



Original Article:

Delay in DOTS for new pulmonary tuberculosis patient from rural area of Wardha District, India

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Abstract:

Vast majority of active tuberculosis patients seeks treatment, do so promptly, still many patients spend a great deal of time and money "shopping for health" and too often they do not receive either accurate diagnosis or effective treatment, despite spending considerable resources. **Objective:** To find out the time taken to, for diagnosis of tuberculosis and to put patient on DOTS from the onset of symptoms and pattern of health seeking behavior of new pulmonary tuberculosis patients. A cross-sectional rapid assessment using qualitative (FGD) and quantitative (Interview) methods conducted at DOTS center of tertiary care hospital from rural Wardha. **Participants:** 53 pulmonary tuberculosis patients already on DOTS, in intensive phase. **Main outcome measure:** Delay in initiation of DOTS & health seeking behavior **Results:** Median total delay for starting DOTS was 111 days, (range: 10 to 321 days). Patient delay was more than provider delay. Patients delay was more in patients above 60 years, illiterate, per-capita income below 650 Rupees and HIV TB co-infection. Pattern of health seeking behavior was complex. Family physician was the preferred health care provider. Patient visited on an average four providers and spent around 1450 rupees (only direct cost) before DOTS begin. Time taken from the onset of symptoms and start of DOT is a cause of concern for the tuberculosis control program. Early case detection is important rather than mere achieving target of 70% new case detection. Program manager needs to implement locally relevant & focused strategies for early case detection to improve the treatment success, especially in rural area of India.

Key Words: Tuberculosis, RNTCP, DOTS treatment delays, health seeking behavior

Introduction:

Tuberculosis remains a world-wide public health problem despite of advances in science and availability of highly effective drugs against it. Tuberculosis (TB) causes approximately 2 million deaths per year and 98% occur in low-income countries.[1,2] India accounts for 30% of all tuberculosis cases in

the world.[3] Directly observed therapy short-course (DOTS), the main strategy for TB control globally, relies on self-presentation of adults from the community and sputum smear for diagnosis. Even in the presence of substantial drug-resistance, it is highly effective at reducing tuberculosis transmission.[4] India Formally launched the Revised National Tuberculosis Control Program (RNTCP) on March 26, 1997, and DOTS is one of its core component. Since its inception, RNTCP in India has achieved its objectives of 85% cure rate of new smear positive cases and detection of 70% of the new smear positive cases in the community.

Despite these achievements, access to tuberculosis diagnosis and treatment services still remain a major concern for tuberculosis control programme of India. The vast majority of patients with active tuberculosis seek treatment for their disease. They spend a great deal of time and money "shopping for health" before they begin treatment, and all too often, they do not receive either accurate diagnosis or effective treatment, despite spending considerable resources.[3] Studies have shown that despite eight encounters with one or more health care provider system and expenditure of around 1600 rupees only one third of patients with symptoms of tuberculosis undergo sputum examination for tuberculosis and even for patients who eventually diagnosed, successful treatment of tuberculosis is the exception rather than the norm in both public and private sector.[3,5] Poverty, illiteracy, and stigma attached to disease, especially in rural India further complicate the problem.[3]

Detection of mere 70% of the new cases is not enough, detecting them early and putting them on treatment and ensuring cure should be the highest priority.[5,6] One untreated case of smear positive pulmonary tuberculosis can spread infection to 10 to 12 other non infected persons.[7]

We conducted this rapid assessment study to find out the time taken to start patient on DOTS from the onset of symptoms and pattern of health seeking behavior of pulmonary tuberculosis patients from rural area of Wardha District.

Materials and Methods:

This was a cross sectional study conducted at a DOTS center of a tertiary care hospital of medical college in a rural area of Wardha District, in Central India. This hospital has a DOTS center and designated microscopy center that function as per the RNTCP guidelines.

Study participants were new adult pulmonary tuberculosis patients from rural area, and registered under RNTCP (already taking DOTS) from January to July 2007. Children less than 12 years were excluded from the study. Other exclusion criteria's were patients from urban area, re-treatment cases (not a new case) or extra-pulmonary tuberculosis. Total 76 patients were eligible but 53 participants gave consent and subsequently included in the study. Response rate was 70%.

Data was collected by quantitative (interview schedule) and qualitative methods (Focus group discussion). Two methods were used to improve the internal consistency and validity of information.

