Factors associated with delay in treatment seeking among new Sputum Smear positive pulmonary tuberculosis patients registered under DOTS Centre, Nahan, Himachal Pradesh, India: A Cross Sectional study

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Introduction

Tuberculosis (TB) remains a significant public health problem worldwide affecting about one third of the global population. India alone account for an estimated one quarter of all TB cases worldwide. In India, the overall prevalence of infection is 30%. In high prevalence countries, delays are noticed in health seeking, diagnosis and treatment. Information about the factors associated with various delays often assist the programme managers to improve case finding and thus reduce the disease transmission.

Objectives

To estimate the various delays, the risk factors associated with such delays and to know the health seeking behaviour and stigma of tuberculosis faced by the patients in the society.

Study design and setting

Descriptive Cross Sectional Study in Directly Observed Treatment Short Course (DOTS) Centre

Methods and material

Using modified and pretested WHO multi-country questionnaire, pulmonary tuberculosis patients were interviewed regarding socio-demographic characteristics, treatment seeking behaviour and risk factors for tuberculosis.

Statistical analysis used

Descriptive statistics such as frequency, mean and standard deviation, Chi-square test for qualitative/categorical variables and backward regression model for predictors.

Results

Among 58 patients, 31 (53.4%) were males and 27(46.6%) were females. Mean age of the patients was 41.29 years (SD 16.80). Delay in seeking treatment for pulmonary tuberculosis was present in 40(68.96%) patients .The total mean delay was 44.98 days (SD 18.85). Assessment of predictors for perceived causes of delay depicted fear of what would be found on diagnosis and fear of social isolation as most significant (r square=0.267,p=0.028)

Conclusion

Delay in initiating treatment for sputum smear positive pulmonary tuberculosis is attributed to patient and health system related factors. Early detection followed by effective therapy is extremely important in controlling TB.

Key words: Tuberculosis, Treatment seeking, Delay.

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INTRODUCTION

Tuberculosis (TB) remains a significant public health problem worldwide affecting about one third of the global population. Despite implementation of various preventive and control strategies over the years, it still remains a major cause of morbidity and mortality and is the leading infectious disease causing death among adults worldwide[1]. The number of persons infected with the TB bacillus is estimated to be 1.7 billion, of which 1.3 billion live in the developing countries[2]. Asia carries the largest number of TB cases worldwide. Globally, estimated cases of infectious TB are 16-20 million, estimated new cases are 4-5 million, and estimated deaths as three million every year[3].According to Global Tuberculosis report 2020, majority of tuberculosis patients were in World Health Organization (WHO) regions of South-East Asia (44%), Africa (25%) and the Western Pacific (18%).Eight countries accounted for two thirds of the global total which included India. India alone account for an estimated one quarter (26%) of all TB cases worldwide[1]. In India, the overall prevalence of infection is 30%[2].

TB can affect any age, caste or class but mainly poor people are affected. Slum dwellers, tribal population, prisoners and people already sick with compromised immune systems are commonly affected. The cost of diagnosis and treatment is high especially the treatment cost of Multi Drug Resistant Tuberculosis and Extensively Drug Resistant Tuberculosis. Tuberculosis is the major burden to the country's economy. Studies have shown that tuberculosis is one of the major hindrances to economic development of country, costing approximately Rs. 13,000 crores in a year[4].The economic burden of TB is extremely high. Between 2006 and 2014, TB affected the Indian economy as massive economic brunt of USD 340 billion[5]. The End TB Strategy by WHO has defined milestones (2020-2025) and targets for (2030-2035) for reductions in TB cases and deaths .Though there has been an increase in TB notifications, gap is still there between the number of new cases reported (7.0 million) and the estimated 10.0 million (range, 9.0– 11.1 million) incident

