

Original Research Article

Study of Awareness of Caregivers about Tuberculosis Treatment and its Compliance

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Abstract:

Background: It is estimated that one third of the world's population is infected with Mycobacterium tuberculosis (the bacterium which causes tuberculosis). In 2017, TB caused an estimated 1.3 million deaths (range, 1.2–1.4 million) among HIV-negative people and there were an additional 300 000 deaths from TB (range, 266 000–335 000) among HIV-positive people.

Objectives: To study awareness of caregivers about tuberculosis treatment and its compliance.

Methods: A Cross-sectional study was conducted among 150 patients of paediatric tuberculosis which included the age group of 0-14 years attending various DOTS centres and some private clinics/hospitals of Lucknow district. All the major tuberculosis centres of Lucknow district were included in the study. Questionnaire was pretested on 10 percent of the calculated sample size at the DOTS centre at KGMU and later modified on the basis of the inputs obtained while pretesting.

Results: Friends and relatives were the major source of knowledge about tuberculosis. While most (77%) of the participants knew that TB is a communicable disease, 7.5% believed that there is a supernatural cause for the disease. Out of 59% participants who knew about mode of diagnosis, most knew of X ray as the mode of diagnosis, while only 34% knew of Sputum examination. Nearly 72% believed that TB is curable. 59 percent knew that TB has a relation with nutritional status. 68% of caregivers had poor or average knowledge and awareness score (≤ 9) about tuberculosis. Most (75.3%) showed a high score in Morisky medication adherence scale.

Conclusion: Most of the participants knew that TB is a communicable disease, this shows that common public is aware about the communicability of the disease. And 72% believed that TB is curable, which shows that common public is aware about curability of the disease.

Keywords: Awareness of caregivers about Tuberculosis, Medication adherence in Tuberculosis

1. INTRODUCTION

It is estimated that one third of the world's population is infected with Mycobacterium tuberculosis (the bacterium which causes tuberculosis). In 2017, TB caused an estimated 1.3 million deaths (range, 1.2–1.4 million)¹ among HIV-negative people and there were an additional 300 000 deaths from TB (range, 266 000–335 000) among HIV-positive people. Globally, the best estimate is that 10.0 million people (range, 9.0–11.1 million) developed TB disease in 2017: 5.8 million men, 3.2 million women and 1.0 million children. There were cases in all countries and age groups, but overall 90% were adults (aged ≥ 15 years), 9% were people living with HIV (72% in Africa) and two thirds were in eight countries, with 27% cases in India.²

India accounts for one fourth of global TB burden. In 2017, an estimated 27 lakh cases occurred and 4-8 lakh people died due to TB. About 40% percent of India's population is under 15 years of age.² Although childhood tuberculosis in India is estimated to be approximately 10 percent of total incidence, only 6 percent of total cases reported to Revised National Tuberculosis Control Programme (RNTCP)³. Globally, children accounted for only 6.9% of the new cases that were notified in 2016.⁴ Under and delayed diagnoses of TB in children remains an obstacle to effective management of childhood TB due to which cases often remain under reported. In high TB burden settings, it is estimated that childhood TB contributes to 15–20% of all TB cases and is one of the leading causes of childhood mortality.⁵

Considering the global presence of the disease, affecting all age groups, involving almost all the organs of the body, affecting marginalized and poverty stricken areas of society, changing disease patterns and drug sensitivity, it calls for the highest level of joint collaboration.

Objectives

1. To study awareness of caregivers about tuberculosis treatment and its compliance.

2. MATERIALS AND METHODS

Study Area –DOTS Centres of Lucknow District under RNTCP Programme.

Study Setting –District Tuberculosis Centre Rajendranagar, DOTS centre at KGMU, DOTS Centre at Dr Shyama Prasad Mukherjee civil hospital and DOTS Centre at Government Hospital Thakurganj.

Study Population- Patients of Paediatric tuberculosis which includes the age group of 0-14 years as defined by RNTCP programme.

