

# Socioeconomic impact of TB on patients registered within RNTCP and their families in the year 2007 in Chennai, India

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## ABSTRACT

**Background:** Tuberculosis patients are registered in government clinics under Directly Observed Treatment Short-course (DOTS) program in Chennai city catering to 4.34 million population. With the entire country geographically covered under the DOTS program, research into socioeconomic impact of TB on patients and their households is crucial for providing comprehensive patient-friendly TB services and to document the benefits of DOTS. **Objective:** To assess the social and economic impact of TB on patients registered under DOTS program and their families. **Materials and Methods:** A cross-sectional study of 300 TB patients was done using a pre-coded semi-quantitative questionnaire between March and June 2007 in all the Tuberculosis Units (TUs) of Chennai city. **Results:** Social and economic impact was perceived by 69.0% and 30.3% patients, respectively. About 24.3% suffered from both social and economic impact, while 75% patients suffered from any one form of impact. Social impact was perceived by more female patients as compared to males (80.7% vs. 62%;  $P < 0.001$ ). More patients with extra-pulmonary disease (44.4%) and patients belonging to joint families (40.7%) perceived economic impact ( $P < 0.05$ ). **Conclusion:** After 8 years of DOTS implementation, the present study has shown that with the availability of DOTS, percentage of patients who mortgaged assets or took loans has reduced. Social impact of TB is still perceived by two-thirds of the patients (69%). Elimination or reduction of social stressors with specific, focused, and intense social support services, awareness generation, and counseling to patients and families need to be built into the program.

**KEY WORDS:** Chennai, DOTS, economic impact, social impact, tuberculosis

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## INTRODUCTION

India is highest tuberculosis (TB) burden country globally, accounting for more than one-fifth of the global incidence.<sup>[1]</sup> The impact of TB on individuals is often all encompassing, affecting not only physical health, but also social, economic, and psychological well-being.<sup>[2]</sup> Since the disease affects the economically productive age group, households are adversely affected. The social repercussions may include loss of work, divorce, ostracism

by family members and the local community, and loss of housing.<sup>[3]</sup> Discrimination, whether experienced or expected, has been found to be associated with increased anxiety and depression and lower life satisfaction, as well as with higher unemployment and lower income.<sup>[4]</sup>

Effective TB control through Directly Observed Treatment Short-course (DOTS) strategy helps in alleviation of poverty by providing diagnosis and treatment free and by reducing the economic burden that TB inflicts on poor.<sup>[5,6]</sup> Research into socioeconomic impact of TB on patients and their households is crucial for providing comprehensive patient-friendly TB services and to document the tangible benefits of DOTS. Impact of TB could result in long-term implications beyond the treatment duration. From an economic point of view, the primary impact of disease manifests mainly among individual economic agents (such as individuals and households).<sup>[7]</sup> An assessment of the socioeconomic impact of TB would therefore have to start at this micro-level of analysis.<sup>[7]</sup>

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Eight years post Revised National Tuberculosis Control Program (RNTCP) implementation, the program has endeavored to take into consideration several factors such as Directly Observed Treatment (DOT), decentralization to minimize the costs to patients, improving accessibility by providing many microscopy centers, etc. While studies<sup>[7,8]</sup> have been conducted to assess the socioeconomic impact of TB before and during early phase of RNTCP implementation, there is very little information about the socioeconomic impact of TB after 100% geographic coverage by RNTCP. Therefore, the present study was undertaken to assess the social and economic impact of TB on the new patients (who have never had treatment for TB or have taken anti-tuberculosis drugs for less than 1 month) registered under RNTCP and their families in Chennai city.

## MATERIALS AND METHODS

### Study Setting

Chennai city has a population of 4.34 million and is spread over 174 km<sup>2</sup>. The city is divided into 10 administrative zones with one Tuberculosis Unit (TU) in each zone. This study has been conducted so as to cover TB patients registered in all the TUs of the city over 4-month period.

### Study Design and Period

In this cross-sectional study, the data were collected during the period from March 2007 to June 2007.

### Study Population

Adult TB patients of both the sexes, registered under RNTCP, with the following eligibility criteria were enrolled: patients who came to TU for DOT; who have completed a minimum of 2 months of continuation phase of TB treatment; patients under category-I and -III treatment regimens; patients who were HIV negative.