cases in 2018.This gap is due to a combination of underreporting of detected cases and under diagnosis because of various factors like lack of access to health care or not diagnosed at appropriate time. In high prevalence countries, delays in diagnosis and treatment is often prolonged[6].These delays occur at the level of patients as well as health system. Specific patient groups based on gender, rural/urban area nationality add on to the determinants[7].Also, the availability and accessibility to health services plays a major role[8,9,10].There is an increase in infectivity rate of tuberculosis in any community whenever the correct diagnosis and start of treatment at the earliest is hampered[11].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[12].Hence, delay in TB diagnosis and treatment plays a major role in increasing the transmission of tuberculosis in the community leading to an increased burden of tuberculosis.It also results in enhancing the risk of treatment failure, mortality and emergence and transmission of multi drug resistant(MDR) TB strains in the community[13,14,15].Additionally delayed treatment worsens the prognosis and increase the risk of mortality. The treatment delay affects individual, the community and country's health and economy. Early detection followed by effective chemotherapy is extremely important for the effective control of TB. In Himachal Pradesh, tuberculosis is quite wide spread in the poor socio-economic class where women are the most sufferers[16].Information about the impact of various kinds of delays and the factor associated with those delays often assists the programme managers to improve case finding and thus reduce the disease transmission. Therefore, present study was planned among the new sputum smear positive tuberculosis patients registered under DOTS Centre, tertiary care hospital, North India with objectives to (1) Estimate the various delays (2) To ascertain the

risk factors associated with such delays (3) Know the health seeking behaviour and to assess the stigma of tuberculosis faced by the patients in the society

Methodology
Study design and setting
Descriptive Cross Sectional Study among tuberculosis patients registered in DOTS Centre, Nahan, Himachal Pradesh, India.

Study population
New sputum smear positive pulmonary tuberculosis patients

Study period
1st July 2021 to 31st August 2021

Inclusion criteria
New sputum smear positive tuberculosis patients
Age ≥18 years

Exclusion criteria
Patients who did not give consent
Seriously ill patients
Difficulty in understanding language

Material and methods
A Descriptive cross sectional study was undertaken after obtaining institutional ethical committee approval. Clearance no.HFW/ME/DYSPGMC/IEC/2020/09.Convenie nce study sample consisted of new sputum smear positive pulmonary tuberculosis patients registered in DOTS centre under National Tuberculosis Elimination programme (NTEP). Patient information sheet was provided to the patients with the aim of providing information regarding purpose of conducting study and its benefit to the society at large. Written informed consent was obtained from all the cases prior to interview. Questionnaire used in the WHO multi-country study to estimate the diagnostic and treatment delay in TB was used.[7]Using this modified and pretested structured questionnaire for local use, pulmonary tuberculosis patients were interviewed by the principle investigator and two trained health workers.

Details were sought regarding socio-demographic characteristics, risk factors of tuberculosis and
treatment seeking behaviour. The addresses of the enrolled patients were geocoded and mapped using Quantum Geographic Information System (QGIS)3.16.

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, duration of treatment and type of drugs used for treatment. Stigma was measured using variables such as feeling ashamed of having TB, has to hide TB diagnosis from others, social isolation due to TB and the extent to which tuberculosis affected the following: relations with others, work performance, family responsibilities, marital relations. History of risk factors like current alcoholic and current drinkers was also enquired. Current smokers were those who smoked ≥100 cigarettes in their lifetime and reported current smoking.[10]Current drinker, whose baseline alcohol consumption is categorized into eight predefined groups according to the amount in grams consumed per week: >0–≤25, >25–≤50, >50–≤75, >75–≤100, >100–≤150, >150–≤250, >250–≤350, and >350 g per week. Episodic heavy drinking (dichotomized as binge drinkers who consumed ≥100 g per drinking occasion or non-binge drinkers who consumed <100 g per drinking occasion)[11]. A standard drink is represented by 340 ml of beer,115ml of non-fortified wine,43ml of beverages like whisky, Gin, Vodka each containing 10-15 gms of ethanol[12].Delay in seeking treatment is defined as the time interval from the onset of illness until the initiation of anti-tuberculosis drugs. Delay was defined as those with a cough ≥4 weeks. The 4 week cutoff has been used in previous studies of delay in accessing care for Tuberculosis [12,13].

