Original Research Article

Diagnostic delay and out of pocket expenditure in extra pulmonary tuberculosis patients: a cross sectional study in DOTS centre of a tertiary care hospital in South India

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ABSTRACT

Background: Extra pulmonary tuberculosis (EPTB) accounted for 15% of the cases. Diagnosing EPTB is challenging as it frequently has non-specific clinical presentation and it may simulate other conditions, which may contribute towards delay in diagnosis. Delay in diagnosis and treatment could lead to increased disease severity, increased complications and economic burden for the patient and the families affected.

Methods: This Descriptive cross-sectional study was conducted in directly observed therapy short-course (DOTS) center, Mandya institute of medical sciences (MIMS), India. Patients who are diagnosed with EPTB with age $\geq$ 18 years were selected, informed consent was taken from 60 patients before collecting data. Data was analysed using Epi-Info (version 3.5.1) software. Descriptive statistics like mean, standard deviation and proportion are used

Results: Of the 60 patients, majority 76.7% were in the age group 18-45 years, 68.3% were male, 75% from rural background and 55% belonged to class III socioeconomic status. Statistically significant diagnostic delay was seen with respect to female sex (total delay = 75.1±9.1 days), age group 18 to 30 years (74.5±5.1 days), lower socio-economic status (74.0±4.5 days), negative HIV status (72.7±4.4 days) and site of tuberculosis. Out of pocket expenditure was significantly higher in male sex (Rs. 22,839.0±5,174.7), age group more than 45 (Rs. 34,335.7±5,134.1) and among higher socioeconomic status

Conclusions: Many EPTB patients, presenting to DOTS center, experience a long delay in the initiation of treatment, particularly patients with TB lymphadenitis. The patient delay is the major contributor to the total delay.

Keywords: Extra pulmonary tuberculosis, Diagnosis delay, Economic burden, Tuberculosis, TB, EPTB

INTRODUCTION

Tuberculosis (TB) remains to be a major global public health problem. In 2018, the world health organization estimated that there are 10 million incident cases of TB worldwide out of which, extra pulmonary tuberculosis (EPTB) accounted for 15% of the cases.[1] The proportion of EPTB was found to be higher in people of African and Asian origin, female sex, TB and HIV co-infected patients and in younger age group.[2] Early detection and proper treatment of TB are two key elements of an effective TB control program. According to WHO`s 'End TB strategy', which states that not only early diagnosis and treatment of TB cases but also follow-up of EPTB cases should be given priority.[3] Diagnosing EPTB is challenging as it frequently has non-specific clinical presentation and it may simulate other conditions, which may contribute towards delay in diagnosis. In addition, lack of rapid, simple, fast and accurate diagnostic tools for diagnosing EPTB may prolong and increase chances of diagnostic delay. Since EPTB is rarely infectious, the transmission is not as important as in pulmonary TB

patients, but delay in diagnosis and treatment could lead to increased disease severity, increased complications and economic burden for the patient and the families affected. Most studies have been done on the diagnostic delay in PTB among adults. Only few studies have included EPTB patients, and these studies have reported longer diagnostic delays among EPTB patients as compared to PTB.[4] However, the knowledge is insufficient on the reasons causing various types of delay and the associated factors among EPTB patients. It is important to identify factors contributing to different types of delay in EPTB, which could provide information for evidence-based intervention to improve case-finding and prompt diagnosis and treatment. Earlier studies conducted before implementation of RNTCP in south India showed that even after offering free diagnosis and treatment by the government, out-of-pocket expenditure burden on TB patients annually was more than US$ 3 billion (21,362 crores INR).[5] As it is very common to miss the diagnosis of extra pulmonary tuberculosis due to no accurate diagnostic method and further to diagnose EPTB patients have to undergo various diagnostic tests which leads to out-of-pocket expenditure. With this background the present study will be undertaken to estimate the diagnostic delay at various level, overall cost and pattern of expenditure borne by the patients registered under DOTS for the treatment of extra pulmonary tuberculosis in Mandya district.