### Tool for Data Collection

A pre-tested, semi-structured, pre-coded interview schedule was used to collect information on demographic and socioeconomic characteristics of patients. Information on economic and social impact was collected. In addition, open-ended questionnaire was used to obtain information pertaining to the patient's perception of only the impact of TB and TB control program on self/family. Social impact was measured in terms of information about TB shared with spouse, family members, friends, relatives, employers, colleagues, teachers, perceived/actual rejection/discrimination, and mental anguish, as reported by the patients. Economic impact was measured in terms of reduction of savings, indebtedness, and mortgaged assets, as perceived by the patients.

### Data Collection

List of TB patients who met the eligibility criteria was compiled from TB register. All patients who met the eligibility criteria were interviewed after obtaining written informed consent at the TU. Purpose of the study was

explained to the patients and they were told about the confidentiality of data collected and also of their right to withdraw from the study at any time. Ethical approval for the study was obtained from the Ethics Committee of Sri Ramachandra University, Porur, Chennai. Data were validated throughout the interview by repeated questioning.

### Data Management

Data were checked for errors, entered, and analyzed using the SPSS (15.0 version). In univariate analysis, the Chi-square test was used to compare the association between economic and social impact with patient characteristics. A *P* value <0.05 was considered statistically significant.

## RESULTS

Among the 335 patients who met the eligibility criteria, 300 (89.6%) were interviewed. The remaining patients could not be interviewed due to migration, transfer, and non-availability.

### Socioeconomic Profile of the Patients

Majority of the patients (54%) belonged to the 25–54 years age group and the study group included 186 (62%) males and 114 (38%) females. Most of the patients [90 (30%)] had primary school education and about 71 (23.7%) were unemployed/retired or were students. About 158 (52.7%) had a monthly per capita income in the range US\$ 24.4 to 50 [Table 1].

### Clinical Characteristics of the Patients

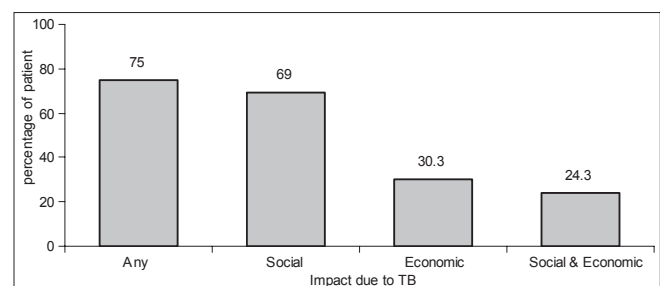
Among the 300 patients, 149 (49.7%) were sputum positive, 70 (23.3%) were sputum negative, and 81 (27%) were extra-pulmonary TB patients. About 223 (74.3%) patients were on category-I and 77 (25.7%) on category-III treatment in RNTCP [Table 1].

### Impact of TB on Patients and Their Family

Of the 300 TB patients studied, 207 (69%) felt social impact, 93 (30.3%) felt economic impact, 73 (24.3%) felt both social and economic impact, and 225 (75%) felt either the social or the economic impact [Figure 1].

### Economic Impact of TB

Of the 300 patients, economic impact was perceived as follows. 24.3% had their savings reduced, 7.3%



**Figure 1:** Socioeconomic impact of TB on TB patients and their family (multiple responses) *N* = 300

got indebted, and 6% had to mortgage their property [Figure 2]. Of the 25 patients who took loan/mortgage either before or during treatment, the average loan taken was US\$ 81.8, median was US\$ 66.7, and range was US\$ 11.1–222.2. Significantly, economic impact was felt by more patients belonging to joint family as compared to patients belonging to nuclear family (40.7% vs. 26.2%;  $P = 0.013$ ) and by more extra-pulmonary patients as compared to pulmonary patients (44.4% vs. 25.1%;  $P = 0.001$ ). Economic impact was also felt by higher proportion of female patients (32.5%), those with an education of higher secondary and above (33.3%), unemployed (32.5%), and those with monthly per capita income less than US\$ 24.4 (39.2%) [Table 2].

