

## Health seeking behaviour among tuberculosis patients registered under RNTCP Tumkur district, Karnataka

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### Abstract

**Background:** Delay in Tuberculosis diagnosis and treatment is associated with increased transmission, morbidity and mortality. Patient and provider factors are responsible for such delays. We conducted a study to estimate these delays and identify associated factors among new sputum positive (NSP) Tuberculosis patients in Tumkur district, Karnataka.

**Methods:** We interviewed 234 NSP patients to collect information on their health seeking behavior. We conducted univariate and multivariate analysis to identify factors associated with longer delays.

**Results:** Median patient, health system and total delay were 15, 13 and 36 days respectively. Significant factors associated with total delay included patients' knowledge about Tuberculosis, seeking care from non-specialized individuals as the first action, consulting >2 health facilities before diagnosis and consulting private health facilities. Patients with low family income and those who had high expenditure on consultations before initial diagnosis were associated with patient and health system delay respectively.

**Conclusion:** It is necessary to increase community awareness about Tuberculosis symptoms and availability of free treatment at public health facilities. Educating private physicians about the need for maintaining a high index of suspicion of tuberculosis and sensitizing drug-store owners to refer the chest symptomatic to government health facilities would also help in reducing these delays.

**Key words:** Tuberculosis, TB treatment, RNTCP, Tumkur

Access this article online	
Quick Response Code:	Website: www.innovativepublication.com
	DOI: 10.5958/2394-6776.2016.00033.3

### Introduction

India is the highest tuberculosis (TB) burden country in the world accounting for one fifth of the global incidence.<sup>1</sup> The Revised National TB Control Programme (RNTCP) which was launched in the country in 1997, achieved a nationwide coverage in 2006. In 2007, the programme for the first time achieved the target of 70% case detection while maintaining the cure rate of more than 85%. As a result of the successful implementation of the programme, Tuberculosis mortality in the country has reduced from over 42/100,000 in 1990 to 24/100,000 in 2008 while the disease prevalence has reduced from 568/100,000 to 185/100,000 during the same period.<sup>2</sup>

RNTCP emphasizes on achieving a target of 70% case detection as well as 85% cure of TB patients. Delay in diagnosing the patient or initiation of treatment; however, is not taken into account in any of the programme evaluation indicators. Early detection followed by effective therapy is extremely important in controlling Tuberculosis. Delay in diagnosis results in

increased infectivity in the community.<sup>3</sup> Smear positive cases are more likely to infect other individuals and it is estimated that an untreated smear-positive patient on an average can infect about 10 contacts annually and over 20 during the natural history of the disease until death. Delay in tuberculosis diagnosis may also lead to a more advanced disease state at presentation, which contributes to adverse sequelae and overall mortality.<sup>4</sup> In high prevalence countries, delays in diagnosis in treatment are often prolonged.<sup>5</sup> These delays occur at the level of patients as well as health system. Patient delays occur when patients consult the healthcare provider late after the onset of Tuberculosis symptoms while the health system delay is on account of time taken for diagnosis and initiation of anti-tuberculosis treatment.<sup>5</sup>

Information about the magnitude of different kinds of delays as well as risk factors associated with those delays is often helpful for the programme managers to improve the case-finding and thereby reducing the transmission of the disease. In view of this, we conducted a study among the new sputum smear positive (NSP) tuberculosis patients registered under RNTCP in Tumkur district, Karnataka.

### Objectives

1. To Estimate the magnitude of various delays
2. To Know the health seeking behavior
3. To identify the factors associated with such delays

## Methods

**Study area and population:** We conducted a cross-sectional analytical study among the new sputum positive (NSP) Tuberculosis patients registered under the district TB programme in Tumkur district, Karnataka.

**Operational definitions:** We defined the 'total delay' as the time interval from the onset of symptoms of TB until the initiation of anti-tuberculosis drugs.<sup>5</sup> It is the sum of two time intervals: 'patient delay' defined as time interval between onset of symptoms and presentation to a health care provider and 'health system delay' defined as time interval between the consultation at a health facility and the initiation of anti-tuberculosis treatment. The total delay was also considered as the sum of diagnostic delay and treatment delay. Diagnostic delay was defined as the time interval between the onset of symptoms and labeling of the patient as a tuberculosis patient (tuberculosis diagnosis) while treatment delay was defined as the time interval between tuberculosis diagnosis and initiation of antituberculosis drugs. Health facility was defined as all government and private health facilities manned by a qualified health care provider (HCP).

