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## RESEARCH ARTICLE

### PERCEPTION REGARDING TREATMENT AMONG PARENTS/GUARDIANS OF PEDIATRIC TB PATIENTS IN DELHI

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#### ABSTRACT

**Introduction:** Tuberculosis is a major health problem in many countries. In India, TB kills 14 times more people than all tropical diseases combined, 21 times more than malaria and 400 times more than leprosy. TB has become a major barrier to social and economic development. The objective of the study was to study the perception regarding the treatment under revised national tuberculosis control programme among parents/guardians of pediatric tuberculosis patients.

**Material and Methods:** We conducted cross-sectional study during January 2014 to October 2014. Out of 10 RNTCP zones of Delhi state, two zones namely south zone and south west zone were selected by convenient sampling method and all pediatric tuberculosis patients who were declared as cured or treatment completed at these two zones had been selected by complete enumeration method. Parents/guardians of these study subjects were interviewed for the perception regarding the treatment of their children under RNTCP.

**Results:** Out of 462 informants, Only 105(22.7%) informants were aware about correct cause of TB i.e. Germ. Majority 145(31.9%) were not having any idea about mode of transmission of TB. About 432(93.5%) informants were aware about TB is curable and 420(90.9%) correctly said that TB is preventable disease.

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## INTRODUCTION

Tuberculosis (TB) is an infectious disease caused by *Mycobacterium tuberculosis*, and rarely by other organism of tuberculosis complex (Central TB Division 2005). Tuberculosis, one of the oldest disease known to affect human, is a major cause of death worldwide (Raviglione and O'Brien, 2008) Globally, out of 9 million cases, about 1 million cases (11%) occur in children (under 14 year of age) every year with more than 1, 00,000 deaths. In India, TB kills 14 times more people than all tropical diseases combined, 21 times more than malaria and 400 times more than leprosy. TB has become a major barrier to social and economic development. (Central TB Division 2012) Infected children represent the pool from which a large proportion of future cases of adult TB will arise. In addition, childhood TB is a sentinel event, indicating ongoing transmission of TB within communities. (Walls and Shingadia, 2004) Childhood TB is a neglected aspect of the TB epidemic. This "Orphan disease" exists in the shadow of adult TB and is

significant child health problem, but is neglected. (Donald, 2007) Therefore, it is necessary that parents should be aware about etiology, transmission and treatment of tuberculosis. The Revised National Tuberculosis Control Programme (RNTCP) depends on the patients passive reporting of the chest symptomatic to the health institutions. Thus, it is necessary that people in community should have information regarding tuberculosis cause, transmission and treatment facilities available under RNTCP. Therefore, RNTCP conducts wide spread IEC campaign to spread awareness regarding tuberculosis and treatment facilities available under it. It is important that the basic information about the disease and the availability of treatment reaches clearly to the individuals in a community. Equally important is to learn about unhealthy practices so that appropriate remedial steps can be implemented. The present study was undertaken in Delhi with the objective of assessing perception among the parents of tuberculosis affected children.

## MATERIALS AND METHODS

**Study Design:** A community based cross-sectional study.

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**Study Period:** January 2014 to October 2014.

**Study Area:** Delhi state is the capital of India. It is located 28° N Latitude and 77° E Longitude. It has a population of 16 million (census 2011) with 10 RNTCP zones, 26 chest clinics, 42 tuberculosis units, 196 Designated Microscopic Centres (DMC). DMCs are located in Municipal hospitals, Government hospitals and Medical colleges. This study was conducted in coverage area of four chest clinics of south and south west zones of Delhi. There are 2 chest clinics in each zone. South Delhi Zone has three tuberculosis units (TU) catering for 15 lakh population (1 TU at Malviya Nagar chest clinic and 2 TU at Nehru Nagar chest clinic). South West Zone has three tuberculosis units (2 TU at LRS chest clinic and 1 at RTRM chest clinic) catering for 15 lakh population. Tuberculosis units are having DOTS Centres under them.

