from poor economic class face more discriminations than other economic classes. Women with extra pulmonary tuberculosis faced less discrimination than pulmonary tuberculosis. At the same time, old female patients (retreated cases) are more likely to face a number of discrimination than new cases. Knowledge shows negative relation with discrimination among females, this is probably because of high reporting among them. Additionally, it has also been observed that increase in number of moves for treatment increases the risk for a number of discriminations.

7.3 Conclusions

The study demonstrated the differentials in treatment seeking process of tuberculosis patients and inequity in health and economic condition. It also brought out the gender and morbidity differentials in the process of treatment.

Despite of attempts made by Revised National Tuberculosis Programme (RNTCP) to make people aware about the availability of free treatment under DOTS and symptoms of tuberculosis; generally, people visit two healthcare providers before DOTS for treatment. Similar to earlier studies, present study also reflects the strong preference for private allopathic doctor as first source of treatment (Suganthi et al., 2008; Hazarika, 2011). Further, involvement of private providers into the programme has not shown satisfactory result because on an average patient delayed 24 days in visiting healthcare services before consulting DOTS. The private sector in India, which manages more than half of all TB patients is a continuing source of mismanagement of TB, and is largely outside the scope of the RNTCP (Bhargava et al., 2011) and quality of treatment offered by private providers are often substandard (Udwadia, 2010; IIPS and Macro International, 2007). Furthermore, some amount of health system delay is also caused due to switch within the government facilities as observed in the pathways, which is probably due to unavailability of diagnostic facilities. This kind of delay can be minimized by improving the quality of services provided by decentralization of diagnostic and treatment services so that people are diagnosed early at their first point of contact with health services.

Gender and morbidity differentials in choice of pathways clearly show that female and co-morbid patients prefer longer pathways and delay substantially long to consult DOTS. Women with significantly longer health system delay of 31 days is much higher than the threshold of 15 days for consistent cough, raises a grave concern for tuberculosis program.
Reasons behind such behaviour are due to tendency to choose number of healthcare providers before consulting DOTS and noted more among women. Knowledge about tuberculosis shows significant influence on successful treatment outcome of patients, clearly noted among women. This shows that low knowledge gap about tuberculosis is important in order to have successful health outcome. It is also demonstrated in previous studied that low knowledge about tuberculosis coupled with fear of stigma related to TB and its social and economic impact affect willingness to undergo TB screening and seek effective medical care after onset of symptoms (Watkins & Plant, 2004; Courtwright & Turner, 2010) but these relations are not found significant in present study. Further, although female delay long in initiation of effective treatment but were adherent to treatment and thus, resulted more with successful treatment outcome. Nevertheless, study clearly shows the linkages between gender, discrimination and health outcome of patients where, women who experienced discrimination resulted less with successful treatment outcome than those who did not experience any discrimination. This reveals that social implications in form of discrimination have strong negative implications on health outcome of women than men.

Economic consequences are serious for patients who have been hospitalized during their process of treatment, who are at 14 folds higher chances of impoverishments as compared to non-hospitalized cases. Further, economic implications are found significant higher on males and poor than their counterparts where contribution of indirect cost is more. It reflects that RNTCP’s provision of free drugs for tuberculosis treatment has been successful in reduction of medical cost and reduce economic burden to certain extent. Patients with no move also had to face high economic burden due to high indirect cost involved. Additionally, direct pathway to DOTS is mostly used by poor who are daily wage worker and due to prolonged treatment duration, had to bear high wage losses. However, still patients face economic hardship for tuberculosis treatment due to high indirect cost involved. Therefore, currently program has challenge in order to reduce the burden of indirect cost of treatment especially among poor. It is also noted that consultation with government facility before DOTS has emerged as cost effective pathway rather than consulting any other health care provider. This certainly implies that government healthcare services have been efficient to reduce the cost burden for patients.

As RNTCP enters its new phase (2012-2017), there is an urgent need to engage, incentivize and integrate the private sector into national TB control and facilitate universal access to co-morbid diseases. This is required to curb mismanagement of TB by private healthcare
providers which have threatened India’s TB control efforts. Solely medical approach to control TB through health sector interventions seems to be insufficient to address the tuberculosis scenario. Therefore, there is need to relook into the program in perspective of gender, discriminations, knowledge about TB and economic burden, to achieve long term success.

7.4 Policy implications

1. It is found that very few patients went directly to DOTS after realisation of symptoms. This shows that tuberculosis program has either failed to reach out to people or not able to convey it’s messages to them. Therefore, in order to facilitate this, focussed interventions are needed to increase their awareness level.

2. Typically, patients shop around for treatment and reach to DOTS after visiting two providers. This again points out that quality of services provided by private healthcare providers for tuberculosis treatment is not satisfactory. There is a need to check the quality of services provided by private practitioners related to symptoms of tuberculosis in slum areas.

3. Although, RNTCP program has succeeded in reducing the direct cost for tuberculosis treatment but still indirect cost has been catastrophic for patients. This is largely because of high wage losses of patients and their care takers. Therefore, in order to reduce the overall cost burden on patients, risk pooling mechanism like provision of subsidies for transport and leave compensation need to be developed.

4. In order to address non-adherence, it is important to have effective knowledge program and consistent follow ups of patients at each visit with regular health check-ups and educate them about symptoms and adverse reactions to drugs they are taking, whether minor or serious. If required, some incentives can also be given to encourage patient adherence.

5. Women are vulnerable in almost all the aspect like low level of knowledge about tuberculosis and HIV, making more number of moves, longer health system delay, and high direct cost of treatment in case of non-hospitalization and experience of more number of discrimination. Except positive health outcome, their condition is of concern. Therefore, tuberculosis programme needs to focus more on women registered under DOTS along with other member in their surroundings. This can be done by creating awareness through educational programs among family and community members.
7.5 **Limitations of the study**

Findings of the study need to be interpreted with caution because it is based on special population of high prevalence area. Study could not throw more light on TB-HIV co-morbid and drug resistance cases due to few cases.

Findings of the study need to be interpreted in the light of certain limitations because there may be a recall bias with reference to treatment expenditure because the participants provided retrospective responses about the cost incurred.

Economic burden cannot be generalised as overall burden because income is collected for all the members in the household, but expenditure is only for tuberculosis treatment of respondent. Treatment expenditure is also likely to suffer from recall bias especially for those who have suffered for long duration. Qualitative data support could have been given especially for those who are making more than four moves for treatment, in order to give more insights into their treatment seeking behaviour and magnitude of discrimination.

7.6 **Future scope of the study**

This study has brought out few research gaps which are not covered in the present study. Few of them are as follows:

- Study can also be done to understand the problems in addressing tuberculosis patients, difficulties in follow-ups and how services can be improved for better service utilisation from the provider’s perspectives.

- Exclusive study can be done on co-morbid tuberculosis patients, their behaviour and problems. It will give more insights in addressing the co-morbid patients if, nature of their diseases is known and associated factors related to treatment and health outcome.

- Studies can also be done exclusively on quality of services availed by tuberculosis patients, especially from private providers before DOTS, and it’s implications on health outcome, giving special focus on multi-drug resistance.