Research Article

Understanding pediatric tuberculosis: Perspectives and experiences of the parents in a city of India

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ABSTRACT

Background: Although there have been several studies related to tuberculosis (TB) in adult, there is little published research investigating experiences in pediatric TB. **Objectives:** The objectives of our study are to explore experience of pediatric TB patients. **Materials and Methods:** A total of 11 in-depth interviews were conducted with caregivers of children below 15 years of age. The sample size was established using the information saturation criteria. Data were treated by categorizing and analyzing content with the help of Atlas Ti. **Results:** Parents mostly went to private doctors first, followed by treatment seeking at government facilities. Children and caretakers developed an emotional bond with TB health visitor (TBHV) due to the support received during their treatment. Directly observed treatment provider and patient wise boxes (PWBs) are helped the parents to feel connected during the long course of therapy. Due to stigma and discrimination associated with TB, disclosure was avoided to other. **Conclusion:** Most participants felt satisfied and connected to Revised National TB Control Program due to TBHV support and PWBs.

KEY WORDS: Pediatric; Tuberculosis; Experience; Tuberculosis Health Visitor

INTRODUCTION

Tuberculosis (TB) is an infectious disease caused by *Mycobacterium tuberculosis*. Its description has been found in the ancient Buddhist and Chinese literature.[1] TB has been still a global health problem, particularly in high-burden areas, namely, Africa, South East Asia, Eastern Mediterranean regions, and Western Pacific, with respective incidences of 280, 183, 121, and 87 cases per 100,000 population per year.[2,3]

The contribution of children to the total TB caseload is poorly documented, especially in countries with a high burden of disease, and it is mostly reported from low-burden countries.[4,5] Recently, this condition has stimulated interest since 15–20% of all TB cases are children and this figure may reach up to 40% in countries where the disease is endemic. Moreover, diagnosis of TB is particularly challenging in children.[3] The burden of TB mortality and morbidity among children (<15 years) is larger than often realized. 2017 is the 5th consecutive year in which the WHO global TB report highlights the burden of disease among children.[6]

The authors of this study presuppose eliciting TB patients' experience from start of symptoms to diagnosis and from diagnosis to completion of treatment.

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MATERIALS AND METHODS

This paper draws on the 11 in-depth interviews (IDIs) taken with pediatric TB patients and their guardian in a city of Gujarat. Ethical approval was taken before starting the study

Background of respondents

Int. number	Respondent	Education of respondent	SE status	Sex of patient	Age of patient	Clinical form	Satisfaction of the guardian
1	Father	Primary	3	Male	2	Extrapulmonary	Somewhat satisfied
2	Father	Primary	3	Male	13	Pulmonary	Neutral
3	Mother and father	Secondary	3	Female	13	Pulmonary	Somewhat satisfied
4	Aunty	Secondary	3	Male	0.9	Pulmonary	Not satisfied
5	Mother	Primary	2	Male	7	Extra-pulmonary	Completely satisfied
6	Mother and father	Primary	4	Female	14	Pulmonary	Somewhat not satisfied
7	Mother	Primary	3	Female	14	Pulmonary	Completely satisfied
8	Mother	Secondary	3	Female	13	Extra-pulmonary	Somewhat satisfied
9	Mother and father	High secondary	3	Female	14	Pulmonary	Completely satisfied
10	Mother and grandmother	Illiterate	5	Female	10	Extra-pulmonary	Completely satisfied
11	Mother	Secondary	4	Male	11	Extra-pulmonary	Completely satisfied

*Socioeconomic status recorded with the help of modified Prasad classification

from the human research Ethical Committee of Veer Narmad South Gujarat University, Surat.

Before starting the IDI, we prepared background by collecting the information about the total registered patient (331). After that, the 111 participants were randomly selected to gather the information of their experience with the help of close-ended questionnaire. This gathered information helped us in making the interview guide for the IDI of participants. While collecting information from these 111 participants, they were asked about their level of satisfaction in 5-point Likert scale ranging from 1 to 5 (where 1 shows complete dissatisfaction and 5 shows complete satisfaction). During conduction, IDI participants selected from all this scale.

IDIs were performed at home of participants or at Urban Health Center (UHC). All interviews were performed in Gujarati or Hindi language according to the understanding of participants. Recorded tapes of the interviews were translated into English and initial themes identified by the interviewer. These interviews were conducted until the saturation point came.

The focus of the interviews was experienced from the start of symptom to the final outcome of patients given in Revised National TB Control Program (RNTCP).

The analysis followed these steps: (1) Reading all material to get an overall impression; (2) identifying units of meaning that represent different factors related to their experience; (3) condensing and summarizing the content of each of the coded groups (subthemes); and (4) integrating the insights from the condensed meaning units (subthemes) into generalizes descriptions that reflect apparently the overall experience of participants' (themes).