**Sample size and sampling procedure:** In Tumkur district, Karnataka, during 2015 about 475 NSP cases were registered under RNTCP in any two quarters. Assuming longer delay in 50% of patients, maximum allowed error of 5%, 95% confidence interval and 10% nonresponse; the required sample size for the study was 234.

**Data collection:** We used the questionnaire used in the WHO multi-country study to estimate the diagnostic and treatment delay in Tuberculosis.<sup>5</sup> The questionnaire was pilot-tested on 10 Tuberculosis patients and then based on results of pilot testing it was suitably modified for local use. Using this questionnaire, the trained health workers interviewed the Tuberculosis patients to collect information on socio-demographic characteristics, risk factors of tuberculosis and their health seeking behavior. We also collected information about the factors that might influence patients' health-seeking behavior including their knowledge about the disease, fear of what would be found on diagnosis, fear of social isolation and stigma. Variables measuring knowledge and stigma were recorded on a three (0 best, 2 worst) and five point (0 the highest and 4 the lowest degree of stigma) Likert scale respectively. Variables measuring patients' knowledge included knowledge about its causes, curability, existence of vaccine, duration of treatment and type of drugs used for treatment. Stigma was measured using variables such as feeling ashamed of having Tuberculosis, had to hide Tuberculosis diagnosis from others, social isolation due to Tuberculosis and the extent to which tuberculosis

affected the following: relations with others, work performance, family responsibilities, marital relations, work performance, chance of marriage, etc. To calculate different delays, we asked the respondents to recall the time of first clinical manifestation (cough or other symptoms) and date of first action. For ascertaining time of first contact with health facility and subsequent health encounters, we reviewed the records available with the patients. Where records were missing or not available, patients were asked to recall the dates. We confirmed these dates with first degree relatives. Local religious festivals and agricultural events were used as a calendar to collect information for those patients who were unable to recollect the exact date of onset of first presenting symptoms and health care consultations. We also abstracted information about the dates of diagnosis and initiation of anti-Tuberculosis treatment from RNTCP records. Data analysis: We analyzed the data using Epi-Info (CDC, Atlanta, 3.5.1) and open Epi software. We calculated the mean and median delays along with their ranges. We conducted univariate analysis to identify risk factors associated with patient, health system and total delays. For the outcome variable, we used the median delay as a cut-off to dichotomize the Tuberculosis patients into two groups (> median versus < median). We added the scores for different variables used to measure the knowledge about Tuberculosis and stigma associated with Tuberculosis and used the median score to dichotomize these variables. Median was also used to dichotomize expenses incurred during consultations before diagnosis. Variables with p-value <0.2 in univariate analysis were included in multiple logistic regression. The study was approved institutional ethical committee and concerned authorities.

## Results

We interviewed 234 new sputum positive patients registered in the district in 2015. Characteristics N=234 (%) Socio-demographic characteristics.

### Profile of TB patients (Table 1)

About half of patients were more than 35 years' old, two-thirds were males and one fourth was illiterates. Most of the patients were living in rural areas and had monthly income of less than Rs. 3000. Smoking, either current or ex-smoking, was reported by more than half of the patients. Current smokers smoked a median of 10 cigarettes per day. About 30% of patients reported consumption of alcohol daily.

**Table 1: Socio-demographic characters, risk factors and symptoms profile of tuberculosis patients Tumkur, Karnataka**

S. No	Characteristics	N =234	(%)
Socio-demographic characteristics			
Age (years)			
1	<35	115	49.1
2	>35	119	50.9
3	Female Sex	78	33.3
Residence			
4	Urban	18	7.7
5	Suburban	2	0.9
6	Rural	214	91.4
Community			
7	General	123	52.6
8	Scheduled caste/Tribe	111	47.4
Education			
9	College /University	20	8.6
10	Primary/secondary	154	65.8
11	Illiterate	60	25.6
Occupation			
12	Employed	93	39.7
13	Unemployed	141	60.3
Marital status			
14	Married	177	75.6
15	Single	57	24.4
Income			
16	<3000	193	82.7
17	>3000	41	17.5

**Health Seeking Behavior (Table 2)**

As a first action to the symptoms of Tuberculosis, 54% of the patients contacted health facility, 39% purchased the medications over the counter while a small proportion of patients resorted to self-medication or went to traditional healer. Health care facility first consulted by the majority of the patients included health sub-centre, Primary, Ayurvedic and Community Health Centre (42%), Civil and District hospitals (31%) and

private clinic/hospital (22%). The commonest reasons for consulting these health facilities included proximity to patients' residence (73%) and patients' belief in these facilities (20%).

