Socio-economic dimensions of tuberculosis control: Review of studies over two decades from Tuberculosis Research Center

M. Muniyandi*, R. Ramachandran*, R. Balasubramanian* 
and P.R. Narayanan*

ABSTRACT
Tuberculosis (TB) affects the most productive age group and the resultant economic cost for society is high. Even though diagnostic and treatment services under TB control are offered free of cost, TB patients do incur out of pocket expenditure. Tuberculosis Research Centre undertook a series of studies on economic aspects of TB.

We interviewed TB patients enrolled under TB control programme in south India, and assessed the following: socio-economic status of patients (SLI - standard of living index) and economic impact on patients, families both before and after Revised TB Control Programme (RNTCP) and the impact of parental TB on children. In addition, patient’s perceptions of physical, mental, social well being during and after completion of treatment were also elicited.

A TB patient incurs out of pocket expenditure of Rs 5986 amounting to about 13,000 crores a year for the country; 11% of children dropped out of school on account of parental illness and 20% of the children had to take up employment in order to supplement income especially if the father had TB. About 64% of TB patients registered under RNTCP were poor (low SLI). The provider cost to treat a TB patient under RNTCP was Rs 1587/- for Category I, Rs 1924/- for Category II and Rs 1417/- Category III. At the end of treatment even though 47% of patients continued to have respiratory symptoms, 54% of patients perceived ‘happy mental status’.

Majority of the patients registered under RNTCP were poor. Patients’ and provider costs and the impact on patients including families on account of TB were enormous. About half of TB patients, despite completing treatment successfully had persistent respiratory ill
health resulting in frequenting health facilities. This information is vital for programme planners indicating that the existing control programs have been ineffective. To achieve success in control programs, the existing ones should be amended as there is evolution of resistance in the parasite as well as the vector. Public health education, to make the people aware about preventive aspects of the disease is important. The possibility of the existence of animal reservoirs should also be considered and checked out for better control measures.

**Key words:** Tuberculosis, Prevalence of TB, economic impact, social impact, RNTCP, India

**INTRODUCTION**

Chronic diseases such as tuberculosis cause considerable morbidity and mortality. Despite the existence of a National Tuberculosis Programme (NTP) for four decades, the burden of TB in India is enormous. Since late 1998, India began rapid expansion of the World Health Organization recommended strategy, directly observed treatment, short-course (DOTS) and the present coverage is 100% of the population.\(^1\) Even though the programme provides free diagnostic and treatment services to all the patients registered, since tuberculosis affects the most productive age group, the resultant economic cost for society is high.\(^2\)\(^-\)\(^5\)

The health sector has become an area of concern for economists relatively recently and studies have been undertaken to identify the socio-economic burden of illnesses. Economic studies are relevant to the health sector as the findings are likely to influence the budget allocation.\(^6\) The commission on Macroeconomics and Health\(^7\) had suggested that, if by improving health in general or controlling TB in particular is shown to have a positive impact on economic growth, this can help to justify increased investment of resources in the health sector and in TB control. A clear understanding of these issues will aid planners to give adequate priority in the allocation of funds.

Tuberculosis Research Centre (ICMR), Chennai undertook a series of studies on economic aspects of TB and TB control to strengthen the existing TB control programme in India.\(^8\)\(^-\)\(^14\) The main objectives of these studies were to document (1) the socio-economic impact of TB on patients and family both before and after implementation of RNTCP, (2) the socio-economic impact of parental TB on children, (3) the economic status of patients registered under Revised National Tuberculosis Control Programme (RNTCP), (4) estimation of provider cost for treating TB patients under RNTCP and (5) assessment of the intangible costs in terms of perceptions about their physical, mental and social
well being of TB patients during and at the end of treatment and also at one year after completing treatment. In these studies we assessed the economic impact in terms of direct, indirect and intangible costs of disease to the patients and their family. In addition, we assessed the utilization of government tuberculosis control programme by different economic strata. This report discusses the salient findings of all these studies.