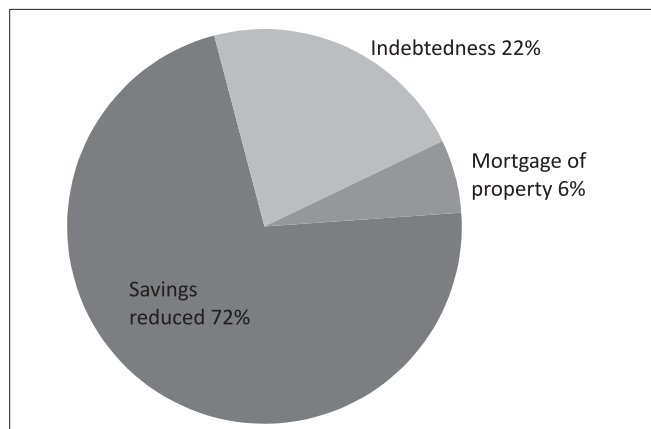
The impact was observed by a 44-year-old daily wage earner as “Initially, I was very sick and unable to do any work. We had to mortgage property and take loan at 15% interest to run the household.”

Another 35-year-old man working as a watchman said, “I was not able to work for 2 months and so lost wages. We had to run the household from the little that we had saved for my sisters’ marriage.”

**Social Impact**

The 300 patients perceived social impact as follows: 37.7% patients expressed fear of rejection, 30.7% expressed fear of discrimination, 19.7% had depended on others, 14% had not revealed their disease status to their family, 6% patients discontinued job, 5.4% were worried/had mental anguish, and 3.3% did not tell their spouse. About 1% patients felt guilt that the child got TB from them, 0.7% of the patients (both females) were sent out of home, 0.7% felt employers look down on them, 0.3% had to discontinue school, and 0.3% had to change job [Table 3].

Social impact as felt by the patients in their own words is as follows: A 24-year-old woman said, “On knowing that I have TB, my husband and my in-laws were shocked and took me to my parent’s place and left me there. In spite



**Figure 2:** Types of economic impact among those who perceived it

of reassurance by health visitors from hospital, they are refusing to accept me because of TB.”

A 40-year-old man working as an Office Assistant said, “I told my employers that I had TB and wanted some leave. Immediately they told me that I should discontinue the job and come back only after the doctor gives me the certificate that I am cured.”

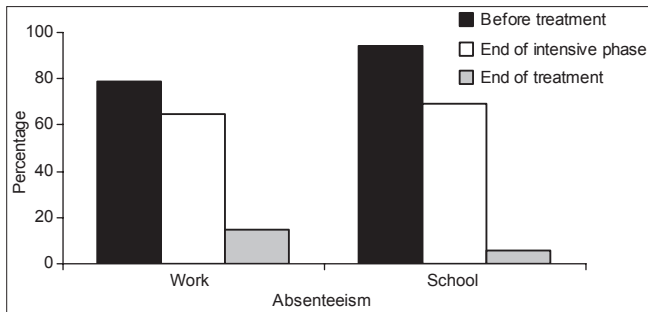
A mother of 17-year-old female TB patient said, “There is great tension in the family. We have not told anyone,

**Table 1: Socioeconomic profile and disease details of the patients (N = 300)**

	Profile of patients	No.	%
Age (in years)	≤24	98	33
	25–54	162	54
	≥55	40	13
Sex	Male	186	62
	Female	114	38
Education	Graduation	51	17
	High school	58	19
	Middle school	59	20
	Primary school	90	30
	Illiterate	42	14
Occupation	Professional	4	1.3
	Clerical, shop owner, farmer	40	13
	Skilled worker	109	36
	Semi-skilled worker	43	14
	Unskilled	33	11
	Unemployed/retired/students	71	24
Family size	≤4	196	65
	>4	104	35
Type of family	Nuclear	214	71
	Joint	86	29
Per capita income/month	US\$ <24.4	74	25
	US\$ 24.4–50	158	53
	US\$ >50	68	23
Type of TB	Pulmonary sputum positive	149	50
	Pulmonary sputum negative	70	23
	Extra-pulmonary	81	27
Category	Category-I	223	74
	Category-III	77	26