Study Units- Diagnosed cases of Paediatric tuberculosis attending various DOTS centres and some private clinics/hospitals of Lucknow district.

Sample Size- For this study required sample size was calculated using following formula

where,

$$n = [(z_{1-\alpha/2})^2 \times p \times (100-p)]/d^2 \quad \text{(Daniel WW, 1999)}$$

n = sample size

z = value of two tailed alpha error

p = prevalence of paediatric tuberculosis

d= allowable error

According to study of **Tenali R et. al. (2018)**⁶ which was conducted in a tertiary care, centre proportion of cases in age group of 5-9 years was 49% which was highest comparing to other age group falling in paediatric tuberculosis age group (0-14 years) hence taking the value of p 49%

To calculate the sample size based on the prevalence with an approximate 99% confidence level, we can use the following formula:

$$n=z^2 \times p \times (100-p)/d^2$$

proportion – Estimation	
Proportion (p)	49.00%
Absolute error	08.50%
Significance level (α)	0.05
Sample size	133

where,

z= 1.96 at 95% confidence interval

P= 49%

L=Absolute error = 8.5%

$$n = (1.96 \times 1.96) \times 49 \times (100-49)/8.5 \times 8.5 \\ = 9600/72.75$$

n= **133** paediatric tuberculosis cases

As minimum sample size according to above formula was **133** for this study but we were able to collect data of **150** cases during the study period.

Sampling Technique

It was a Cross-sectional study in which all the major tuberculosis centres of Lucknow district were included in the study.

- District Tuberculosis Centre, Rajendranagar
- DOTS, KGMU
- Dr Shyama Prasad Mukherjee Civil Hospital and
- Government Hospital Thakurganj

In the start of the study i.e. from 1st of January 2019 cases registered in the previous month were taken, and study days were divided according to the number of patients enrolled in the previous month (as of here its December), and also considering convenience of the patient. Only those cases were taken for further sessions who fits into the inclusion and exclusion criteria.

Similar pattern was followed for the coming months, like in February data of newly enrolled patient in January was taken and study days were planned accordingly. Same sequence was followed for the coming months of data collection period, which was till 30th June. Thus, the latest data available for the study was of May, 2019.

Total number of newly enrolled patient obtained as per the data base from December 2018 to May 2019 were around 350. Out of which, 150 cases were taken for the study as per the inclusion and exclusion criterion.

Sampling frame

All the paediatric tuberculosis patients registered as per the main database of DTC Rajendranagar uptill 31st of May 2019.

All patients registered in selected DOTS centre, fulfilling the inclusion criteria will be taken.

Selection Criteria of Cases

Inclusion Criteria –

Children in age group of 0-14 years diagnosed as TB and registered under Nikshay Portal
Those children whose parents were willing to participate in the study with informed consent.

Exclusion Criteria –

Those children whose parents were not willing to participate in study. Those children who were defaulters

Pretesting of the Interview Schedule -

Questionnaire was pretested on 13 (10 percent of the calculated sample size) patients at the DOTS centre at KGMU and later modified on the basis of the inputs obtained while pretesting.

Data Collection Procedure

Information of the cases had been obtained from the District Tuberculosis Centre, Rajendranagar which maintains the database of the patients of tuberculosis. Along with those, DOTS centres and DOTS providers were also contacted, to provide information about the cases and to arrange visits with the patient and their principal caregiver. During visit to the patient their principle caregivers were asked certain set of information in an interview based session using a predesigned and pretested schedule. Following the interview session anthropometric detail, clinical history, treatment and investigation details was taken from clinical records/treatment card of the patient. To check the authenticity of the clinical records,

similar questions as mentioned in the records were also asked in the interview session.

Data Analysis

Data has been expressed in form of frequency and percentages of variables.

Data collected was analysed using SPSS 23.0.