An interview schedule was used to study the time taken for initiation of DOTS from the onset of symptom and to investigate the health seeking behavior of the new pulmonary tuberculosis patients. Questions on demographic data, duration of symptoms, knowledge of tuberculosis, time taken to seek healthcare, type and level of care hunted, facility from where DOTS started and direct cost of treatment were included in

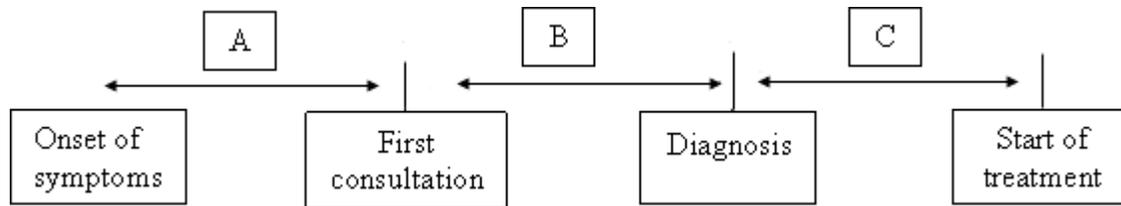
schedule. Tracking of events from the onset of symptoms was made to study the pattern of health seeking behavior. Schedule was pilot tested. Interviews were conducted by the trained medical social worker at a place convenient to the patients ensuring the strict confidentiality. Interviews were taken in the local language. Informed consent was taken before commencing interview.

Two Focus Group discussions (FGDs) were conducted (one each for male and female) to study the health care seeking pattern of the patients from the rural area and the various factors related to their treatment seeking behavior. FGDs were conducted in the DOTS center.

The study protocol was approved by the institutional ethical committee.

Definitions:

We studied the time taken for initiation of DOTS from the onset of symptoms as a total delay. It was further categorized as a patient delay and provider (health system) delay. Patient delay was defined as time between onset of symptoms and the patient's first contact with health services. Provider delay was defined as time between patient's first contact with the health services for their illness and initiation of DOTS. Total delay was defined as the sum of the patient delay and the provider delay.



A= Patient delay; B + C = Health system (provider) delay (B= diagnosis delay, C= treatment delay); A+B+C = Total delay

As per the RNTCP guidelines pulmonary tuberculosis patients refers to persons, either sputum smear positive or negative, with TB disease of lung parenchyma and new patients was defined as those who have not taken tuberculosis treatment in the past or taken treatment for less than 28 days.[7]

Analysis:

Data was presented as a proportion with 95% confidence interval and test of significance was applied wherever appropriate. Data from the interview schedule and the focus group discussion was triangulated to check for the interval consistency and improve the internal validity of the study.

Median (range) total delay, patient delay and provider delay was estimated from the interview and it was compared with the various patients characteristics. Tracking of the individual patients was done to study pattern of health care facility / provider visited for treatment for their initial symptoms. Direct cost incurred by the patient for seeking health care before ac-

tual starting on DOTS was also estimated. The date of onset of symptoms was estimated from ensuring the recognitions of at least one of the six symptoms namely cough, fever in the evening and night, anorexia, chest pain, weight loss, and hemoptysis.

FGDs were transcribed and content was studied with regard to context, internal consistency, extensiveness, intensity, specificity of issues and also emergence of big ideas.

Results:

The mean age was 28.2 (SD = 9.1). The mean age of males (29.1 years; SD = 10.82) and female (26.6 years; SD=10.5) was not significantly different (p >0.05). Forty percent were studied till primary. In 77.4% currently married patient average family size was 5 (SD 4.2). Out of 81% currently employed, most of them were laborer (39.6%) and farmers (35.8%) The average per-capita monthly income was Rs 650 (Table 1).