The reason cited by 51 (21%) patients who visited private health facility for not consulting a government health facility initially included long waiting time at government clinics (73%) and distance from their residence (24%). When asked about the perceived causes of delay in health seeking, 63% felt that there was no delay in reaching a health facility while 23% felt that their symptoms would subside on their own.

**Table 2: Health seeking behavior of Tuberculosis patients**

S. No	Health-seeking Behavior	N=234	(%)
First action			
1	Health facility*	127	54.3
2	Self-medication	13	5.5
3	Traditional healer	3	1.3
4	Purchased medicine from Drug stores	91	38.9
Health Facility* of health care provider from whom patients first sought consultation			
5	Health sub-center	5	2.1
6	Primary health center 28 12.0	28	12
7	Ayurvedic health center	32	13.7
8	Community health center	32	13.7
9	Civil hospital	43	18.4
10	District hospital	29	12.4
11	Private clinic/hospital	51	21.8
12	Other (medical college)	14	6

\*Any health facility, private or government, manned by qualified health care provider.

**Table 3: Correctness of patient's knowledge about tuberculosis and stigma**

S. N	Items	Males(156)	%	Females	%	Total	%
Knowledge							
1	Is TB Hereditary?	99	63.5	40	51.3	139	59
2	Is TB contagious?	102	65.4	45	57.7	147	63
3	Is TB curable?	139	89.1	63	80.8	202	86
4	Is there a Vaccine for TB?	22	14.1	11	14.1	33	14
5	Do you know Duration of treatment?	116	74.4	54	69.2	170	73
Stigma							
6	Feel ashamed?	63	40.4	61	78.2	124	53
7	Have to hide?	82	52.6	65	83.3	147	63
8	Affect relations with other?	64	41	49	62.8	113	48
9	Prefer to live isolated after	85	54.5	60	76.9	145	62

	diagnosis?						
10	Work performance?	113	72.4	69	88.5	182	78
11	Marital relations?	67	42.9	55	70.5	122	52
12	Does TB affect family responsibilities?	96	61.5	60	76.9	156	67
13	Is there less chance of marriage due to TB diagnosis?	107	68.6	75	96.2	182	78
14	Does TB affect your family relations?	61	39.1	50	64.1	111	47

Would be found on diagnosis (6%) and fear of social isolation (5%)

### Knowledge and perceived stigma related to tuberculosis (Table 3)

Majority of the TB patients knew that TB was curable (86%) and the duration of anti-TB treatment (73%). Nearly 60% of the patients knew that TB was not a hereditary disease. Knowledge about the disease was not different among males and females; median knowledge score was six among both males and females. 37% of the males had poor knowledge as compared to 45% females ( $\div 2=0.98$ ,  $p=0.32$ ). TB related stigma was highly prevalent among the patients. More than three fourth of the patients felt that TB affected their work and TB diagnosis would reduce the chances of getting married. More than 60% of the patients reported that they had to hide their diagnosis of disease from others, preferred to live isolated and affected their family responsibilities. The median stigma score among females and males was 15.5 and 22 respectively. 78% of the females had high stigma as compared to 40% males ( $\div 2 =28.36$ ,  $p\text{-value} = 0.000000$ ).