METHODS

Study design and duration

Current study was a cross-sectional study conducted from 01 May to 30 June 2019.

Study population, sample size and sampling method

The study population will be patients of all ages above 18 years who are diagnosed with EPTB and registered in DOTS centre in government tertiary care hospital (MIMS) of Mandya. Sample size in current study was 60. Whole population study-based sampling method was adopted in current investigation.

Inclusion criteria

Inclusion criteria for current study were; patients ≥18 years of age of either gender, extra pulmonary tuberculosis patients registered at DOTS centre MIMS, Mandya, patients who have completed intensive phase of treatment and patients who gave consent for the study.

Exclusion criteria

Exclusion criteria for current study were; those patients who are seriously ill or debilitated at the time of interview and patients who does not gave consent for the study.

Method of data collection (study tools)

A semi-structured questionnaire is developed in English and translated to local language Kannada. The questionnaire includes questions related to socioeconomic characteristics of patients, symptoms, duration of symptoms, estimated time interval from the onset of symptoms till the first contact with a health care provider, number of different health care providers (doctors) contacted due to the current illness and other questions related to medical history and health care seeking behaviour. The questionnaire also includes information on out-of-pocket expenditure towards consultation fees, money spent on medicines, money spent on investigations, travel, and other expenses before and during treatment.

Statistical analysis

Data will be collected and entered in to Microsoft Excel sheet and analysed using Epi-Info (version 3.5.1) software. Data will be presented as mean, standard deviation and proportion. The test of significance used were student t test and ANOVA for the association.

RESULTS

Table 1: Sociodemographic and clinical characteristic of study participants.

Variables		N (%)
Sex	Male	41 (68.3)
	Female	19 (31.7)
Age (years)	18-30	24 (40.0)
	31-45	22 (36.7)
	>45	14 (23.3)
Residential status	Rural	45 (75.0)
	Urban	15 (25.0)
Educational status	≤primary	17 (28.3)
	>primary	43 (71.7)
Occupation	Agriculture	25 (41.7)
	Government or private sector	12 (20.0)
	Self employed	13 (21.7)
	Others	10 (16.7)
Housing	Own	55 (91.7)
	Rented	5 (8.3)
Socio economic status	I	12 (20.0)
	II	9 (15.0)
	III	33 (55.0)
	IV	6 (10.0)
HIV status	Negative	27 (45.0)
	Positive	14 (23.3)
	Unknown	19 (31.7)
Presumptive site of infection	Lymphadenitis	30 (50.0)
	Pleuritis	23 (38.3)
	Other sites	7 (11.7)

Sociodemographic and clinical characteristics

Total 60 patients of EPTB were interviewed. Among 60 patients 68.3% were male, 76.7% patients belonged to age group of 18-45 years, 75% belonged to rural area, 71.7% had schooling more than primary, 41.7% were involved in agriculture, 91.7% had their own house, majority 55% belonged to class III socio economic status, 45% didn't know their HIV status and 50% had site of infection as lymph nodes.

Table 2: Patient delay, health system delay and total delay among study participants.

Variables		N	Patient delay days±SD	P value	Health system delay days±SD	P value	Total delay days±SD	P value
Diagnostic delays		-	38.07±3.6	-	26.6±2.4	-	64.7±4.3	<0.05
Sex	Male	41	34.0±5.5	>0.05	25.8±3.0	>0.05	59.8±6.5	<0.05
	Female	19	46.8±9.0		28.3±3.9		75.1±9.1	
Age (years)	18-30	24	45.5±3.9	>0.05	29.0±3.1	>0.05	74.5±5.1	<0.05
	31-45	22	24.9±2.7		28.2±3.8		53.1±3.1	
	>45	14	45.8±4.0		20.1±3.2		66.0±3.6	
Socio economic status	I	12	31.2±2.5	>0.05	24.2±1.6	>0.05	53.6±3.6	<0.05
	II	9	21.5±3.3		20.2±1.1		41.7±3.2	
	III	33	42.8±3.8		31.2±2.1		74.0±4.5	
	IV	6	50.0±4.8		19.6±1.2		69.6±4.5	
HIV status	Negative	27	45.1±4.1	<0.05	27.6±2.5	>0.05	72.7±4.4	<0.05
	Positive	14	18.7±2.1		26.6±1.8		45.4±2.7	
	Unknown	19	42.2±3.6		25.2±1.5		67.4±2.9	
Presumptive site of infection	Lymphadenitis	30	49.4±3.6	<0.05	30.1±2.0	>0.05	79.5±4.6	<0.05
	Pleuritis	23	25.3±3.2		21.2±1.3		46.6±3.0	
	Other sites	7	31.0±4.0		29.5±1.8		60.5±4.4	

