# Original Article

# REASONS FOR PATIENT DELAYS & HEALTH SYSTEM DELAYS FOR TUBERCULOSIS IN SOUTH INDIA

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## ABSTRACT

**Background:** Globally, the burden of Tuberculosis is escalating. Early diagnosis and prompt initiation of tuberculosis treatment is essential for an effective tuberculosis control programme.

**Objectives:** To study the self reported reasons for patient and health system (diagnosis & treatment) delays in Tuberculosis patients.

**Methods:** A community based cross sectional study was conducted among 98 new sputum positive TB cases aged $\geq$ 15 years registered under RNTCP from Oct 2006 to June 2007 & receiving treatment under DOTS in Udupi taluk by interviewing them.

**Results:** Total 98 patients were recruited and 68% were males. Out of 17 patients with patient delays, 82% felt that their symptoms were not severe, 71% felt that patient delay was due to lack of awareness and 71% did not take it seriously. Out of 86 patients with health system delays, 82.6% of patients mentioned that doctor has not advised for sputum examination, 76.7% of patients told that they first consulted a private doctor, 21% of them mentioned that doctor was unaware to diagnose TB.

**Conclusion:** Symptoms not severe is the main reason for the patient delay and doctor didn't advise for sputum examination is the main reason for health system delays.

**Key words:** Tuberculosis, patient, doctor, health system delays.

## Introduction

Compared with Tuberculosis, all other communicable & preventable diseases sink into relative insignificance.[1] India is the highest TB burden country accounting for one fifth (21%) of the global incidence and 17th among 22 High Burden Countries in terms of TB incidence rate.[2] Various reasons including poverty, population growth, migration and HIV/AIDS are the major factors for the continued threat of TB in the world, but a significant problem lies with the fact that many cases remain undiagnosed. This could be due to a number of factors, principally found within the categories: patients delaying seeking healthcare or failure of the health care systems to diagnose patients in a timely manner[3]. Delayed diagnosis & treatment may result in more extensive disease, more complications and lead to a higher mortality. Early diagnosis and prompt initiation of tuberculosis treatment is essential for an effective tuberculosis control programme[4]. The magnitude and risk factors for patient and health system delays have been well documented in a number of studies[3-10], but are little known in Indian studies[11-13] accounting for nearly 20% of the global tuberculosis burden. There is a need to understand these delays in different diverse social and cultural communities in India. With these facts in mind the present study was conducted to study the various reasons for different delays i.e. patient and health system (diagnosis and treatment) delays in tuberculosis patient.

## Methods

This study was conducted in Udupi taluk, one amongst the three taluks of Udupi district of Karnataka, south India. RNTCP (Revised National Tuberculosis Control Programme) has been implemented in Udupi taluk since 24th March, 2004. The taluk caters to the health needs of TB patients through one Tuberculosis unit, 8 Microscopy centers and about 450 DOTS centers.

Approval from ethical committee was first obtained. The present cross sectional study included all new sputum smear positive TB cases aged $\geq$ 15 years registered under RNTCP from 1st October 2006 till 30th June 2007 in three quarters and receiving treatment under DOTS from various DOTS centres in Udupi taluk, who gave written informed consent for inclusion in the study. Seriously and terminally ill patients who were not in the condition to give interview were excluded from the study.

Eligible cases were identified from the TB register (RNTCP sites) and the address of each patient were noted down at District TB Center. All the patients were contacted in their intensive phase of treatment within 30 days to minimize the recall bias. The patients who were not available at home on three different days of home visit were declared not available. All enrolled cases were interviewed by using the pre-tested interview schedule with semi structured questionnaire. The data included socio-demographic information and patient self reported reasons for patient and health system delays, if any.

The sample size was calculated using the formula, $n = (Z_{(1-\alpha/2)}^2 \sigma^2)/(\varepsilon^2\mu^2)$ by taking a previous study (Rajeswari et al[11]) done on patient delay in Tamilnadu, which showed a median patient delay of 20 days (range 0-240), and a 95% confidence interval and 20% relative precision, the sample size was calculated to be 96. Considering 20% non response rate, a sample size of 120 was finally selected. Sequential sampling was used and continued till the required sample size was obtained.

Patient delay included the time interval between appearance of symptoms suggestive of pulmonary tuberculosis and their first contact with a health care facility.[4]

Diagnosis delay included the time interval between first contact with the facility and confirmation of diagnosis.[4]

Treatment delay included the time interval between confirmation of diagnosis and initiation of anti-tuberculosis treatment.[4]

Health System delay included both Diagnosis delay and Treatment delay. Total delay was the sum total of patient and Health system delays.[4]

As no scientifically agreed criteria could be found in the literature upon which to base a definition of delay, a committee consisting of District Tuberculosis Officer (DTO) and specialist physicians treating tuberculosis patients on a routine basis at Government District hospital, Udupi were asked to choose 'acceptable' delay, based on their medical knowledge, experience and taking into account the socio-economic conditions of their patients. From this, a period of 30 days was chosen

as maximum acceptable patient delay and 7 days as maximum acceptable health system delay.