**Table 2: Association between economic impact in different socioeconomic groups**

Characteristic		Economic impact (%)	$\chi^2$	$P$ value
Sex	Male	29	0.392	0.531
	Female	32.5		
Educational qualification	Higher secondary and above	33.3	0.501	0.778
	Up to high school	28.2		
	Up to primary	31.1		
Employment status	Employed	29	0.392	0.531
	Unemployed	32.5		
Per capita income/month	US\$ <24.4	39.2	4.347	0.114
	US\$ 24.4–50	29.1		
	US\$ >50	23.5		
Type of family	Nuclear	26.2	6.128	0.013
	Non-nuclear	40.7		
Type of TB	Pulmonary	25.1	10.45	0.001
	Extra-pulmonary			



**Figure 3:** Proportion of TB patients who were absent for work/school/college before and during treatment

as she has to get married in a few years and fear that no proposals may come.”

Social impact was significantly perceived by more female patients as compared to males (80.7% vs. 61.8%;  $P = .001$ ). Social impact was high among those who had studied higher secondary and above (74.5%), those who were unemployed (75.4%), those with monthly per capita incomes above US\$ 50 (70.6%), those belonging to nuclear family (69.2%), and extra-pulmonary patients (74.1%). But the above differences were not found to be statistically significant [Table 4].

#### Work/School/College Absenteeism

Before the start of TB treatment, of the 186 employed patients, 147 (79%) were not able to go for work [Figure 3]. The average work absenteeism was mean 9.5 days (median 5 days, range 0–60 days). Similarly, of the 36 school/college going students, 34 (94.4%) were not able to go for classes. The mean school/college days absenteeism was 10.9 days (median 10 days, range 0–30 days) [Figure 3].

During the intensive phase of treatment over 2 months period, of the employed patients, 121 (65.1%) were not able to go for work and the mean work absenteeism was 18.4 days (median 6 days, range 0–60 days). Of the school/college going students, 25 (69.4%) were not able to go for classes and the mean of school/college absenteeism was 10.9 days (median 3 days, range 0–30 days). During continuation phase of treatment over 4 months period, work absenteeism was further reduced to 27 (14.5%) and the average work absenteeism was 8.6 days. Among the students, only 2 (0.06%) were not able to go for classes and the average days of absenteeism was 5 days.

## DISCUSSION

The present study in an urban setting had covered all TUs of the city and had included both pulmonary and extra-pulmonary TB patients. This study has shown that social impact was perceived by 69% of patients and economic impact by 30.3% patients registered under the program, while 75% patients felt any one form of impact and 24.3% patients felt both types of impact. Following the universal geographic coverage of DOTS program in India, this

**Table 3: Different types of social impact\* among TB patients registered under RNTCP (N = 300)**

Types of impact	No.	%
Overall		
Fear of rejection	113	38
Fear of discrimination	92	31
Had to depend on others	59	20
Family members not informed	42	14
Spouse not informed	10	3
Sent out of house (all females)	2	0.7
Worry/mental anguish	16	5
Guilt that the child got TB from the parent	3	1
Employed patients		
Employers look down	2	0.7
Discontinued job	18	6
Changed job	1	0.3
School going children		
Discontinued school	1	0.3

\*Multiple responses

**Table 4: Association between social impact in different socioeconomic groups**

Characteristic	Economic impact (%)	$\chi^2$	P value
Sex			
Male	62	11.771	0.001
Female	81		
Educational qualification			
Higher secondary and above	75	2.46	0.292
Up to high school	72		
Up to primary	64		
Employment status			
Employed	65	3.564	0.059
Unemployed	75		
Per capita income/month			
US\$ <24.4	65	0.788	0.674
US\$ 24.4–50	70		
US\$ >50	71		
Type of family			
Nuclear	69	0.009	0.925
Non-nuclear	69		
Type of TB			
Pulmonary	67	1.336	0.248
Extra-pulmonary	74		

information is vital for health managers in their efforts to improve the quality of program.