Table 3: Out of pocket expenditure in study participants.

Variables			Medical expenses Rupee±SD	P value	Non-Medical Expense Rupee±SD	P value	Indirect cost Rupee±SD	P value	Total Cost Rupee±SD	P value
Overall		N	10863.3±248.0	-	2711.1±255.2	-	5600.0±715.0	-	19025.0±2829.3	<0.05
Sex	Male	41	12907.3±4642.5	<0.05	3102.4±454.5	<0.05	7048.7±119.5	<0.05	22839.0±5174.7	<0.05
	Female	19	6452.6±1094.7		1868.4±273.7		4647.2±106.6		10794.7±2046.7	
Age	18-30	24	5837.5±461.9	>0.05	1795.8±114.6	>0.05	2416.6±412.7	<0.05	10050.0±816.9	<0.05
	31-45	22	9550.0±110.7		3159.0±340.6		6772.7±661.1		19072.7±1720.2	
	>45	14	21542.8±4882.5		3578.5±240.8		9214.2±980.7		34335.7±5134.1	
Socio economic status	I	12	10466.6±5483.4	>0.05	3350.0±157.7	>0.05	15166.6±1004.5	>0.05	28983.3±5312.6	>0.05
	II	9	25933.3±6170.2		3322.2±441.4		4777.8±615.9		34033.3±655.6	
	III	33	7712.2±945.6		2169.7±163.8		2848.4±308.3		12739.3±126.6	
	IV	6	6333.3±553.0		3500±432.4		2833.3±172.2		11166.6±693.7	
HIV status	Negative	27	7718.5±594.5	>0.05	2570.3±153.6	>0.05	4148.1±410.1	>0.05	14437.0±896.9	>0.05
	Positive	14	22914.2±4969.8		4007.1±433.9		7071.4±823.8		33350.0±5325.8	
	Unknown	19	6452.5±578.5		1957.8±155.2		6578.9±940.6		14989.4±1588.8	

Continued.

Variables			Medical expenses Rupee± SD	P value	Non-Medical Expense Rupee±SD	P value	Indirect cost Rupee± SD	P value	Total Cost Rupee± SD	P value
Presumptive site of infection	Lympha-denitis	30	6003.3± 508.3	>0.05	1950.0± 137.4	<0.05	4300.0± 611.4	>0.05	12253.3± 1101.9	>0.05
	Pleuritis	23	16613.0± 3836.8		3730.4± 341.5		7521.7± 874.3		27473.9± 414.5	
	Other sites	7	12800.0± 1666.1		2628.5± 229.8		4857.1± 429.8		20285.0± 2186.6	

Diagnostic delay and associated factors

The patient, health system and total delays observed in TB patients are described according to different variables in Table 2. The mean patient delay was 38.07 days. Patients with HIV showed significantly lesser patient delay (18.7±2.1 days) compared to HIV negative status (45.1±4.1 days). Patients with TB lymphadenitis reported a significantly longer patient delay (49.4±3.6 days) compared to patients with other sites of TB disease. The mean health system delay among TB patients was 26.6±2.4 days. The mean total delay among TB patients was 64.7±4.3 days, significantly longer total delay was seen in female sex (total delay of 75.1±9.1 days), 18-30 years age group (total delay of 74.5±5.1 days), higher socio-economic status and site of infection being the lymph nodes (total delay of 79.5±4.6 days). Significantly lesser total delay was seen in HIV positive patients.