3. RESULTS

Table 1. Knowledge Awareness Regarding Tuberculosis Disease and Symptoms

	Frequency(n=100)	Percentage (%)
Source of Information (Multiple Response Type)		
Television	66	44.0%
Radio	53	35.3%
Newspaper	21	14.0%
Friends or relative	112	74.6%
After the child got disease	15	10.0%
Others	09	6.0%
Disease type		
Communicable	115	77.6%
Non-communicable	19	12.6%
Genetic of hereditary	05	3.3%
Supernatural cause	11	7.3%
Mode of spread (Multiple Response)		
Touching or contact	38	25.3%
Infected water of food	36	24.0%
Airborne	98	65.3%
Don't know	30	20.0%
Caused By Germs		
Yes	63	42.0%
No	51	34.0%
Don't Know	36	24%
Symptoms of TB (Multiple Response)		
Knows	130	86.6%
-Cough (≥ 14 days)	112	74.6%
-Weight loss	62	41.3%
-Loss of appetite	26	17.3%
-Fever (≥ 14 Days)	102	68.0%
-Other	03	2.0%
Don't know	20	13.3%
Organs affected from Tuberculosis(Other than Lung)		
Knows	58	38.6%
- Bone/Joints	33	22.0%
-Abdomen	34	22.6%
- Gland	45	30.0%
-Brain	05	3.3%
Don't Know	92	61.3%

Table 1 shows that friends and relatives were the major (75%) source of knowledge about tuberculosis, followed by television (44%) and radio (35%).

While most (77%) of the participants knew that TB is a communicable disease, 7.5% believed that there is a supernatural cause for the disease.

Less than half (46.2%) believed that the disease was airborne, 25.8% thought of it to be spread by consuming infected food or water and 16.1% did not know about the mode of spread at all.

Out of the participants who knew about symptoms of TB (87%), 75% responded as cough for more than two weeks as a symptom of TB, followed by Fever for more than two weeks and Weight loss, responded by 68% and 41% participants respectively.

Table 2. Knowledge and Awareness regarding diagnosis and Treatment of Tuberculosis

Mode of Diagnosis (Multiple Response)		
Knows	88	58.6%
Sputum	34	22.6%
Blood	16	10.6%
X-ray	61	40.6%
Others	05	3.3%
Don't Know	62	41.3%
Treatment Effectiveness		
Curable	72	72.0%
Curable but can recur	15	15.0%
Don't Know/Can't Say	13	13.0%
Treatment duration		
2-5 month	02	2.1
6 month	62	66
9-12 months	10	7.4
According to type of TB	08	8.5
Don't know	18	16
Effect Of Stopping Treatment		
A worse form of disease may occur	65	43.3%
Symptoms or disease may reappear	40	26.6%
Treatment will start from beginning	31	20.6%
Nothing will happen	02	1.3%
Don't Know	12	8.0%

Out of 59% participants who knew about mode of diagnosis, most knew of X ray as the mode of diagnosis, while only 34% knew of Sputum examination.

Nearly 72% believed that TB is curable and around 66% knew that the duration of treatment of TB is 6 months. 8.5% of participants knew that the duration varies with the type of TB.

Table 3. Knowledge and Awareness Regarding Preventive Factors of Tuberculosis

Vaccine Preventable		
Yes	33	22.0%
No	84	56.0%
don't know	42	28.0%
Name of Vaccine		
BCG	14	42.4%
Don't Know	19	57.5%
Relation of TB with nutritional status		
Yes	89	59.3%
No	36	24.0%
Don't Know	26	17.3%
TB-Malnutrition Relation		
Malnutrition Risk Factor For TB	08	5.3%
TB causes Malnutrition	06	4.0%
Improved Nutrition hastens healing	75	84.2%
Don't Know	23	25.8%
Repeat Investigations		
2 months	05	5.3%
6 months	29	30.9%
2 and 6 months	08	8.5%
Others	05	5.3%
Don't Know	47	50%

Fifty six percent of participants did not believe that TB is a vaccine preventable disease and 59 percent knew that TB has a relation with nutritional status. About repeating the investigation, most of them (30.9%) believed that it should be done after six months of taking treatment while 8.5 percent knew that it should be done at the end of 2nd and 6th month of treatment intake.