Acceptable patient delay = 30 days

Acceptable health system delay = 7 days

- Acceptable diagnosis delay = 5 days

- Acceptable treatment delay = 2 days

Total Acceptable delay = 37 days

Data was analyzed using the software SPSS version 11.0.1 for windows. Common descriptive statistics (mean, median, standard deviation, inter-quartile range, proportions) were used to summarize the results of continuous variable & chi square test for discrete variables. P values < 0.05 were considered significant.

### Results

Total 141 new sputum positive TB patients under Category I were registered under RNTCP for DOTS during the study period in Udupi Taluk. Among these, sample size of 120 patients were contacted by visiting their house or DOTS centers. According to sequential sampling, out of 120 cases, 49 were enrolled in 4th quarter of the year 2006, 45 were enrolled in 1st quarter and 26 were enrolled in 2nd quarter of 2007 respectively out of the total 141 patients registered under DOTS in three quarters. Among 22 non-respondents, 13 were not available at home in spite of 3 home visits, 4 were mentally retarded, 3 were not able to speak and 2 patients were not new cases. Non response rate was 18.3%. Hence data was analyzed for 98 patients.

### Socio-demographic characteristics

Of the 98 patients interviewed, 68% were males, 73% were literate, 91% were Hindu, 54% were SC/ST and OBC and 64% were unskilled workers, 69% were married and 62% were from rural area, 88% were from low socioeconomic status, 54% were having ≥5 family size and 43% and 33% reported alcohol use and smoking respectively (Table 1). The mean age of the patients was 39.3 years.

The patient delay was seen in 17 (17.3%) patients with median patient delay of 30 days (IQR 6.5-58.5). The health system delay was observed in 86 (87.7%) patients with median health system delay of 56.5 days (IQR 23.7-112.7). Diagnosis delay was seen in 86 (87.7%) patients and treatment delay was seen in 52 (53.1%) patients respectively (Table 2).

Our findings (Figure 1) shows that out of total 17 patients who were asked regarding the reasons for the patient delay, 14 (82%) felt that their symptoms were not severe, 71% felt that patient delay was due to lack of awareness and 12 (71%) did not take it seriously. Six (35%) of the patients mentioned that they had self medication and six (35%) were busy in their work & due to domestic pressure. Alcohol dependence as a reason for patient delay was mentioned by three (18%) of the patients. Other reasons included patient waited for rainy season to get over and patient was not willing to go to doctor.

Figure 2 shows that out of 86 patients, who were asked regarding the reasons for health system delay, 71 (82.6%) of them mentioned that doctor has not advised for sputum examination, 66 (76.7%) of them told that they first consulted a private doctor, 18 (21%) of them mentioned that doctor was unaware to diagnose TB, 13 (15%) of them told that it was their own delay which contributed to health system delay and 11 (13%) of them told that doctor advised very late.

**Table 1: Socio-demographic & care seeking characteristics of new smear positive tuberculosis patients:**

| Characteristic | | Total No. (%) n = 98 (100) |
|---|---|---|
| Age (Years) | 15-29 | 27 (27.6) |
| | 30-44 | 33 (33.7) |
| | ≥45 | 38 (38.8) |
| Sex | Male | 67 (68.4) |
| | Female | 31 (31.6) |
| Religion | Hindu | 89 (90.8) |
| | Muslim | 1 (1.0) |
| | Christian | 8 (8.2) |
| Caste | SC/ST | 32 (32.7) |
| | OBC | 21 (21.4) |
| | Others | 45 (45.9) |
| Educational Level | Illiterate | 26 (26.5) |
| | Primary | 36 (36.7) |
| | Secondary and above | 36 (36.7) |
| Marital Status | Married | 68 (69.4) |
| | Single | 30 (30.6) |
| Occupation | Skilled | 12 (12.2) |
| | Unskilled | 64 (65.3) |
| | Others | 22 (22.4) |
| Socio Economic Status | Low | 86 (87.8) |
| | Middle | 12 (12.2) |
| Area of Residence | Urban | 37 (37.8) |
| | Rural | 61 (62.2) |

**Table 2: Average number of days of delay according to types of delay among new smear positive TB patients:**

| | No. of Patients N (%) | Median (Inter-quartile Range) (Days) |
|---|---|---|
| Patient delay | 17 (17.3) | 30 (6.5-58.5) |
| Diagnostic delay | 86 (87.7) | 54.5 (21.2-109.7) |
| Treatment delay | 52 (53.1) | 2 (1.2-4) |
| Health system delay | 86 (87.7) | 56.5 (23.7-112.7) |
| Total delay | 90 (91.8) | 57.5 (24.7-112.7) |