Patients characteristics	No	%	Patient delay	Provider delay	Total delay Median (Min – Max)
Age group					
< 20 years	11	20.8	93	48	141 (20 - 226)
20 to 25 years	31	58.4	82	41	123 (10 - 196)
26 to 30 years	5	9.5	116	60	176 (32 - 321)
> 30 years	6	11.3	88	45	133 (28 - 274)
Gender					
Male	37	69.8	109	27	136 (10 - 221)
Female	16	13.2	89	70	159 (38 - 321)
Educational					
Illiterate	3	5.7	96	38	134 (29 - 321)
Primary	21	39.6	80	46	126 (30 - 226)
Secondary	15	28.3	52	44	96 (37 - 206)
Higher secondary	11	20.7	83	26	109 (10 - 222)
Graduate & Above	3	5.7	42	19	61 (31 - 212)
Marital status					
Unmarried	9	17	54	39	93 (10 - 261)
Currently married	41	77.4	72	30	102 (28 - 236)
Widow / widower	2	3.8	112	79	191 (37 - 296)
Divorced	1	1.9	98	41	139 (21 - 321)
Occupation					
Not working	10	18.9	88	55	143 (29 - 292)
Farmer	19	35.8	82	40	122 (10 - 236)
Labourer	21	39.6	134	54	188 (48 - 321)
Other	3	5.7	77	36	113 (21 - 251)
Income (per-capita)					
< 650 rupees	21	39.6	73	60	133 (43 - 235)
> 650 rupees	32	60.2	80	33	113 (10 - 321)
Family type					
Nuclear	31	58.5			87 (15 - 289)
Joint	22	41.5			91 (10 - 321)
Total median delay	-	-	95	47	118 (10 - 321)

The median patient, provider and total delays for all patients were 95, 47 and 118 days respectively. The median patient delay was longer than the median health system delay. Total delay was more in females, patients between 26 to 30 years of age, illiterate, widowed/ widower, laborer by occupation, per-capita income less than Rupees 650/-, and those staying in joint family (Table1). Common reasons for delay are mentioned in Table 2.

Probable reason for delay	Percentage
Patient Attributed Delay:	
Patients did not perceive symptoms seriously	69.1
Tried home remedies for their symptoms (usually advised by the seniors in household)	45.8
Fear of stigma	37.3
Frequent travel / migrant	22.9
Did not have anyone to accompany to hospital	22.2
Did not know where to go for treatment	18.1
No money, so tried home remedies	13.3
Feared of stigma and discrimination in hospital	9.7
Patient regularly consuming alcohol	63.5
Health Services Attributed Delay	
Delay in getting report (due to logistic issues and lab technician on leave)	81.7
Delay in making diagnosis by doctor about category of treatment	43.3
HIV Patient already on ART. This may be due to doctors are not aware of the guidelines for treatment of HIV/TB co-infection.	15.1

Cough for more than 3 weeks as an initial symptom was reported by 77.4%, followed by fever (49.1%), loss of appetite (28.3%), chest pain (24.5%) and coughing blood (10%). 71.6% patients recognized more than one symptom initially (table 3). In 31 (71.6%) patients with delay of more than a month, illness started with weight loss (100%), fever (80.7%), chest pain (61.5%) and cough (46%) (Table 3).

Table 3 proportion of patient with delay for more than a month with source of first consultation and recognition of the first symptom			
	No (%) (n=53)	% with delay of more than 1 month (n=31)	95% CI
First symptom recognized			
Cough	41 (77.4)	46.4	18.2 – 82.6
Fever	26 (49.1)	80.7	21.8 – 83.9
Loss of appetite	15 (28.3)	13.3	10.2 – 94.2
Chest pain	13 (24.5)	61.5	32.3 – 78.3
Weight loss	2 (3.8)	100	-
Coughing blood (hemoptysis)	5 (9.4)	20	13.3 – 94.3
First consultation			
Family physician	13 (24.5)	53.8	25.1 – 80.8
Primary Health Center	6 (11.3)	74.9	31.8 – 93.9
Government Hospital	4 (7.5)	2.3	12.2 – 84.6
Private hospital / consultant	1 (1.9)	100	15.7 – 84.3
Chemist shop	7 (13.2)	71.4	21.3 – 79.1
Home remedies	19 (35.8)	63.1	36.4 – 79.3
Traditional healer / quack	3 (5.7)	33.3	22.9 – 61.7

* Multiple symptoms recognized by patients and values in the parenthesis indicate percentages

For treatment of their initial symptoms 24.5% first approached to family physician (private practitioner/ general practitioner), where as government health facility (Primary Health Center and Government hospital) was preferred by less than 19% patients. Home remedies were tried by 35.8% before visiting health facility. Most of the patients who have visited PHC (74.9%), chemist shop (71.4%) for first consultation or tried home remedies (63.1%) have a delay of more than a month in starting DOTS. One patient who visited private consultant also has a total delay for more than one month (Table 3).