Overall medical, non-medical, indirect cost and total cost

The mean medical cost was Rs. 10863.3±248.0, non-medical cost Rs. 2711.1±255.2, indirect cost Rs. 5600.0±715.0 and total cost being Rs. 19025.0±2829.3. There was statistically significant difference in various cost and medical cost was statistically higher than other costs (p<0.05).

All the four out of pocket expenditure were significantly higher among male (Rs. 22,839.0±5,174.7) than female patients. With respect to age, it is seen that there is statistically higher expenditure in indirect and total cost among elderly patients with age group more than 45 (Rs. 34335.7±5134.1). Non-medical cost was significantly higher in patients with pleuritis (Rs.3730.4±341.5) or other site of involvement

Health care seeking behaviour

The distribution of health care seeking behaviour of EPTB patients is mentioned in (Table 4). All the study participants did self-care before start of the treatment, 73.3% participants first contact to the health care providers (HCP) were from private sectors, nearest health care providers were less than 5 km in 41.7% patients, 56.7% patients visited 2 or less than 2 different HCP and 88.3% patients visited HCP more than 3 times.

Table 4: Health seeking behaviour of study participants.

Variables	N (%)
Self care before start of treatment	
Yes	60 (100)
No	0 (0)
First HCP visited	
Private	44 (73.3)
Public	16 (26.7)
Distance to nearest HCP	
<5	25 (41.7)
5-10	21 (35.0)
>10	14 (23.3)
Antibiotics given in first visit	
Yes	29 (48.3)
No	31 (51.7)
Number of different HCP visited	
≤2	34 (56.7)
>2	26 (43.3)
Number of visits to HCP	
≤3	7 (11.7)
>3	53 (88.3)

DISCUSSION

In this study the results indicate that Many EPTB patients, presenting to DOTS center, experience a long delay in the initiation of treatment, which include patient delay of 38.07 days particularly patients with TB lymphadenitis reported a significantly longer patient delay compared to patients with other sites of TB disease, along with this mean health system delay among TB patients was 26.6 days which adds up to 64.7 days of total delay from day of first symptom to initiation treatment. These findings are similar to study conducted by Melissa Davidsen et al Showed the median total delays were 62 days.[10]

This delay may be due to lack of awareness in public regarding extra pulmonary tuberculosis and non-specific clinical presentation which simulate other medical conditions, which contributes towards delay in diagnosis, this delay in diagnosis directly increases the economic burden on the patient and his family. Our study showed that the mean total cost being Rs. 19,025±2,829 which is greater than the study conducted in Chennai by Ramya et

al found that the overall estimated total costs incurred right from the onset of symptoms until treatment completion were found to be Rs. 3,211.[11]

Tuberculosis is the leading cause of death among HIV infected individuals. There is 16-27 times greater risk of contracting TB in people living with HIV than among those without HIV infection.[12] Patients who had previously diagnosed with HIV showed significantly lesser patient delay compared to HIV negative patients, this may be due to increased health concerns and awareness regarding TB as a coinfection.

Lack of awareness regarding signs and symptoms of extra pulmonary tuberculosis among the general population is the main cause of the patient delay. This can be decreased by conduction public awareness programs, multimedia advertisements, awareness campaign etc. limitation of our study is simple size, higher sample size would provide better statistical significance.

CONCLUSION

As EPTB presents with atypical symptoms, it gets too difficult to make an early diagnosis and it is important to know how different factors play a role in the delay. The evidence from the study is clear that the delay was more than the mean delay in female sex, 18-30 years age group, HIV negative status, EPTB site being TB lymphadenitis. Statistically higher out of pocket expenditure was seen in the males and elderly age group. All of the participants opted self-care followed by majority of them contacting the health care providers. The study indicates that the delay in the diagnosis is due to the patient delay to reach out for care which is mainly due to lack of awareness regarding the disease and its presentations which ultimately leads to increase in the economic burden on the patient.

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