**Figure 1: Self reported reasons for patient delay among new smear positive TB patients:**
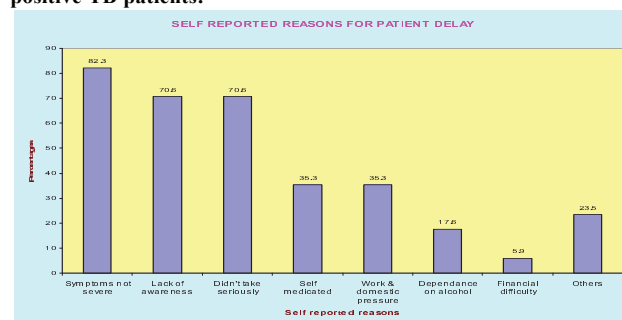


n = 17

**Figure 2: Self reported reasons for health system delays among new smear positive TB patients:**



SELF REPORTED REASONS FOR HEALTH SYSTEM DELAYS
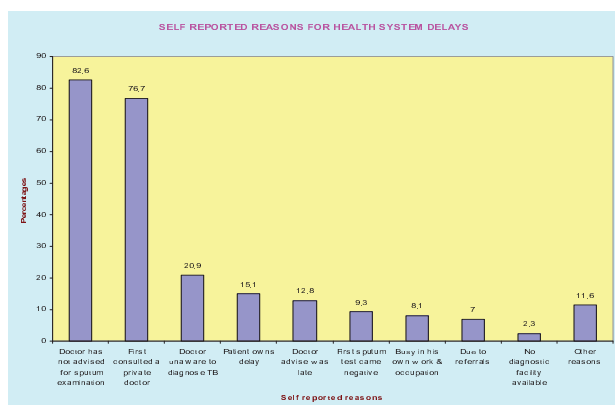
## Discussion

The findings of the present study regarding the reasons for patient delay are in contrast to a study conducted by Rajeswari et al[11] where they observed that lack of awareness about TB (40%) and poor socio-economic conditions (36%) were the most common reasons cited for delaying care seeking followed by lack of awareness of health facility (13%) and domestic preoccupation (8%). Our findings are inconsistent to the findings of a study conducted by Wondimu et al[14] who observed that 33% of patients assumed that symptoms will disappear itself, 32% had financial constraints and 7% had absence of transportation. Another study conducted by Auer et al[15] observed that illness considered harmless (59%) and lack of money (22%) were the most frequent responses for the patient delays. In a study by Asch et al[16], 33% of the patients who had delay were unsure where to go for cure, 23% lacked the regular doctor, 23% felt that symptoms were not serious.

Our findings are inconsistent with the findings of Fatiregan et al[17] where reasons given by respondents with prolonged delay included health facility too far 22.2%, lack of awareness of DOTS service on time 12.7%, and domestic work prevented coming on time 9.5%.

The findings of our study were in contrast with the findings of a study done by Tobgay et al[4] where 31% of patients thought that their cough was not serious. Distance was a factor for 16.1% and 8.7% relied on their parents/relatives or friends, as they were too young/old or severely ill; 3.7% reported that they went to private doctors. Lack of monetary resources was the reason behind the delay for 7.4% of cases.

The findings of the present study regarding the reasons for health system delay are in contrast to a study done by Tobgay et al[4] in Sikkim where only 3.7% patients reported that they went to private doctors, 16.1% of them mentioned that microscopy centre was far away from their residence and 15.8% of them mentioned that they were too busy and had no time.

The most common reason (82.6%) for health system delay identified by patients was that doctor has not advised for sputum examination. We examined these patients (82.6%) with the type of provider contacted first and observed that a higher proportion of patients have contacted a private provider first as compared to government provider (84.5% vs. 15.5%, p=0.006) which was statistically significant (p<0.05).

There is an element of recall bias in our study. We, however, limited participants to recently diagnosed cases to minimize the recall bias. The study relied entirely on responses as given by the respondents and only hope for honest responses. One limitation of the study is that the results of this study cannot be generalized to the population in Udupi taluk as the study included patients who were on treatment only at the government health facilities and not those treated in the other sectors. Another limitation is that only patient perspective is seen for various reasons for delays in Tuberculosis. Further studies are required to study the provider perspective to better understand these delays.

## Conclusion

Considerable delay exists between symptom onset and treatment initiation among

tuberculosis patients. While a substantial delay was attributed to health system in

diagnosing the tuberculosis disease. Symptoms not severe & lack of awareness about Tuberculosis were the main reasons for the patient delay and doctor didn't advise for sputum examination and first contact with a private provider were the main reasons for health system delays.

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