**Table 4: Different types of delay for tuberculosis patients**

Total delay (days)		N
Patient delay (days)	Mean (SD)	24.5(28.42)
	Median(range)	15(0-180)
Health system delay (days)	Mean (SD)	23.54(28.39)
	Median(range)	13(1-204)
Diagnostic delay (days)	Mean (SD)	46.3(36.9)
	Median(range)	33.5(6-210)
Total delay (days)	Mean (SD)	48(37.16)
	Median(range)	36(7-210)

### Delays (Table 4)

After the onset of symptoms, patients consulted the health care provider (patient delay) after a median duration of 15 days (range: 0-180 days). The median duration between the first consultation and initiation of treatment (health system delay) was 13 days (range 1-204 days). The median duration between the onset of

symptoms and initiation of anti-TB drugs (total delay) was 36 days (range: 7-210 days). This included a median diagnostic delay of 33.5 days (range: 6-210 days) and treatment delay of one day (0-20 days). Among 79 (34%) TB patients, the total delay ranged between one – two months while in 67 (29%), the delay was more than two months; in rest of 88 (37%) it was less than one month. Median total delay in males and females was 36 and 37 respectively ( $p > 0.5$ ).

### Factors associated with delays

On univariate analysis, TB patients who were illiterate (OR=1.94, 95% CI=1.06-3.54), smokers (OR=1.86, 95% CI 1.09-3.14), had poor knowledge about TB (OR=1.96, 95% CI=1.15-3.14), who sought care from no specialized individuals (traditional healers, purchased the medicines over the counter or received self-medication) as the first action for their symptoms (OR=2.34, 95% CI=1.38-3.96), who consulted more than two health care facilities before diagnosis (OR=2.53, 95% CI=1.46-4.39) and consulted private health facilities (OR=2.52, 95% CI=1.30-4.87) were more likely to have the longer total delay (Table-5). Patients who had family income below 3000 (OR=2.40, 95% CI=1.18-4.86) and whose first action for their symptoms included seeking care from non-qualified providers (OR=6.21, 95% CI=3.50-11.03) were more likely to have the longer patient delay. Significant factors associated with health system delay included high expenditure (>than median i.e. 200 rupees) on consultations before initial diagnosis (OR=3.37, 95% CI=1.96-5.77), consulting private health facilities (OR=6.14, 95% CI=2.82-13.36) or consulting two or more health facilities before diagnosis (OR=7.75, 95% CI=4.13-14.54).

**Table 5: Risk factors for delay in diagnosis and treatment of pulmonary TB on multivariate analysis**

Delay		AOR	95% CI
Patient delay	Income of family < 3000	2.75	1.23-6.15
	First action Drug stores/self-medication	7.80	4.17-14.58
	Stigma (high)	1.81	0.99-3.32
	Knowledge (Poor)	2.04	1.10-3.79
Health system delay	Sex (Female)	1.54	0.78-3.05
	Caste (scheduled caste/Tribe)	1.70	0.89-3.55
	Education (Illiterate)	1.67	0.79-3.55
	Expenses incurred before initial diagnosis (>median)	2.58	1.34-4.95
	Multiple Health seeking encounters with HCP	8.03	4.00-16.17
	Health facility first consulted (Private)	6.68	2.75-16.23
Total delay	Age > 35 yrs. (median)	0.89	0.44-1.81
	Caste ( scheduled caste/tribe)	1.53	0.84-2.78
	Education (Illiterate)	1.51	0.70-3.28
	Smokers	1.41	0.61-3.23
	Alcohol consumption	1.42	0.62-3.24
	First action (non-qualified persons)	2.79	1.53-5.10
	Health facility first consulted (Private)	2.42	1.14-5.17
	Multiple Health seeking encounters with HCP	3.21	1.71-6.03
	Knowledge (poor)	2.27	1.21-4.25

On multivariate analysis, the significant risk factors associated with total delay included poor knowledge about the disease (Adjusted odds ratio, AOR=2.27, 95% CI=1.2-4.25), seeking care from non-qualified persons as the first action (AOR= 2.79, 95% CI=1.53-5.10), consulting more than two health facilities before diagnosis (AOR= 3.21, 95% CI=1.71-6.03) and consulting private health facilities (AOR= 2.42, 95% CI=1.14-5.17). Besides these variables, patients with lower income and those who had high expenditure on consultations before initial diagnosis were associated with patient and health system delay respectively (Table 5).