Patients shall be interviewed in context of time to reach health facility, first health-seeking behaviour before diagnosis ,speciality of healthcare provider that made initial diagnosis, satisfaction with care, perceived causes of delay in health seeking behaviour , date of initiation of treatment , time to reach from home to the nearest public health facility, distance (in Km) from home to the nearest health facility providing treatment, time interval between the date of health-seeking behaviour at a health care provider and the initiation of anti-tuberculosis treatment .

Data analysis
Data was entered in Excel sheet and analysed using SPSS 23 version. Descriptive statistics such as frequency, mean and standard deviation, median, minimum and maximum was calculated. Comparisons between groups was made using the Chi-square test for qualitative/categorical variables. Predictors for perceived causes of delay in health seeking among the study participants were assessed using backward regression model. P value<0.05 was considered statistically significant.

Results
A total of 58 patients were recruited .The study period for two months was considered as per recommendations under ICMR -Short Term Studentship (STS) project 2020 .All the new sputum smear positive pulmonary tuberculosis who qualified the inclusion criteria were enrolled. Among 58 patients,31(53.4%) were males and 27(46.6%) were females. Mean age of the patients was 41.29 years (SD 16.80).The majority of the respondents 26(44.8%) were in the age group of 18–34 years. Patients belonging to the rural area were 42(72.4%) as compared to 16(27.6%) from urban area. Mapping of residential addresses of the study participants reflected areas of disease burden (Fig 1). Majority 17(29.3%) were educated upto twelfth standard. Four(6.9%) patients were illiterates. Occupational assessment showed 21(36.2%) belonging to the worker class and 9(15.5%) were unemployed. Forty (75.9%) were married and 14(24.1%) were unmarried. Family size of more than five was present among 44(75.9%.) patients and overcrowding was present in 23(39.7%).No history of smoking was present in 37(62.1%) patients. However,17(29.3%) were current smokers and 4(6.9%) had quitted smoking. History of current drinking was present in 18(31.0%) patients. Time taken to reach from home to nearest health by vehicle was less than half an hour in 21(36.2%) patients, Half an hour to one hour in 20(34.5%) and more than one hour in 17(29.3%) patients Regarding health seeking behaviour of the study participants, first action for treatment seeking showed that majority 21(33.9%) adopted the practice of self medication. Only 14(24.1%) opted for treatment from medical officer/physician. Health seeking encounters to health care professionals before initial TB diagnosis varied from zero and five with majority 17(27.4%) seeking atleast two consultations. Initial tuberculosis diagnosis was made by physician in majority 45(72.5%) of patients followed by government medical officer in 10(16.1%) and by general practitioner in 3(6.8%) (Table 1).

Table 1Sociodemographic profile and health seeking behaviour of study participants (N=58)

Variable	Frequency n (%)
Sex	
Male	31(53.4)
Female	27(46.6)
Age group (years)	
18-34	26(44.8)
35-51	17(29.3)
52-68	11(19.0)
>68	4(6.9)
Area	
Rural	42(72.4)
Urban	16(27.6)
Education level	

Illiterate	4(6.9)
Read and write	3(5.1)
Primary school	13(22.4)
Middle school	8(13.8)
High school	8(13.8)
Plus 2	17(29.3)
Graduate	4(6.9)
University or higher	1(1.7)
Occupation	
Technical	2(3.4)
Professional	1(1.7)
Clerical	4(6.9)
Student	7(12.1)
Worker	21(36.2)
Unemployed	9(15.5)
House wife	14(24.1)
Marital status	
Married	44(75.9)
Single	14(24.1)
Number of household Members	
1-4	14(24.1)
>5	44(75.9)
Overcrowding	
Yes	23(39.7)
No	35(60.3)
History of smoking	
Current smoker	17(29.3)
Never smoked	37(62.1)
Quitted smoking	4(6.9)
Current drinker	
Yes	18(31.0)
No	40(68.9)
Time to reach from home to the nearest public health facility	
<1/2 hr	21(36.2)
1/2-1 hr	20(34.5)
> 1hr	17(29.3)
Health seeking behaviour First action for health seeking	
Medical officer/Physician CHC	3(5.1)
Dispensary	9(15.5)
Pharmacist	13(22.4)
Medical officer PHC	5(8.6)
Private practitioner	3(5.1)
Self-medication	21(36.2)
Traditional	4(6.8)
Number of health seeking encounters to health care professional before initial TB diagnosis	
0	4(6.8)
1	11(18.9)
2	17(29.3)
3	10(17.2)
4	12(20.6)