**Study Methodology:** The permission for conducting the study was sought from State TB Officer (STO), Delhi state. TB register present at tuberculosis unit was used to collect details of pediatric tuberculosis patients who has completed the treatment. They were traced on given address. The parents or guardians of all the study subjects were also informed about the study and the consent for the same was taken. Parents or guardians of pediatric tuberculosis patients were interviewed about socio-demographic profile, perception regarding Tuberculosis and its treatment using a pre-structured, semi-open ended questionnaire.

#### **Inclusion Criteria:**

- Parents/guardians of pediatric tuberculosis patients who gave consent.

#### **Exclusion Criteria:**

- Patients who can't be traced out even after 3 tracing attempts.
- Patients who have migrated.
- MDR-TB patients.

#### **Sample Size**

Out of 10 RNTCP zones two zones namely South zone and South West zone are selected by convenient sampling method. All tuberculosis units in four chest clinics under south zone and south west zone (3 TU in each zone) have been taken for the study. By complete enumeration method all pediatric tuberculosis patients who were declared as cured or treatment completed, registered at six tuberculosis units have been selected. We got 84 pediatric TB patients meeting the inclusion criteria from Malviya nagar chest clinics, 180 pediatric TB patients from Nehru nagar chest clinics, 186 pediatric TB patients from LRS chest clinic and 72 pediatric TB patients from RTRM chest clinic. Total 522 study subjects were selected from these four chest clinics. We visited parents/guardians of these 522 pediatric TB patients on their given address. We met parents/guardians of 465 pediatric TB patients and 57 parents of pediatric TB patients were not available on given address. Out of 465 study subjects, 3 study

participant's parent not given consent. Thus, data was collected from 462 parents/guardians out of 522 parents/guardians.

**Ethical Consideration:** Informed written consent was taken from parents or guardians and the personal information was kept strictly confidential. Study protocol was approved from Institution Ethics Committee of VMMC and Safdarjung hospital, New Delhi. Administrative approval was obtained from State TB Officer (STO) of Delhi state.

**Data Analysis and Statistical Methods:** Data Entry was done on Microsoft Excel 2013 spread-sheet. IBM SPSS v20 statistical software was used for data analysis. Descriptive analysis was done (mean, proportion and percentages) for socio-demographic data. Categorical variables were compared using chi-square test and Fisher's exact test.  $P < 0.05$  was considered as statistically significant value.

## **RESULTS**

### **Demographic Data**

A total of 462 informants were studied among which 281(60.8%) were females and 181 (39.2%) were males with male-female ratio of 0.6: 1. The present study revealed that 347 (75.1%) of informants were Hindus, 78(16.9%) were Muslims, 23(5%) were Sikhs and 14 (3%) were Christians. The majority of informants 405 (87.7%) lived in nuclear family. (Table 1)

### **Socio-economic Status**

The socio-economic status was measured using revised Kuppuswamy classification 2012. In this study majority of the informants 207(44.8%) belonged to upper-lower class followed by lower-middle class 184(39.8%). Only 5(1.1%) study participants belonged to upper class. (Figure 1)

### **Perception of cause and transmission of TB**

We studied the perception regarding TB treatment among the parents/ guardians (informants) of 462 pediatric tuberculosis patients. Only 105(22.7%) informants were aware about correct cause of TB i.e. Germ. One forty five (31.9%) were not aware about any cause of tuberculosis. One sixty five (35.7%) informants reported correct mode of transmission of TB, majority 145(31.9%) were not having any idea about mode of transmission of TB. (Table 2)

### **Perception of symptoms of TB**

Among the 462 informants, majority 310 (67.1%) informants reported persistent cough as symptom of TB, followed by fever 290 (62.8%). One seventy nine (38.8%) reported swelling of lymph node as symptom of TB. Among 310 (67.1%) informants who reported persistent cough, more than half 174(56.1%) were aware about correct duration of persistent cough. (Table 3)