In India about 70% of population live in rural areas and the main occupation is agriculture mostly daily wages. In most of the places there are only mud roads and travel facilities are poor. The urban areas are well connected both by rail and road; travel expenses are more in urban areas. The occupational profile of urban population is different from rural; majority are self-employed and salary earners. However the prevalence of TB is similar in both rural and urban areas of India.

The health care delivery system, in India is complex and includes Government, private and non-governmental organisations (NGOs). The Government health care system comprises of primary health care centres in rural areas, Taluka hospitals in towns and tertiary care speciality hospitals in cities. In all these places, services are offered free of cost to patients of the low income group. In the case of NGOs, a nominal fee is collected for diagnosis and treatment. The private for profit providers charge their patients for rendering their services and the cost is always higher, compared to the other two health providers.

The Government health care system in rural areas is such that there is one primary health centre for every 30,000 population. But these centres are not always easily accessible due to poor travel facilities in rural areas. A sick person may have to travel 25 km to reach the nearest PHC. NGOs are situated in both rural and urban areas and they are accessible by road and patients may have to spend more for travel to attend these centres. Both qualified and unqualified private for-profit providers are available in both rural and urban areas, more so in urban areas. They are available, acceptable and accessible to the patients, even though the patients may have to pay for their services. Inspite of this, private providers have been observed to be the first point of contact, in more than 50% of the patients. Traditional healers are found more in rural areas and their charges are variable.

The RNTCP, based on the internationally recommended DOTS strategy, began on a pilot scale in India in 1993 and gradually expanded, at present 100% of population covered under RNTCP. DOTS is a systematic strategy which has five components: political and administrative commitment, diagnosis through sputum microscopy, uninterrupted supply of quality drugs, directly observed treatment and systematic monitoring and accountability. All patients registered are treated with Short Course Chemotherapy (SCC) regimens of 68 months duration in three different categories (category I, category II and category III).
MATERIAL AND METHODS

Study design and population

The socio-economic impact of TB on patients/family and the impact of parental TB on children in particular (1 & 2 studies) were studied in rural and urban areas of Tamil Nadu before and after the implementation of RNTCP. Prior to RNTCP the study population included 304 (184 males, 120 females) newly detected sputum positive pulmonary TB patients receiving short course chemotherapy from government, Non-Governmental Organization (NGO) and private hospital in Tamil Nadu. After RNTCP the study population included 455 TB patients registered under RNTCP between June and December 2000, in government health facilities, Tiruvallur district. The following information was collected through interview: socio-demographic characteristics of patients, particulars of employment, income/assets of patient/family, expenditure incurred during the illness, effect of illness on normal activities and employment, source of finance for expenditure incurred during illness, and the effect of the illness on children, with special reference to schooling. All information was cross-checked wherever possible by verifying patients' prescription slips and hospital discharge summaries.

The third study was on assessment of the economic status of all TB patients registered for treatment under RNTCP, during the 6-month period from July to December 2000 in Tiruvallur district. All were interviewed using a semistructured precoded questionnaire. Data on economic characteristics such as income, assets of the patient and family were collected. Based on the information collected, standard of living index (SLI) was computed using the National Family Health Survey (NFHS) definition.¹⁶

The fourth study focused on the estimation of provider cost for treating TB patients under RNTCP. All the government health facilities including sub centers situated in one tuberculosis unit of Tiruvallur district were visited and all the records pertaining to the TB programme were perused. The following information was collected using a checklist: staff salary, costs incurred for reagents, drugs, maintenance, stationary and fuel cost. Based on the information collected the personnel cost including supervision and monitoring, the cost of a drug regimen, the cost of a sputum smear examination and cost of an X-ray chest were calculated. From these we estimated the total provider cost for management of a tuberculosis patient.

In the fifth study the intangible costs in terms of perceptions of TB patients about their physical, mental and social well being was assessed in two tuberculosis units in Tiruvallur district covering a population of 1.16 million. Patients attending 37 government health facilities in this area were considered for this study. Data on perceptions of their illness before the onset of illness and during the treatment period were collected, using a modified SF36 questionnaire. Data on physical and social functioning, role limitations due to physical or emotional
problems, mental health, energy and vitality, pain and general health perceptions with special reference to 'good health status'. Patients were questioned about their mental status such as a feeling of happiness, impatience, fear, worry, tension, perceived energy level to cope with daily activities and the effects of illness on activities other than 'occupation'. In addition presence or absence of physical symptoms at the end of treatment, patient's reaction to initial diagnosis and stigma, as perceived by the patient before, during and at the end of treatment were collected.