Table 4. Distribution of Caregivers according to Grading Score of their Knowledge and Awareness

Score Grade	Frequency	Percentage
Good(≥10)	48	32
Average(6-9)	53	35
Poor(≤5)	49	33

Table shows that about 68% of caregivers had poor or average knowledge and awareness score (≤9) about tuberculosis.

Table 5. Medication adherence among Cases

Score#	Number	Percentage
High (Score8)	113	75.3%
Medium (Score 6-7)	36	24%
Low (< 6)	1	0.7%

As per the calculated scores of 8 point modified MORISKY scale
Most (75.3%) showed a high score in Morrisky medication adherence scale.
Nearly a quarter (24%) of studied patients had a medium score. A small proportion of 0.7 percent constituting only one participant showed a low score.

4. DISCUSSION

Though multiple studies have been conducted in India on knowledge of adult tuberculosis patients about the disease symptoms and management, not much work has been done to assess the knowledge of caregivers of tuberculosis patients in pediatric age group. In a similar study conducted on adult patients with respiratory symptoms and pulmonary tuberculosis cases by **Suganthi P et al**⁷ in Bangalore, it was found that, 87% of the patients knew of at least one of the four common symptoms of PTB. Only 6% knew about germs as the cause and 21% were aware that it is transmitted by air; 47% were aware of sputum examination as a reliable method for diagnosing PTB; 83% knew that TB is curable with proper treatment and most were aware of the duration of treatment and number of doses to be consumed every week. About 64% of the cases knew about the reappearance of symptoms, multidrug-resistant TB and death as the possible consequences of interrupting treatment. Only 40% were aware of cough hygiene measures to prevent the spread of TB among family members. 82% were conscious that TB is communicable, 63% were conscious of distinct methods of TB transmission, 97% were conscious of TB diseases, and 76% were conscious of TB curability.

Though this study was done on adult patients, a near similar result was obtained in our study, when the caregivers were asked questions regarding their knowledge about causation, transmission, symptoms, investigations and treatment about the disease. Out of 87 percent of participants who knew about symptoms of TB, 75% responded as cough for more than two weeks as a symptom of TB, followed by Fever for more than two weeks and Weight loss, responded by 68% and 41% participants respectively. While most (77%) of the participants knew that TB is a communicable disease, a 7.5% believed that there is a supernatural cause for the disease. Less than half (46.2%) believed that the disease was airborne, 25.8% thought of it to be spread by consuming infected food or water and 16.1% did not know about the mode of spread at all.

Samal J et al⁸ in their study reported that ninety-five percent of participants were conscious that TB is caused by bacteria, 82% were conscious that TB is communicable, 63% were conscious of distinct methods of TB transmission, 97% were conscious of TB diseases, and 76% were conscious of TB curability.

In our study out of 59% participants who knew about mode of diagnosis, most knew of X-ray as the mode of diagnosis, while only 34% knew of Sputum examination. Nearly 72% believed that TB is curable and around 66% knew that the duration of treatment of TB is 6 months. 8.5% of participants knew that the duration varies with the type of TB.

It can be noticed that the knowledge seemed to be slightly better in our study group as compared to that in the fore mentioned study, probably because the level of awareness is expected to be higher in caregivers of pediatric patients than the adult patients themselves.

Fifty six percent of participants in our study did not believe that TB is a vaccine preventable disease. **Jani Y et al**⁹ in their study reported that 32.3% caregivers of the patients knew that TB can be prevented by BCG vaccine.

Of the total respondents, 59 percent knew that TB has a relation with nutritional status. About repeating the investigation, most of them (30.9%) believed that it should be done after six months of taking treatment while 8.5 percent knew that it should be done at the end of 2nd and 6th month of treatment intake

Overall, the study showed that about 68% of caregivers had poor or average knowledge and awareness about tuberculosis, with the average score of ≤ 9 (maximum score was 13). It is unfortunate, as after a family member, especially a child, has caught the disease and the caregiver had an exposure with the health facility, the knowledge of caregivers was expected to be high. The probable cause of this low knowledge is because the study group consisted mostly of urban population, while most of the health awareness programmes in India are concentrated in rural region.