### **Perception of Cure and Prevention of TB**

Among 462 informants, 432(93.5%) aware about TB is curable and 420(90.9%) correctly said that TB is preventable disease. only 190(41.1%) informants were aware about correct method of keeping TB patient non-infectious to other. Majority of informants 310(67.1%) said isolation of patient for keeping patient non-infectious to other. (Table 4)

### Preference for treatment of TB

Majority of informants 409(88.5%) gave preference to DOTS centre for treatment of TB. Most common reason according to 385(94.1%) informants for choosing DOTS centre was more effective and more trusted treatment than private clinic. Fifty three 53(11.5%) informants chosen private clinic for the reason of short waiting period and being more sympathetic than DOTS centre. (Table 5) Among the 462 informants, majority 450(97.4%) said that treatment of TB essential and 430(93.1%) informants perceived that Completion of whole course of treatment is essential. Two seventy three (59.1%) informants were aware about re-occurrence of TB after successful treatment and 362(78.4%) were aware about harmfulness of leaving treatment in between. only 77(16.7%) informants were aware about the adverse-effects of DOTS. The most common adverse effect reported by informants was nausea or vomiting 12(70.4%) followed by skin rash 7(43.2%). (Table 6)

### Factors associated with Perception

We analysed the perception of informants with socio-economic class using chi-square test. High proportion of upper socio-economic class were aware that leaving TB treatment in-between is harmful and re-occurrence is possible after successful treatment completion. The difference was statistically significant ( $p$ -value < 0.05). (Table 7)

**Table 1. Distribution of informants according to basic demographic profile (n=462)**

Variable	No. (%)
<b>Gender</b>	Male 181 (39.2)
	Female 281 (60.8)
	Hindu 347 (75.1)
<b>Religion</b>	Muslim 78 (16.9)
	Sikh 23 (5.0)
	Christian 14 (3.0)
<b>Type of family</b>	Nuclear 405 (87.7)
	Joint 57 (12.3)

**Table 2. Distribution of informants according to perception of cause and transmission of TB (n=462)**

Perception	No. (%)
<b>Cause of TB</b>	Germ 105(22.7)
	Unhealthy food 47(10.2)
	Weakness 88(19.1)
	Unhygienic condition 68(14.7)
	Other 8(1.7)
	Don't know 145(31.9)
<b>Transmission of TB</b>	by air 165(35.7)
	by food 17(3.7)
	by water 53(11.5)
	don't know 223(48.3)

**Table 3. Distribution of informants according to perception of symptoms of TB (n=462)**

Perception	No. (%)
<b>Symptoms of TB*</b>	persistent cough 310 (67.1)
	loss appetite 250 (54.1)
	loss weight 197 (42.6)
	fever 290 (62.8)
	tiredness 54 (11.7)
	breathlessness 69 (14.4)
	haemoptysis 56 (12.12)
	swelling of lymph node 179 (38.8)
	pain in abdomen 65 (14.1)
	other 19 (4.1)
	> 1 week 114 (36.8)
<b>Duration of persistent cough (n=310)</b>	> 2 week 174 (56.1)
	>3 week 80 (25.8)
	>1 month 34 (10.9)
	Other 7 (2.2)

\*multiple response

**Table 4. Distribution of informants according to perception regarding cure and prevention of TB (n=462)**

Perception	No. (%)
<b>TB is curable disease</b>	Yes 432(93.5)
	No 24(5.2)
	Don't know 6(1.3)
<b>TB is preventable disease</b>	Yes 420(90.9)
	No 10(2.2)
	Don't know 32(6.9)
<b>How TB patients can be kept non-infectious to other*</b>	Covering mouth during coughing 190(41.1)
	Proper disposal of sputum 50(10.8)
	Isolation of patient 269(58.2)
	Avoid sharing of food 310(67.1)
	Other 210(45.5)
	Don't know 50(10.8)