5	4(6.8)
Health care professional who made the initial tuberculosis diagnosis	
Physician	45(77.5)
Govt medical officer	10(17.2)
General practitioner	3(5.1)

Perceptions pertaining to availability of services at DOTS centre among the study participants were reflected as of poor quality services and inadequate staff attitude in 46(79.3%), waiting time more than 30 minutes in 39(67.2%) and delayed action from health care professional among 19(32.8%) patients.

Interpretation of the knowledge related to tuberculosis assessed by likert scale depicted that awareness regarding the disease was good in 28.73%, Knowledge related to non-hereditary nature of the disease was labelled as best in 14.94%, knowledge related to contagious nature of the disease was good in 30.45% patients, fair knowledge was there in 36.20% related to whether tuberculosis can be cured.13.21% had best knowledge about the

duration of antitubercular drugs and 44.82 % had good knowledge about kind of drugs used in treatment. Stigma perceived by the patients pertaining to tuberculosis as assessed by 5 point likert scale showed that 68.53% people were not ashamed of having TB, 64.22% patients thought that there is no need to hide TB diagnosis from other people, preference for living isolated since the diagnosis, whether tuberculosis affects the marital relations, family relations and less chances of marriage because of disease was labelled as average stigma in 55.17%, 69.82% and 49.13% patients respectively. Any effect on the work performance because of disease was refused by 73.20% and 68.82% did not agree for any effect in performing family responsibilities (Table 2).

Table 2 Knowledge and stigma regarding tuberculosis among study participants (N=58)

Parameter	Mean value	Percentage
Knowledge		
1. What disease do you have?	0.86	28.73%
2. Is TB hereditary?	0.44	14.94%
3. Is TB contagious?	0.91	30.45%
4. Is TB curable?	1.08	36.20%
5. Do you know the approximate duration of treatment?	0.39	13.21%
6. Do you know the kind of TB drugs?	1.34	44.82%
Stigma		
1. Do you feel ashamed for having TB?	2.74	68.53%
2. Do you have to hide TB diagnosis from the other people?	2.56	64.22%
3. Does TB affect relation with the others?	2.37	59.48%
4. Do you prefer to live isolated since you got TB diagnosis?	2.2	55.17%
5. Does the TB affect your work performance?	2.94	73.70%
6. Does TB affect marital relation?	1.96	49.13%
7. Does TB affect family responsibilities?	2.79	69.82%
8. Do you think less chances of marriage due to TB diagnosis?	1.96	49.13%
9. Does TB affect your family relations?	1.84	46.12%

Delay in seeking treatment for pulmonary tuberculosis was present in 40(68.96%) patients Comparison for sociodemographic and clinical characteristics between patients with delay in

seeking treatment and those without delay 18(31.03%) did not show significant differences. except for overcrowding (p=0.015)(Table 3).

Table 3: Sociodemographic and clinical characteristics of study participantsbased on duration from onset of symptoms to initiation of treatment