In this study, about 7.3% got indebted. Earlier studies have shown indebtedness incurred in rural areas as 75% by Rajeswari *et al.*<sup>[8]</sup> and 71% by Muniyandi *et al.*,<sup>[9]</sup> while the study done in urban area in 1998 showed 61% by Needham *et al.*<sup>[10]</sup> The present study has shown that only 6% had mortgaged their property. The above findings emphasize the fact that when DOTS is widely available, free of cost, and readily accessible, patients do not have to either sell their household assets or take loans.<sup>[11]</sup>

Though economic impact was felt by one-third of patients, most of the impact was due to reduction in savings. This finding shows that despite country's pro-poor DOTS implementation, it is probable that households cannot be protected from all costs. Probable ways to mitigate the impact of TB borne by family could be provision of social security measures by government such as linking with Public Distribution System, innovative social support activities such as provision of vocational rehabilitation

and linking up patients to self-help groups and micro-credit systems.

Economic impact was significantly perceived by more patients belonging to joint families (40.7%) as compared to patients belonging to nuclear family (26.2%). While joint families share tasks and obligations, more patients in these families perceive impact probably because of the larger number of dependant people. Economic impact was felt by more extra-pulmonary TB patients (74.1%) as compared to pulmonary patients (25.1%). Since the primary focus of RNTCP is sputum-positive patients, this finding emphasizes that extra-pulmonary TB patients need equal support, and in DOTS program, there is a need for streamlining of services for diagnosis of extra-pulmonary TB.

This study has highlighted the fact that more than two-thirds of patients perceive social impact. Stigma associated with TB remains deep-rooted and efforts are needed to address this in a comprehensive manner. Individual counseling of TB patients and their family to reduce perceived/actual stigma could be considered under the program throughout the duration of treatment. Quality of interaction of patient with provider needs to be strengthened. Establishment of networks of support groups with patients on treatment and cured patients needs to be considered and they should be encouraged to meet regularly. Strengthening advocacy to community as a whole and to create a “demand for DOTS” would help in overcoming the stigma in the long run.<sup>[12]</sup>

Further, the social impact was significantly felt more by female patients (80.7%) as compared to male patients. Similar findings have been reported from other studies done in Gambia,<sup>[13]</sup> India,<sup>[14,15]</sup> Pakistan,<sup>[16]</sup> and Korea.<sup>[17]</sup> Probable reasons could be that females are socially disadvantaged, and fear rejection and discrimination by other family members, relatives, and friends. In addition, with the present scenario of women bearing the triple burden (housework, childcare, and employment), the impact of disease increases. The above fact emphasizes the need for encouragement to organize special support groups for women, who are vulnerable for rejection by family/community. TB helplines could be a vital option for these women for seeking counseling services in anonymity.

In this study, the mean work absenteeism before treatment was 9.5 days, which is less compared to that reported in previous studies.<sup>[8,10,18,19]</sup> This could probably be due to early diagnosis and treatment including decentralization of DOT with the help of community volunteers. Similarly, mean work absenteeism was 27 days during the entire treatment duration as compared to the finding in the study by Rajeswari *et al.* (35 days).<sup>[8]</sup> The above findings document improved productivity of workers by reducing work absenteeism due to TB and early return to work. Since DOT centers are accessible to patients, they would have been able to take medicines at the center and also attend work.

Among the school/college going students, the absenteeism was reported by 94.4% before treatment, by 69.4% in the intensive phase of treatment, and by 5.6% in the continuation phase of treatment. This finding highlights that school/college students are important target groups for creating awareness on TB symptoms to facilitate early diagnosis and treatment.

The findings of the study need to be interpreted in light of certain limitations. There may have been recall bias on the part of patients when answering questions on impact. The study was done in an urban area and does not reflect the situation in rural areas. This study has included only those TB patients registered in the government TB clinics and the impact of TB could be different for TB patients getting treated in the private health sector.

## CONCLUSION

The present study has shown that with availability of DOTS, percentage of patients who mortgaged assets or took loans has reduced. While work absenteeism has reduced as compared to previous studies, presence of school/college absenteeism points out to the need for integration of TB control program with educational health services. Social impact still remains a huge challenge that needs to be addressed. RNTCP is a well-structured program that has covered a large population in a short span of 10 years. The finding from this study that social impact is perceived by nearly two-thirds of TB patients should be taken into consideration, and specific, focused, and intense social support services, awareness generation, and counseling to patients and families need to be built into the program.

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