DOTS was started Primary Health Center (43.4%), secondary or tertiary level care (56.6%). On an average a pulmonary tuberculosis patients has visited 4.3 health care worker / facilities and spent an average of 1450 rupees (only direct cost) shopping for treatment before initiating on DOTS.

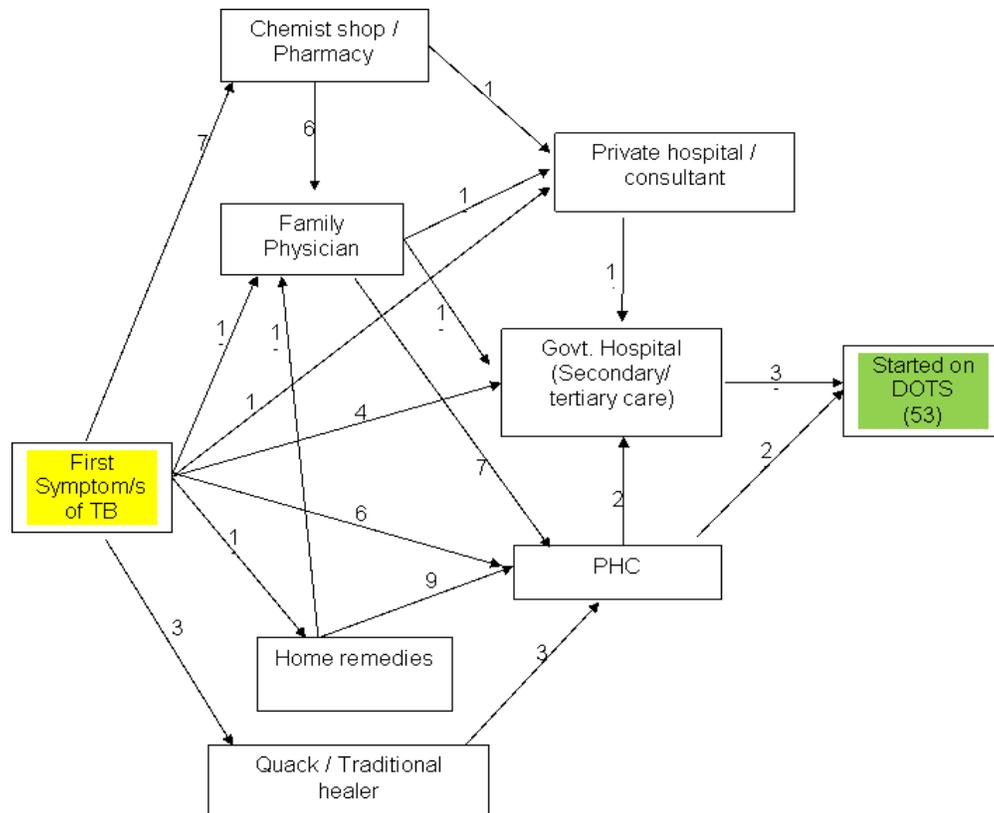


Figure 1: Pattern of visit to health provider for treatment of the symptoms. Arrow line indicates the direction of flow and the values represent the number of patients

Majority of these new pulmonary tuberculosis cases were put on category 1 treatment (56.6%). Two (3.8%) diagnosed as primary MDR tuberculosis (based on culture and sensitivity) and 15.1% had HIV – TB co-infection. Thirty six (67.9%) of the 53 patients were hospitalized at the time of diagnosis (Table 4). MDR patients have delay for more than a month. However, association between delay of more than a month and type of patient by category was not statistically significant ($p>0.05$).

Table 4: Patient characteristics and total delay for more than one month before starting on DOTS

Patients characteristics	Percentage (n=53)	Percentage with delay of more than 1 month (n=31)	(95 % CI)
Disease category			
Cat 1	56.6	61.5	31.6 – 86.1
Cat 3	39.6	47.8	28.8 – 69.4
MDR tuberculosis	3.8	100	--
TB HIV co-infection	15.1	73.0	39.3 – 93.2
Need hospitalization	67.9	63.9	41.3 – 82.8
Alcohol*			
Never	28.3	46.8	21.3 – 74.3
Sometimes	30.2	37.5	15.2 – 64.3
Regular	41.5	81.8	59.7 – 94.8
Smoking			
Never	62.3	44.4	13.7 – 78.8
Sometimes	20.7	45.5	16.7 – 76.6
Regular	16.9	66.8	48.2 – 82.0
Migration			
Never	24.5	46.2	19.2 – 74.9
Yes (once a year)	45.3	66.8	44.7 – 84.8
Yes (more than once a year)	30.2	56.2	29.9 – 80.2
House			
Rented	43.4	60.9	38.5 – 80.3
Self owned	56.6	56.8	37.4 – 74.5
Distance of health facility from house			
Less than 5 Km	66.0	60.0	42.1 – 76.1
5 to 10 Km	17.0	55.6	21.2 – 86.3
More than 10 Km	17.0	55.6	21.2 – 86.3
Income (per-capita)			
< 650 rupees	39.6	71.4	44.8 – 88.7
> 650 rupees	60.2	50.0	31.9 – 68.1