## Discussion

RNTCP in Tumkur district has been achieving high case detection as well as cure rates since 2000. One of

the major policy decisions taken by RNTCP in the year 2010 was to change the focus of the NSP case detection objective of at least 70% to the concept of universal access to good quality care for TB patients. There is now global consensus that the twin objectives of 70/85 alone are not enough to achieve adequate reduction of TB transmission and reduction in disease burden. Some studies also suggest that mortality remains higher than expected, including post TB treatment mortality. One of the major reasons for death in TB patients is late diagnosis.<sup>6</sup> The present study was conducted to estimate the magnitude of the delay in diagnosis and treatment. TB patients, after the onset of their symptoms, were put on anti-TB drugs after a median duration of 36 days. A major component of this delay was on account of the time spent on diagnosing the disease. We identified several factors associated with these delays including patient's income, their knowledge about the disease, first consultation from non-specialized health providers and consulting private health facilities.

Several studies have estimated the magnitude of total, patient and health system delays among the TB patients in India. These delays ranged between 60-62 days, 6-23 days and 9-34 days respectively.<sup>7-10</sup> The total delay observed among the TB patients in our study was lower as compared to most of the earlier studies conducted in India. Shorter delay reported in our study could be on account of several reasons. First, the district is one of the well-performing districts in Himachal Pradesh with respect to indicators of RNTCP.

Second, the earlier studies were conducted during 1998-2005 while RNTCP has decentralized diagnostic, treatment and monitoring services considerably in the last five years.

First action taken by a chest symptomatic is an important determinant of the patient delay.

Studies conducted in India have shown that chest symptomatics in the community shop around, seeking relief at various health facilities, including private practitioners, before they are actually diagnosed as tuberculosis cases and put on appropriate treatment.<sup>11</sup> About half of the patients in our study either purchased the medications over the counter, resorted to self-medication or went to traditional healers and such patients were found to have significantly longer patient delays. Besides the first action, patients who had family income below 3000 and who had poor knowledge about TB were more likely to have longer patient delays. Similar findings were reported in other studies conducted in India and elsewhere.<sup>7,12-14</sup>

In our study, there was a longer health system delay when the patients first consulted private providers compared with a government provider, a finding similar to the earlier studies.<sup>7,12,13</sup> Uplekar et al. found that many private practitioners ultimately refer patients to the government sector, but generally do so late in the course of the patient's illness and often after partial treatment with a non-standard regimen.<sup>15</sup> To reduce this

delay, efforts to involve private providers in the RNTCP need to be intensified, stressing the importance of timely diagnosis and treatment. In Mandi, half of the patients had to visit more than two health care facilities before the diagnosis of tuberculosis was made. Significant association was also seen between high expenses incurred during seeking care for the symptoms and health system delay. These findings point to the need to train the private providers to suspect TB, recommend appropriate investigations and reduce shopping around by patients for diagnosis/treatment.

Our study has one main limitation. TB patients registered in the last quarter were diagnosed two to four months before the start of study and might not have recalled the exact dates of onset of symptoms and first consultation. This could have affected the median delays. To address this issue, we checked these dates with the first degree relatives of patients and used local religious festivals and agricultural events as a calendar to collect information about dates of onset of symptoms and subsequent consultations. The median total delays among the patients diagnosed in 2015 was 34 and 38 days respectively ( $p$  value > 0.5), indicating that recall was comparable in these patients.

To summarize, Patient delay was more among individuals with low income and was related to their first action as well as their knowledge about the disease. Patients who consulted private health facilities were more likely to have longer health system delays.

Based on these findings, we propose a number of recommendations to reduce the delays in diagnosis and treatment of TB patients. First, efforts need to be made to increase public awareness about the symptoms of tuberculosis and to educate them about the importance of seeking early care and the availability and location of free diagnostic services in government health facilities. Such efforts could be focused among the people who are below poverty line. Second, the private physicians in the area need to be educated about the need to maintain a high index of suspicion of tuberculosis and rapidly performing appropriate tests including sputum examination. This could be achieved by increasing the involvement of private practitioners in RNTCP under various schemes. Third, the district programme officials need to sensitize the traditional healers and drug store owners to refer the chest symptomatics to government health facilities for sputum examination. Finally, various delay durations and the significant determinants of delay identified in the present study could be incorporated into routine surveillance reports. This would allow monitoring of the effectiveness of programme in reducing the duration of delay and thereby reducing the transmission and burden of tuberculosis in the district.

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