We used QOREQ-32 item checklist for the reporting of these qualitative part of this study.[7]

RESULTS

Themes and Subthemes

The main themes derived from IDI were experience with symptoms and health-seeking behavior, experience with health system, experience with family/friend/community and present condition of pediatric patients.

Theme 1: Experience with symptoms and health-seeking behavior

Subtheme: Recognition of symptoms

Participants do not even think that symptoms were of TB while consulting hospitals (private/or government). Only after the person from hospital informed, about the disease, they understood these symptoms were of TB.

> *She had convulsion, so we consulted hospital. For each time after convulsion, we consulted to xyz hospital. When the report of computed tomography scan came, they informed us that my daughter was suffering from TB - Mother of 13-year-old girl.*

Subtheme: Health-seeking behavior

The study showed that all the parents wanted the best treatment for their children and consulted to the place private/government hospital whichever they think best for their children.

> *Yes sir, we knew that there is a government hospital nearby to our home, but we consulted to our family physician. Sir, we love our child we want to give the best treatment to our child that is why we took her to private hospital for the treatment instead of government - Father of 14-year-old girl.*

Many participants confessed that they directly consulted to the government health facility. Nearby availability

and previous good experience at government center were facilitating factors for treatment seeking.

Subtheme: Time lag between first consultation and correct diagnosis
In hope of getting good care, many parents decided to consult private hospital. However, participants had to keep on moving here and there.

> *I did not have money, so I asked for the discharge, but they said that child was serious they cannot give discharge right now. Then, I told to them, "I do not have money and you charged around 7000 rupees in just 2 days, then they asked me," where will you take the child?" I replied, in the xyz hospital - Father of 2-year-old boy.*

Subtheme: Referral
Some participants directly consulted their family doctor or nearby private hospital, but on diagnosis, the doctor counseled them about treatment in government health facility.

> *They said to me, "you could treat your boy wherever you want, in private hospital drugs will cost you around 10,000–15,000 and same drugs are available free of cost in government hospital." Doctor also said to me, "your child is going to be cured wherever you treat either in private or government; you just decide from where you want to take the treatment." - Mother of 7-year-old boy.*

Subtheme: Diagnosis of patients
In the community, people were not aware about the pediatric TB symptoms as adult TB symptoms. In many incidences after diagnosis, they only they understood that their children were suffering from TB.

Theme 2: Experience with healthcare system

Subtheme: Provider attitude
Most of the patients told that health worker had played a key role in their life. It was interesting that not even the patients who were completely cured were satisfied but parents of patients who needed to continue treatment again were also satisfied. They admitted that the directly observed treatment (DOTS) provider supported them very well during the course of treatment.

Its really good. They helped us a lot if there was any problem. We could call him and ask for the help and also he was always available. Never felt that he become annoying because of my questions or calls - Mother of 14-year-old girl.

In the present study, there are two participants not taking drugs in the presence of DOTS provider. In one case, the child was so small, so caregiver used to take drugs, and in another case, the patient was paralyzed and bed ridden so it was not possible for her to go to take drugs at DOTS site.

Subtheme: Advice
The participants were very receptive to the advice given by anyone. They relied on advice and support from other.

Six patients experienced side effect during the course of treatment" instead of "Six participants, during this IDI told us that they had experienced side effect and they informed the health worker about this to. Of these six patients, five were relieved of the symptoms after assurance and advice from health worker, but in one case, the side effect did not relive and that became the reason for switching to private hospital from RNTCP.

We talked about the problems xyz had after taking drugs. He assured me that it will last for few days only and do not take drug with empty stomach - Mother of 7-year-old boy

Here, participants' faith on health workers gets reflected as solely their advice was sufficient in majority of the case for the continuation of treatment.

Subtheme: DOTS
Participants were taking drugs from the nearby health center from patient wise boxes (PWBs). Most of the parents said their children did not skip a single dose. They were so committed that they were accompanying their children and the drugs were given in their presence only.

This commitment even observed in participants who started the treatment again. Parents' took lot of care during treatment although few children need to start treatment again. Now, they were blaming one or the other reasons for the failure of the treatment.

> *We also came in time and did not miss any dose. We used to come regularly, but in last when they advised us to go for checkup we did not go. Because of that, my child had to take treatment again - Father of 13-year-old boy.*

DOTS therapy is very important, as it provides opportunity for participants to interact with DOTS provider and helps in solving the treatment related and other problems which occur during treatment. Thus, the DOTS providers' role was crucial in completing the treatment.

Subtheme: PWBs
All the participants were familiar with their PWBs. These PWBs were really useful as single PWBs for one person so if the health worker is not present at the DOTS site, they can take drugs directly from the PWBs and empty pouch can be put back there in their PWBs.

Subtheme: Problems
All the participants told us that they did not find any difficulty while collecting drugs, as the TB health visitor use to be present there to give the drugs. One participant not having

any problem with the RNTCP staff, but he did not have good experience with a guy working at UHC.