Among 31 patients with total delay of more than a month, regular alcoholics (18; 81.8%) were significantly more compared to occasional or non alcoholic (14; 43.7%) (OR=5.79; 95% CI 1.39-26.14). Smoking was not significantly associated with delay for more than a month ($p>0.05$). Twenty five (62.5%) of the 40 migrant patients have a total delay of more than a month.

Analysis of FGD also supported the findings of the survey (interviews) regarding the barriers to access the health services, preference of health service provider, their pattern of referral (Figure1) and expenses (direct cost) for treatment before initiation on DOTS.

Discussion:

Persons with symptoms of pulmonary tuberculosis seek care promptly, but they are neither reliably diagnosed nor effectively treated.[3] This leads to considerable delay in diagnosis and correct treatment that may further increase the morbidity and mortality among tuberculosis patients and spread of infection from infected to uninfected persons.[8-11]

Median total delay for initiation of DOTS from the onset of symptom was 111 days (16 weeks) with a very wide range of 10 – 321 days. Other studies have also reported a total delay ranging from almost 11 to 17 weeks.[12-14] In our study, patient delay was more than provider delay similar to findings of other studies [10,11], but few studies have also reported opposite.[15-17] Patients delay was seen more in those above 60 years of age, illiterate, per capita work was also found to have long patient delays probably due to lack of education and poverty.

Both survey and FGDs reveals that social and cultural factor, ignorance about symptoms, home remedies, fear of stigma, migration, unaware of services, financial problem, and alcohol consumption were the common reason for the longer patient delay, whereas provider delay was mainly due to delay in get-

ting sputum report (poor logistic and lab personnel on leave) and HIV-TB co-infection. Lian CK et al (1997) also suggested that social and cultural factors influence patients' decision to seek help and it is compounded by the social stigma of TB, that may contribute to a long delay in seeking professional care and even to abandonment of treatment.[17]

Few studies have reported prolonged delays for initiation of treatment in females compared to males.[18-20] Our study also confirms this findings. Provider delay was also more in females. We have not studied the reason for the same, however it could be due to social neglect of females or due to low index of suspicion for tuberculosis among females.[21] Moreover, the findings of FGD reveals poor access to health care system for female from rural Indian due to a number of social reasons. One female FGD participant said.....

“..... I was coughing for almost more than a month, I was taking turmeric and honey (home remedies) for my cough. It was only after I started coughing blood, my husband took me to our family physician. Doctor gave me some medicine and told that I have TB and asked (refer) me to go to government hospital” (F3).

Most TB patients were in the productive age group (i.e. 21 to 30 years). More the delay for initiating on treatment; greater will be the morbidity and mortality. This will have effect on families due to morbidity among the bread earner.[22] The maximum total median delay (176 days) was seen in patients between 26 to 30 years; however our study did not find any specific pattern of delay with the age of the patient.

In India, RNTCP recommends, any adult person with cough more than 3 week should be referred to microscopy center, and the sputum result should be made available within a week. Thus it is logical to expect diagnosis and initiation of DOTS should not be delayed for more than a month. In our study al-

most two third tuberculosis patients has a total delay of more than a month.

Reorganization and interpretation of initial symptoms are important determinants for seeking health care for tuberculosis. [23] In our study nearly two third patients recognized more multiple symptoms initially and the most common initial symptoms recognized by patients was cough for more than 3 weeks followed by, fever and loss of appetite. Around three fourth patients with fever and cough as an initial symptom have a delay for more than a month. Nearly one tenth of patients purchased some medications from shop without consulting any doctor and nearly one third tried home remedies. This could be due to low awareness and misinterpretations of their initial symptoms. Thus there is a great need to educate the community regarding the symptoms of tuberculosis.