This result reflects that the DOTS providers and peripheral health workers are not trained enough to impart knowledge regarding TB in community, and hence it is suggested that an appropriate training be imparted to health care providers at root level.

Most (75.3%) of the cases scored 8 on Morisky scale categorizing them under high adherence category, Medium adherence was observed in 36(24%) cases, only one case was with Low adherence. One of the important reasons for high adherence may be the availability of child friendly formulations in Fix Dose Combinations. **Antonie M et al**¹⁰ in their hospital based retrospective cohort study observed about 25% low adherence. High adherence in our study can be explained by DOTS based treatment which ensures direct observation and high concern of parents about their children. **Yusuf KO et al**¹¹ in their study from Ethiopia reported that among all pediatrics patients 59(64.83%) of them adhered to treatment program while 27(29.67%) patient defaulted (not adhered to) the treatment program.

One important issue noticed while interviewing few caregivers was about the dosing of the medications. As FDCs are to be given according to weight bands, that will decide number of tablets and they should be given as a single dose for one day. Few caregivers were unaware of the fact that tablets should be given as a single dose and not with large spacing. Out of 87 percent of participants who knew about symptoms of TB, 75% responded as cough for more than two weeks as a symptom of TB, followed by Fever for more than two weeks and Weight loss, responded by 68% and 41% participants respectively. While most (77%) of the participants knew that TB is a communicable disease, a 7.5% believed that there is a supernatural cause for the disease. Less than half (46.2%) believed that the disease was airborne, 25.8% thought of it to be spread by consuming infected food or water and 16.1% did not know about the mode of spread at all.

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56 percent of participants in our study did not believe that TB is a vaccine preventable disease. In similar study **Jani Y et al**⁹ reported that 32.3% caregivers of the patients knew that TB can be prevented by BCG vaccine.

Of the total respondents 59 percent knew that TB has a relation with nutritional status. About repeating the investigation, most of them (30.9%) believed that it should be done after six months of taking treatment while 8.5 percent knew that it should be done at the end of 2nd and 6th month of treatment intake

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This result reflects that the DOTS providers and peripheral health workers are not trained enough to impart knowledge regarding TB in community, and hence it is suggested that an appropriate training be imparted to health care providers at root level.

Most of the cases 113 (75.3%) scored 8 on Morisky scale categorizing them under high adherence category, Medium adherence was observed in 36(24%) cases, only one case was with Low adherence. One of the important reasons for high adherence may be the availability of child friendly formulations in Fix Dose Combinations. **Antonie M et al**¹⁰ in their hospital based retrospective cohort study observed about 25% low adherence. High adherence in our study can be explained by DOTS based treatment which ensures direct observation and high concern of parents about their children. **Yusuf KO et al**¹¹ in their study from Ethiopia reported that among all pediatrics patients 59(64.83%) of them adhered to treatment program while 27(29.67%) patient defaulted (not adhered to) the treatment program.

One important issue noticed while interviewing few caregivers was about the dosing of the medications. As FDCs are to be given according to weight bands, that will decide number of tablets and they should be given as a single dose for one day. Few caregivers were unaware of the fact that tablets should be given as a single dose and not with large spacing. Large spacing may affect bioavailability and may cause treatment ineffectiveness or even resistant forms.

5. CONCLUSION

Most of the participants knew that TB is a communicable disease, this shows that common public is aware about the communicability of the disease. And 72% believed that TB is curable, which shows that common public is aware about curability of the disease. Very few participants knew about sputum examination, which shows that public needs to be educated more about modes of diagnosis of Tuberculosis. More than half of public knows that TB has a relation with nutritional status. Results showed a high score in Morisky Medication Adherence Scale, this means that people are aware about giving medications regularly to their children.

Ethical Consideration: Permission was obtained from the Institutional Ethical Committee of the King George's Medical University, Lucknow, U.P. before commencing the study.

Conflict of Interest: None

Sources of Support: Nil

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