**Data collection**

Trained field investigators conducted the interviews after obtaining informed consent at the patient's residence. Patients were informed in their mother tongue or a language that they understood about the purpose of study. Patients were told about the confidentiality of the data collected and also of their right to withdraw from the study at any time.

**Definitions used**

Definition of direct, indirect, medical, non-medical and total costs were as per our earlier studies. Standard of living index (SLI) was computed using the National Family Health Survey (NFHS) definition.

**Data management**

Data was entered in Data Star (MicroPro DataStar version 1.40). To ensure accuracy, all records were keyed in twice by two independent data entry operators. Data were checked for errors and analysed using the SPSS (8.0 version SPSS Inc, Chicago, IL) package. Differences in costs values were tested for significance using nonparametric tests (MannWhitney U-test). In univariate analysis, the \( \chi^2 \) test was used to test significance of differences between proportions.

**RESULTS**

**Socio-economic impact of TB on patients and families before implementing DOTS:** On an average, a patient suffering from TB incurred out of pocket expenditure, while shopping for diagnosis and treatment, Rs 2052 in terms of direct cost, Rs 3934 in terms of indirect cost and the collective total cost was Rs 5986. Based on the prevalence of disease in India, it worked out to total cost of Rs 13,000 crores a year for the country, even though the treatment and diagnosis were offered free of cost to patients (Fig 1). For a daily wage labourer the mean number of work-days lost was 83 (Fig 2). Every year, more than 17 crore work-days are lost to the national economy on account of tuberculosis, amounting to Rs 700 crores. In addition, 67% of rural and 75% of urban patients borrowed money on account of the illness. The average debts incurred as a result of TB including treatment was Rs 1405 for rural and Rs 2762 for urban patients. The proportion of various costs to annual family income was for direct cost 13%, indirect cost 26%, total cost 40% and debts 14%. 
Fig.-1: Mean direct, indirect and total cost to TB patients

Fig.-2: Workdays lost vs. occupation in urban and rural tuberculosis patients

Fig.-3: Total unit provider cost to treat a tuberculosis patient under RNTCP

Fig.-4: Intangible costs in terms of perceived 'good health state' and 'happy most of the time' of TB patients in different time points
Socio-economic impact of TB on patients and families after implementing DOTS:
The median direct, indirect and total costs for 343 patients who successfully completed treatment were as follows: pre-treatment direct costs Rs 340, during treatment direct costs Rs 100. More than 50% of patients did not incur any indirect costs in both pre-treatment and during treatment periods and overall total costs were Rs 1398. About 12% of patients lost more than 60 workdays and after completing treatment, 88% returned to work.

Socio-economic impact of parental TB on children: Eleven percent of children dropped out of school on account of parental illness and 20% of the children had to take up jobs in order to supplement income especially if the father had TB (Table 1). Thus TB is one of the causes of enforced child labour. Based on the study findings, projections have been made for the entire country; 300 000 children become orphans on account of TB and 100 000 Indian women are rejected by their families per year.

Economic status of patients registered under RNTCP: A total of 896 patients registered during the cohort of July-December 2000 were interviewed. Seventy percent of the patients were males and in more than two thirds the family size was more than four. Patients’ standard of living as measured by the standard of living index (SLI) was low in 64%, medium in 32% and high in 4% (Table 2).

Estimation of provider cost for treating a TB patient under RNTCP: In the year 2002, in one TU, chest symptomatic subjects examined were 5717, and 1112 TB patients were detected. For these patients the unit cost was estimated including cost for follow-up sputum microscopy. The unit cost for smear microscopy was estimated to be Rs 10 and for radiography Rs 25. The overall unit provider cost for treating a TB patient was Rs 1587 for category I, Rs 1924 for category II and Rs 1417 category III. Of the overall unit provider cost, about 70% was spent on personnel, 25% on drugs and 5% on diagnosis (Fig 3).