\*multiple response

**Table 5. Distribution of informants according to preference for treatment of TB**

Perception	No. (%)
<b>Preference for TB treatment (n=462)</b>	Private clinic 53(11.5)
	DOTS centre 409(88.5)
<b>Reason for choosing private clinic* (n=53)</b>	more sympathetic 40 (75.5)
	convenient location 10 (18.9)
	short waiting period 45 (84.9)
	more effective and more trusted treatment than dots centre other 10 (18.9)
<b>Reason for choosing DOTS centre*n=409</b>	more sympathetic 66(16.1)
	convenient location 33(8.1)
	free investigation and treatment 278(68)
	more effective and more trusted treatment than private clinic 385(94.1)
	short waiting period 3(0.7)

\*multiple response

**Table 6. Distribution of informants according to perception regarding treatment of TB. (n=462)**

Perception	No. (%)
<b>Treatment of TB is essential after diagnosis of TB</b>	Yes 450(97.4)
	No 0(0)
	Don't know 12(2.6)
<b>Completion of whole course of treatment is essential</b>	Yes 430(93.1)
	No 5(1.1)
<b>Re-occurrence of TB possible after cure/treatment completion</b>	Don't know 27(5.8)
	Yes 273(59.1)
	No 97(20.9)
<b>Leaving treatment of TB in-between is harmful</b>	Don't know 92(19.9)
	Yes 362(78.4)
	No 13(2.8)
<b>Are there any adverse effect of medicines given under DOTS</b>	Don't know 87(88.8)
	Yes 77(16.7)
	No 385(83.3)

**Table 7. Distribution of informants according to association between socio-economic class and perception regarding tuberculosis treatment**

Variable		Socio-economic class			Total	p-value
		Upper no (%)	Middle no (%)	Lower no (%)		
Adverse effect	Yes	13(16.9%)	35(45.5%)	29(37.6%)	77 (100%)	0.118
	No	44 (11.4%)	149(38.7%)	192(49.9%)	385(100%)	
Curable	Yes	55(12.7%)	172(39.8%)	205(47.5%)	432(100%)	0.945
	No	2(8.3%)	10(41.7%)	12(50%)	24(100%)	
	Don't know	0 (0.0%)	2 (33.3%)	4(66.7%)	6(100%)	
Leaving treatment in between is harmful	yes	51(14.1%)	156(43.1%)	155(42.8%)	362(100%)	0.00
	No	2(16.7%)	3(25.0%)	7(58.3%)	12(100%)	
	Don't know	3(3.4%)	25(28.7%)	59(67.8%)	87(100%)	
Re-occurrence possible	Yes	41(15.0%)	120(43.9%)	112(41.0%)	273(100%)	0.002
	No	16(8.5%)	64(34.0%)	108(57.4%)	188(100%)	

## DISCUSSION

### Socio-economic Status

In present study 221(48%) of the informants belonged to low socioeconomic status and 236(51.1%) belonged to middle class and 5(1.1%) belonged to high class. Nearly Similar finding seen in study by Sushmabhai S *et al*<sup>6</sup> in Kottayam district of Kerala slightly more than half (51.8%) belonged to low, 46.2% to middle and 2% to high socio-economic groups.

### Perception of cause and transmission of TB

We studied the perception regarding TB treatment among 462 informants. The present study reported that only 105(22.7%) informants were aware about correct cause of TB i.e. Infection. One forty-five (31.9%) were not aware about any cause of tuberculosis. One sixty five (35.7%) informants reported correct mode of transmission of TB, majority 145(31.9%) were not having any idea about mode of transmission of TB. Similar findings were seen in study by Palash das *et al.* (Das *et al.*, 2012) in April 2011 at west Bengal on Perception of tuberculosis among general patients of tertiary care hospitals of Bengal. Correct answer on cause (infection) was responded by 16.8% patients. The correct response on mode of spread of TB was told by 31.5% patients. Our study reported little high values because our study was done in an urban area of Delhi city where literacy rate is more than Bengal. 82.8% knew about curability of the disease. Khalid *et al.* (2012) observed similar finding in the study on awareness regarding tuberculosis among the patients attending general dispensaries in South Delhi. In this study, only 18% were aware that tuberculosis is caused by an infectious agent, 58% of participants were of the opinion that one gets tuberculosis from air.