Theme 3: Experience with family/friends/community

Subtheme: Stigma

The present study revealed that the gender difference further stigmatized the condition.

We did not disclose the thing to our relatives or friends. Sir, we did not know whether they were going to understand it or not that is why we did not tell them. We are pleased with the thing that we got information now my daughter is completely alright. I do not need anything more - Mother of 13-year-old girl.

Participants who informed their relatives were satisfied with the thing that the relatives understood their condition and advised for completing the course of treatment; we noted that the relative's advice helped them positively in completing the treatment.

In one case, participant told that no relatives understood the thing and no one helped them in that hard time.

Subtheme: Discrimination

On exploring about discrimination, majority of them thought that community treats TB patients differently than others illness. Most of the participants thought hiding the illness will help them in living normal lives.

One participant disclosed this to community and firmly said there was nothing like stigma in their society, but he also thinks that in other community TB patients are treated differently.

Theme 4: Present condition

In the present study, majority of participants' were fully satisfied with the recovery of children. In our study, four patients were currently taking treatment. Of these four patients, three were on Category II and one patient's treatment was extended as she had spinal TB. One patient switched over to private hospital for Category II treatment while other two patients' were taking treatment from government.

DISCUSSION

There was unawareness in community about the symptoms of pediatric TB. Most of the parents knew that TB treatment was good in the government set up, but the symptoms of child were not suggestive of TB. Hence, they think about the other diseases and consulted in private.

It was also noted that some parents were also influenced by close friend, family doctor, and their past experience of family member. In a study done by Dodor *et al*. also found that decision to consult hospital was influenced by family or friend.[8]

The present study findings revealed that parents had to move here and there for the treatment of child, but nothing helped them in this process many parents charged big amount of money in private.

The present study findings revealed that parents had to move from one hospital to other for the diagnosis of child. Many parents charged with big amount of bill without coming to any diagnosis. The present study findings also revealed that when child came in government hospital, their diagnosis was faster and accurate than in private. A study done in Indonesia by Rintiswati *et al*. also reported that there was delay in diagnosis and treatment of TB patients because of their treatment seeking in private sector.[9]

Many participants confessed that health worker helped them in every aspect to complete the treatment. Study done in Brazil by Angélica *et al*. also noted that patient and DOTS provider relation was very vital in the completion of TB treatment.[10]

The present study revealed it was noted that family doctor who counseled and referred made good impact on the completion of treatment. It was also noted that more than half of participant experienced vomiting, nausea, abdominal pain, and drowsiness. All the participants also confessed that this problem relieved after advice or help of DOTS provider. Only in one case where the drowsiness of the patient was not relived, she was forced to shift to a private hospital.

A study done in Peru by Paz-Soldán *et al*. reported that in addition to providing key psychosocial support and encouragement, healthcare providers support also played a crucial role in educating patient.[11]

The present study noted participants thinks that coming to here at health center and taking drugs in the presence of DOTS provider helped them in reminding to take regular treatment and if they forgot or have any problem during the course of treatment, there is someone who can help them. In case of home-based DOTS strategy that would be a question mark as many times child do not want to take drugs and it is hard for mother to convince them compared to taking drugs in the presence of DOTS provider. In a study done in Peru by Paz-Soldán *et al*. reported that parents of pediatric patients described meeting other parents at the health education sessions and striking up mutually supportive friendships that helped them in completing treatment.[11] In a study done by Angélica *et al*. also noted that the support from the family and health worker was imminent in completion of treatment of patients.[10]

In the present study, it was noted that TB is still stigmatized condition which was felt by all the participants. They were worried about the child and do not find it useful or necessary to share this thing with the other. Although the parents did not find that the stigmatization of TB affected their motivation in completing the treatment of TB, they agreed that the TB patients were treated differently in community. Girls' parents were more protective because they think girl has to go to others house after marriage and if we disclose this thing to other it will affect the future of girl. In study done by Paz-Soldán *et al*. also reported that parents of child were really selective in disclosing the condition of their children and parents who disclosed the child condition to other family member got tremendous love and care that helped lot in completing the treatment of child.[11]

In agreement with other studies,[10-12] the suffering experienced by these participants was primarily linked to the likelihood of being discriminated against, which made them feel stigmatized. Despite TB being a curable disease, many professionals' different streams such as psychologists, anthropologists, sociologists, and TB analysts have repeatedly indicated that talking about the disease still causes discomfort and unease.[10]

CONCLUSION

There was unawareness in the community about the pediatric TB. Participants think that even the private practitioner was confused about the symptoms that ultimately resulted in late diagnosis. Private practitioners which are enrolled in RNTCP referred patients quickly to the government hospital that helped in early diagnosis. In IDIs, it was revealed that TB is still stigmatized condition and they had fear of discrimination. In the completion of treatment, healthcare workers support was crucial.

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