Patients’ perceptions of physical, mental and social wellbeing: 610 (males

<table>
<thead>
<tr>
<th>Region / Sex</th>
<th>No of Patients</th>
<th>No of Children</th>
<th>School Discontinued %</th>
<th>Seeking Employment %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rural</td>
<td>153</td>
<td>147</td>
<td>8.5</td>
<td>7.8</td>
</tr>
<tr>
<td>Male Female</td>
<td>98</td>
<td>95</td>
<td>11</td>
<td>12</td>
</tr>
<tr>
<td></td>
<td>55</td>
<td>52</td>
<td>4</td>
<td>0</td>
</tr>
<tr>
<td>Urban</td>
<td>151</td>
<td>129</td>
<td>13</td>
<td>9.6</td>
</tr>
<tr>
<td>Male Female</td>
<td>86</td>
<td>75</td>
<td>13</td>
<td>15</td>
</tr>
<tr>
<td></td>
<td>65</td>
<td>54</td>
<td>13</td>
<td>2</td>
</tr>
<tr>
<td>Total</td>
<td>304</td>
<td>276</td>
<td>11</td>
<td>8</td>
</tr>
</tbody>
</table>

Table 1. Effect of Parental Illness on Children
aspects of TB control conducted during 1997-2005 have shown that 64% of patients taking treatment under TB control programme were from poor economic strata. This implies that free diagnosis and treatment services were accessible to the poor under the current Indian TB control programme. This information is vital for the programme managers and policy makers.

Earlier studies have highlighted the costs of TB to patients and their households\textsuperscript{17-20}. The costs to patients and their families that can be quantified are principally in the form of lost earnings from loss of work due to illness or death. The present study conducted before implementing DOTS showed that expenditure due to tuberculosis accounted for as much as 40% of patients' average annual income, while indirect costs alone were responsible for 26% of annual income. TB affects the most productive age group, and on an average 3 months of work time is lost if an adult has TB, resulting in a loss of earnings.

404, females 206) TB patients were interviewed both at the end of intensive phase and at the end of continuation phase. 'Health status' was 'perceived to be good' before and after treatment in 5% vs. 78% of males and 7% vs. 82% of females respectively (trend chi square \(p<0.05\)). Only 54% of patients perceived 'happy mental status' at the end of treatment (Fig 4). Despite microbiological cure, 47% of patients continued to have respiratory symptoms; this was significantly higher among patients who had delayed taking action for more than 3 months. The reaction of patients to the disclosure of the diagnosis was worry (50%) and suicidal thoughts (9%). The inhibition of both male and females to visit friends before treatment was observed in male 38%, felt inhibited to reveal the diagnosis to friends in 43% and even to their spouse in 16%. This proportion did not change significantly even after treatment.

**DISCUSSION**

The present series of studies on economic aspects of TB control conducted during 1997-2005 have shown that 64% of patients taking treatment under TB control programme were from poor economic strata. This implies that free diagnosis and treatment services were accessible to the poor under the current Indian TB control programme. This information is vital for the programme managers and policy makers.

Earlier studies have highlighted the costs of TB to patients and their households\textsuperscript{17-20}. The costs to patients and their families that can be quantified are principally in the form of lost earnings from loss of work due to illness or death. The present study conducted before implementing DOTS showed that expenditure due to tuberculosis accounted for as much as 40% of patients' average annual income, while indirect costs alone were responsible for 26% of annual income. TB affects the most productive age group, and on an average 3 months of work time is lost if an adult has TB, resulting in a loss of earnings.