### Perception of Symptoms of TB

In the present study, majority 310(67.1%) reported persistent cough as symptom of TB, followed by fever 290(62.8%) and 250 (54.1%) reported loss of appetite. More than half 174(56.1%) were aware about correct duration of persistent cough. In study by Khalid *et al.* (2008), (Khalid *et al.*, 2012) 69.2% participants were aware about the correct symptom with duration i.e. cough >3weeks. Palash das *et al.* (2011) (Das *et al.*, 2012) reported that about 62.1% correctly answered that cough as the commonest symptom of tuberculosis in their study. A cross sectional study done by Khalil *et al.* (2011) of knowledge and awareness regarding pulmonary tuberculosis in

2010 at AMU, Aligarh (U.P) also reported that majority of the patients were aware regarding symptoms of tuberculosis. Cough with sputum 66 (75.0%) was the commonest symptom known, followed by weight loss 48 (54.5%), fever 42 (47.8%), weakness and breathlessness 34 (38.6%), anorexia 32 (36.4%), haemoptysis 28 (31.8%) and chest pain 5 (5.7%). About 17 (19.3%) patients were not aware about any symptom of tuberculosis. The awareness of symptoms was higher in mentioned study because it was hospital study.

### Perception of Cure and Prevention of TB

The present study revealed that, majority 432(93.5%) informants were aware about TB is curable and 420(90.9%) correctly said that TB is preventable disease. Only 190(41.1%) informants were aware about covering of mouth during coughing for keeping TB patient non-infectious to other. Similar finding was seen in study done by Sharma N *et al*<sup>10</sup> on Awareness and Perception about Tuberculosis in the General Population of Delhi in 2003 among the general population of Delhi. About 95.1% of the respondents indicated that TB is curable. Nearly 92.2% perceived Tuberculosis to be a preventable disease. In the study done by Khalil *et al.* (2011), Majority of the patients 84(95.5%) believed that tuberculosis is curable and 34(37.2%) stated that covering of mouth during coughing can prevent the transmission of TB to others.

### Preference for treatment of TB

Majority of informants 409(88.5%) gave preference to DOTS center for treatment of TB. Most common reason according to 385(94.1%) informants for choosing DOTS center was more effective and more trusted treatment than private clinic. In study at LRS hospital by Khalid *et al* (2008), (Khalid *et al.*, 2012) 95.1% patients preferred DOTS center for treatment. This difference in finding can be explained by the fact that mentioned study was conducted in patients of tertiary hospital.

### Perception of treatment of TB

Among the 462 informants, majority 450(97.4%) said that treatment of TB essential and 430(93.1%) informants perceived that Completion of whole course of treatment is essential. Three sixty two (78.4%) were aware about harmfulness of leaving treatment in between and most common harmfulness was death. only 77(16.7%) informants were aware about the adverse-effects of DOTS. In study done

in Delhi among general population on Awareness and Perception about Tuberculosis by Sharma *et al.* (2007), 90.1% participants perceived that DOTS course completion is essential and 12.7% participants were aware about the adverse-effects of DOTS. The difference in finding of our study and mentioned study may be because of our study was done parents/guardians of TB patients.

### Conclusion

This study concludes that awareness regarding cause and transmission of tuberculosis is still low among the parents/guardians of pediatric TB patients. Majority of informants were aware about the tuberculosis is preventable and curable disease. This study revealed that treatment at DOTS centers under RNTCP is trustworthy and more effective than private clinic's treatment. Upper socio-economic class informants are having good perception and knowledge regarding tuberculosis and its treatment.

### Recommendations

Collaboration with NGOs has to be encouraged for outreach activities which would increase awareness regarding the cause, transmission and treatment of TB among lower socio-economic class people. Promotion of IEC activities in field area of chest clinics for increasing the public awareness regarding facilities available under RNTCP and its benefits.

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