Characteristic	Duration from onset of symptoms to initiation of treatment <28 days (N=18) n(%)	Duration from onset of symptoms to initiation of treatment ≥ 28 days (N=40) n(%)	*P value
Sex			
Male	8 (44.4)	20(50)	0.695
Female	10(55.5)	20(50)	
Area			
Rural	13(72.2)	27(67.5)	0.719
Urban	5(27.7)	13(32.5)	
Religion			
Hindu	16(88.8)	36(90)	0.779
Muslim	2(11.1)	3(7.5)	
Sikh	0(0)	1(2.5)	
Overcrowding			
Yes	11(61.1)	11(27.5)	**0.015**
No	7(38.8)	29(72.5)	
Education level			
University or higher	0(0)	1(2.5)	0.554
Graduate	0(0)	4(10)	
Plus 2	6(33.3)	11(27.5)	
High school	3(16.6)	5(12.5)	
Middle	4(22.2)	4(10)	
Primary	2(11.1)	11(27.5)	
Read & write	1(5.5)	2(5)	
Illiterate	2(11.1)	2(5)	
Occupation			
Professional	0(0)	1(2.5)	0.789
Clerical	2(11.1)	2(5)	
Homemaker	3(16.6)	11(27.5)	
Worker	7(38.8)	14(35)	
Technical	0(0)	2(5)	
Student	3(16.6)	4(10)	
Unemployed	3(16.6)	6(15)	
Marital Status			
Married	15(83.3)	30(75)	0.481
Single	3(16.6)	10(25)	
Age group(years)			
18-34	7(38.8)	19(47.5)	0.707
35-51	6(33.3)	10(10)	
52-68	3(16.6)	9(22.5)	
>68	2(11.1)	2(5)	
History of smoking			
Current smoker	6(33.3)	11(27.5)	0.458
Never smoker	12(66.6)	25(62.5)	
Quitted	0(0)	4(10)	
History of Alcohol			
Yes	9(50)	27(67.5)	0.204
No	9(50)	13(32.5)	
Chronic diseases			
COPD	2(11.1)	2(5)	0.779
Diabetes	4(22.2)	4(10)	
Symptoms			
Cough	18(100)	40(40)	-
Fever	17(94.4)	38(95)	0.930
Loss of weight	10(55.5)	14(35)	0.141
Haemoptysis	8(44.4)	11(27.5)	0.203
Chest pain	14(77.7)	25(62.5)	0.251
Duration from onset of symptoms to initiation of treatment			
Mean(SD)	19.89(3.612))	44.98(18.85)	**0.001**

Pearson Chi square value <0.05 considered as statistically significant

The total median delay was 41 days (IQR: 30-55) and the mean delay was 44.98 days (SD 18.85). The minimum and maximum delays were 28 and 122 days, respectively. The median patient delay was 41 days (IQR: 30-51.50) and the mean patient delay was 44.38 days (SD 18.608). The minimum and maximum patient delays were 28 and 120 days. The median health service delay was 2 days (IQR: 1-7) and the mean delay was 3.43 days (SD 2.820). The minimum and maximum delays were 1 and 7 days, respectively (Table 4).

Table 4: Distribution of various time delays (days) among study participants (N=40)

Delay	Mean	SD	Median	IQR	Min	Max
Patient delay	44.38	18.608	41.00	30-51.50	28	120
Health care services delay	3.43	2.820	2.00	1-7	1	7
Total delay	44.98	18.854	41.00	40-55	28	122

Assessment of predictors for perceived causes of delay in health seeking among the study participants (using backward regression model) depicted fear of what would be found on diagnosis and fear of social isolation as most significant factors (r square=0.267,p=0.028) (Table 5).

Table 5: Predictors for delay in health seeking among the study participants (n=53)

Predictors(using backward regression model)	R²	P value
Poor quality of health services, Previous Bad experience, Inadequate staff attitude, Too far health facility, Fear of what would be found on diagnosis , Economic constraints, denial and concealment , Too busy/long waiting time , Fear of social isolation	0.328	0.571
Previous Bad experience, Inadequate staff attitude, Too far health facility, Fear of what would be found on diagnosis, Economic constraints, denial and concealment , Too busy/long waiting time , Fear of social isolation	0.328	0.448
Previous Bad experience, Inadequate staff attitude, Too far health facility, Fear of what would be found on diagnosis, Economic constraints, denial and concealment , Fear of social isolation	0.326	0.332
Inadequate staff attitude, Too far health facility, Fear of what would be found on diagnosis , Economic constraints, denial and concealment , Fear of social isolation	0.324	0.225
Inadequate staff attitude, Too far health facility, Fear of what would be found on diagnosis, Economic constraints, , Fear of social isolation	0.314	0.152
Inadequate staff attitude, Too far health facility, Fear of what would be found on diagnosis, ,Fear of social isolation	0.302	0.095
Inadequate staff attitude, Fear of what would be found on diagnosis, , Fear of social isolation	0.294	0.05
Fear of what would be found on diagnosis, Fear of social isolation	0.267	0.028