---

**Table 2. Patients registered for treatment under government health facilities**

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Group</th>
<th>No</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years)</td>
<td>15-54</td>
<td>664</td>
<td>74</td>
</tr>
<tr>
<td></td>
<td>55+</td>
<td>232</td>
<td>26</td>
</tr>
<tr>
<td>Sex</td>
<td>Male</td>
<td>627</td>
<td>70</td>
</tr>
<tr>
<td>Family size</td>
<td>4+</td>
<td>619</td>
<td>69</td>
</tr>
<tr>
<td>Education</td>
<td>Illiterate</td>
<td>335</td>
<td>37</td>
</tr>
<tr>
<td>Occupation</td>
<td>Not working</td>
<td>240</td>
<td>27</td>
</tr>
<tr>
<td>Standard of living</td>
<td>Low</td>
<td>403</td>
<td>64</td>
</tr>
<tr>
<td></td>
<td>Medium</td>
<td>368</td>
<td>32</td>
</tr>
<tr>
<td></td>
<td>High</td>
<td>125</td>
<td>4</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>896</td>
<td>100</td>
</tr>
</tbody>
</table>

M. Muniyandi et al.
of about 20% to 30% of annual household income. On an average of 15 years of income is lost if an individual dies of disease. One of the key components of RNTCP (DOTS) is that each dose of antituberculosis drugs should be administered to patients under the supervision of a DOT provider, either from the community or the health system. The selection of DOT centre is according to patient's convenience (closer to patient's residence), so that patients do not lose wages or incur transportation charges for treatment in the programme. Prior to implementation of RNTCP the cost to patients on account of TB was about Rs 6000, but after the implementation the patients' costs have decreased to Rs 1398. In addition provider cost to treat a TB patient under RNTCP was about Rs 2000. Thus DOTS strategy is one of the largest public health strategies that has been successful in reducing death rates and increasing cure rates in India.\(^\text{21}\) Since evidence supporting this has mainly come from cost effective analysis (excluding patients costs) against historical controls.\(^\text{22-26}\)

Findings of our study clearly bring out the low standard of living status of most of the TB patients registered under the programme - 64% as against 51% in the community\(^\text{11}\). These findings indicate that the programme is outreaching the poor. It is well known that TB is a disease of the poor and deprivation associated with poverty increases the risk of infection and development of disease. Similar findings have been reported from earlier studies too.\(^\text{27-32}\) In India, almost 100% of the population has access to DOTS strategy; under RNTCP each month more than 100000 patients are being initiated on DOTS. Of them more than 8 of 10 patients are successfully treated and the mortality is reported to be less than 4%.\(^\text{33}\) These facts highlight that TB patients are poor, and they are immensely benefited by RNCTP, considering the benefits accrued from the current TB programme. National TB control programme in case detection and treatment, could be an effective part of an anti poverty approach to development.\(^\text{34}\)

Apart from economic costs TB have social costs too.\(^\text{35-36}\) Tuberculosis affects all age groups, but its greatest impact is on adults. These are parents on whom survival and development of children depend. In our study patients could not afford to send their children to school due to loss of income. Tuberculosis in mothers affected the entire households on account of loss of their earnings outside the household and additional losses due to the reduction of routine household activities, child care and inability to feed their children or take care of their daily nurture and education.\(^\text{9}\) The economic loss on account of parental TB necessitated their children to take-up employment. Study clearly shows that the tuberculosis causes loss of productivity and increase in debts. An episode of illness may reduce a poor household to penury, especially when they have to sell their productive assets in order to cover health care expenses and poverty is thrust upon to the next generation.\(^\text{37}\) Thus, tuberculosis which is already a social menace leads to another
social evil i.e., child labour. Though the number of children forced to become child labourers is relatively small but this can not be ignored, especially when India is working towards eradication of child labour. It is thus the time for health care providers and child care workers to work jointly for the control of tuberculosis.

Assessment of intangible costs (Perceptions of patients) of patients have demonstrated that only 54% of patients perceived 'happy mental status', at the end of treatment, 47% of patients continued to have respiratory symptoms. The social stigma also remained unchanged even after completing treatment in both men and women. These findings suggest that there is a need to allay the needless fears of patients by providing appropriate counseling to patients and health education to community. Increased awareness about TB will remove stigma in the community. Customer satisfaction is crucial for improving TB control programme.

REFERENCES


11. Muniyandi M, Rajeswari R and Balasubramaian R. Is TB control programme Pro-poor ?. SAARC J