The study found that virtually all symptomatic patients seek care promptly. This supports the RNTCP guidelines for finding out the chest symptomatic through passive case findings. However it is important for the provider to suspect the chest symptomatic promptly, investigate the patient, and start an appropriate treatment without delay. This will reduce the provider attributed delay.

Most of the TB suspects in India first consult one of the India's 10 million private medical practitioners.[3] Few studies from 3 states of rural south India found that 64 % to 80% first sought help from the private provider and just 29% went to visit government facility initially.[8,24] Our study also reported that family physician was a preferred health care provider for more than a one fourth and almost one third after trying home remedies visited family physician for their symptoms. RNTCP has recommended a Public Private Mix (PPM) program and has prescribed various schemes for involving private sector health care provider in the program.[25] Also family physicians are first level of contact between the health facility and patients. Therefore if these family physician from rural area are effectively involved in the program, the precious delay, especially provider attributed delay, could be reduced. [25]

Overall the pattern of health seeking behavior in chest symptomatic was complex. An average 4.3 health care worker / facilities visited by patients before starting on DOTS. A study from India reports that the patients are not promptly diagnosed and treated, and therefore go from one doctor to the next before the diagnosis is firmly established and DOTS begins.[26] Mapangu S K et al have also reported multiple health seeking encounters contributed to the prolonged duration of health service delay along with associated medical costs. This reflects the low awareness regarding the tuberculosis among community and also a low level of clinical suspicion of tuberculosis by health providers and failure to order proper investigations or refer patients to 'higher level' contribute in a major way to health service delay.[23]

A study conducted 1997 in Tamil Nadu India reports on an average patient of tuberculosis incurs (direct cost + indirect cost) total cost of Rs 3469/- (US\$99) shopping for diagnosis and treatment. This almost invariably resulted in indebtedness and mortgages of valuables.[15,24] However this situation has hardly changed over last 5 years. Our study reports an average of Rs 1450 rupees (only direct cost) spent by the chest symptomatic for shopping for treatment before DOTS was started.

Regular alcohol consumption was significantly associated with delay of more than a month. Studies from India and abroad also reported similarly.[23,27] Smoking was not significantly associated with delay in diagnosis, 67% regular smokers had a delay of more than a month. In FGD we try to find out the perception of smoking as a cause of tuberculosis associated with prolonged patient delay. The participants at-

tributed their symptoms, especially cough, to smoking rather than Tuberculosis. Migration, distance of residence from nearest health care facility, rented home and per-capita income were not significantly associated with delay of more than a month in initiation of DOTS. ($p>0.05$)

To conclude, India is in 2nd decade of implementation of RNTCP; therefore, should focus on early case detection rather than mere achieving 70% new case detection. Program managers and doctors treating tuberculosis should systematically focus on the awareness program that will bring all tuberculosis suspects from rural area earlier under RNTCP, so that the economic loss/ financial burden of patients due to unnecessary shopping for treatment could be avoided. Communication campaign needs to be targeted towards special groups like alcoholics, laborers and migrants to improve their access to TB diagnosis and treatment services. The study recommend scaling up of Public private partnership program in rural area and more intense training and refresher trainings on TB diagnosis and management procedures for health providers (public as well as private). This will also avoid delay in diagnosis and enhance treatment success.

Limitations:

The previous health records were either not available or were often incomplete. Information about referral was also poorly documented. This made it difficult to find the exact date of patient first contact with provider for their symptoms. It could be validated in only 11 patients as they had referral slip. Thus the recall bias can-not be ruled out. Therefore we may have underestimated the actual delays for these patients. But we assume that the event is significantly related to the life of patients. Moreover all patients studied were in intensive phase of DOTS at the time of study, therefore patients are more likely to remember the events and the data therefore could be reasonably acceptable.

Other limitation was that we studied only the delays in new patients of pulmonary tuberculosis. A selection bias had been introduced, as the study say nothing about re-treatment cases, extra-pulmonary tuberculosis and also tuberculosis from urban area. Some patients had other diseases or co-morbid condition, other than HIV. However, we have not studied it because non availability of the records. Studies have indicated that co-morbid conditions have influenced the health seeking behavior. [21]

Visit to the various health care provider for treatment of their symptoms and expenses incurred was calculated approximately as mentioned by the patient. We included the direct cost incurred by the patients and calculation of indirect cost was beyond the scope of this study.

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