P value<0.05 considered as statistically significant

DISCUSSION

Assessment of factors associated with patient and healthcare services delay is an important step to identify the risk factors and imparting necessary actions for improving the quality of tuberculosis care and control. Our study showed that 40(68.96%) had delayed the treatment for ≥ 28 days after onset of symptoms (p=0.001). Duration of delay in seeking treatment was consistent with the findings from the study conducted by Cordoba C et al in Colombia [17].where the total number of patients included in the study (N = 623), 75.0% had delay in treatment seeking for ≥ 30 days .Among the patients with total delay in seeking treatment, the mean duration was 44.98(SD18.85) days with median of 41 days. Proportion of patient delay is higher than the mean health service delay of 3.43(SD 2.820).These findings of our study suggest less duration of delay in seeking treatment in comparison to the delay observed in a study conducted in Mumbai where median delay was found to be 65 days[18]. Several other 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 [19-22].Another study from our state showed median patient, health system and total delay of 15, 13 and 36 days [23].Our study showed median patient, health services and total delay of 41,2,41 days respectively. The total delay was almost found to be consistent with the range as found in studies conducted in other parts of our country. However, these differences could be due to various factors based on socio-demographic and economic background, factors like perceived stigma and first health seeking from non-specialized health providers. The reason for delay in seeking treatment in our study area can possibly be explained by the reluctance in seeking treatment during COVID 19 pandemic. Delay in seeking treatment among pulmonary tuberculosis patients poses threat to the society as these patients serve as reservoirs of infection and continue to spread the disease resulting in increased tuberculosis burden.

Majority 21(33.9%) of the patients tried self-medication at home as a first health seeking behavior, other patients either purchased the medications over the counter, went to traditional healers. The association between such initial health seeking behavior and delay in appropriate treatment initiation under DOTS was observed as mentioned in other studies conducted in India and elsewhere [19,24-26].

No significant association was noted between various factors like gender, occupation, education, marital status with delay in treatment initiation. Similar findings were observed in study conducted by Mistry N et al in Patna, Bihar[27].However, there was significant association between overcrowding and delay (p= 0.015) . This may be linked to the poverty with fear of loss of wages association between stigma in the form of fear of being diagnosed with TB and other factors with delay in seeking health care and hence postponement of the visit to the health care providers was observed. Despite decades of public health efforts, stigma continue to impede progress in diagnosis and treatment of TB [28]. Findings of our study like other studies found that stigma was independently associated with prolonged patient delay [29-31]. Assessment of predictors for perceived causes of delay in health seeking among the study participants depicted fear of what would be found on diagnosis and fear of social isolation as most significant factors (p=0.028). This is contributed to the fact that mindset of the people in our society is such that they have varied perceptions related to the disease, its treatment mode of spread.

LIMITATIONS

Recall bias might have introduced as the patients didn't remember the accurate date of onset of first symptom and the date of visit to the health facility. Approximate dates were enquired from the patients based on festival days and holidays so as to minimize the bias .However, date of diagnosis and starting of treatment was taken from the patient's record at the DOTS centre. Some of the addresses from the interior areas of the hilly terrain could not be geocoded. To overcome it, the co-ordinates should be taken from the exact location.

CONCLUSION

Delay in initiating treatment for sputum smear positive pulmonary tuberculosis is attributable to the patient delay and health system delay. The major predictors for delay from patient's perspective were fear of what would be found on diagnosis and fear of social isolation. Failure of early recognition of signs and symptoms, seeking early and appropriate treatment are the major factors for delay. Lack of knowledge related to tuberculosis and associated stigma also affects the health seeking behavior. Early detection followed by effective therapy is extremely important in controlling TB. Identification of the areas with high disease burden and focused interventions can help in curbing the transmission with subsequent control of tuberculosis.

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Fig 1: Mapping of residential areas of study participants*