

Exploring Challenges Faced by Parents of Children with Tuberculosis in Klang and Petaling Districts of Selangor State, Malaysia: A Qualitative Study

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ABSTRACT

Introduction: Parents play an essential role in their children's tuberculosis (TB) treatment success despite many challenges from the beginning of their children's symptoms until completion of the TB treatment. The challenges can be described as perceived barriers, according to the Health Belief Model, a theory of behaviour change. This study aims to explore parents' experiences on the challenges in achieving a successful TB treatment for their child in two districts of Selangor state, Malaysia. **Methods:** The research was carried out using a phenomenology study design. In-depth interviews were conducted among purposively sampled parents of children with TB disease who have completed TB treatment or still undergoing treatment from MyTB version 2.1, a national TB surveillance database. The collected data was considered as achieving its saturation level if no new themes arise from the latest interviews' session. The R-based Qualitative Data Analysis (RQDA) package version 0.2-8 was used for the thematic data analysis. **Results:** The total number of participants in this study was 15 mothers of children with TB disease; 12 (80%) of the children had completed TB treatment. There were six subthemes identified from this study focusing on the theme of multiple challenges, such as health symptoms challenges, TB investigation challenges, personal challenges, healthcare facilities challenges, administration medication challenges, and community challenges. **Conclusions:** Parents highlighted many challenges during the child's illness phase, and they should be given adequate education and appropriate support to ensure TB treatment adherence. TB program managers should take action following the relevant parents' feedback regarding the quality of TB care in a healthcare facility.

KEYWORDS: parents, challenges, children, tuberculosis, qualitative.

INTRODUCTION

The World Health Organization (WHO) estimated that TB among children accounted for 11% of the total TB cases worldwide. TB is a curable disease, and the treatment success rate is targeted at 90% globally [1]. However, TB among children has a higher mortality rate for those aged less than five years who do not receive appropriate treatment [2]. Even though Malaysia had achieved the targeted treatment success rate for children in 2014, but it remained at a plateau until 2017 [3]. The national target to reach a treatment

success rate of 95% in 2020 seems unachievable [4]. Children with TB disease are also facing the problem of underdiagnosis and underreporting because of the challenges in making an accurate TB diagnosis due to the non-specific symptoms and mimicking other respiratory illness [5,6]. Children also have a paucibacillary respiratory sample, which further explained the diagnostic challenges and might cause a delay in treatment initiation. [7,8]. A previous study reported a median of 51 days (interquartile range [IQR] 27–86) delay for time-to-treatment initiation among



children treated in one of the general hospitals in India [9].

Parents or caregivers who were looking after a child with TB experienced many challenges such as delay in their child diagnosis and stockout of TB medication as reported by previous exploratory studies [10–12]. Poor TB knowledge among parents was highlighted in many studies as one of the common challenges [10,11,13–15]. Lack of knowledge on TB disease and TB treatment caused parents to seek unnecessary traditional alternatives instead of taking modern medication [16,17]. Parents claimed that they did not receive adequate TB education from the healthcare workers (HCWs) [11]. Parents also experienced difficulties in adhering to TB directly observed treatment (DOT) at health facilities as they need to readjust their work schedules or hire a companion if they cannot accompany their child to the clinic [10,11]. Significant psychological stress and worry about the disease complications were also reported in previous studies [10,18].

Therefore, a holistic approach by involving the family of the children is the recommended method in managing TB disease among this vulnerable group [19–21]. Parents were being targeted as the agent of change as they play an essential role concerning their children's health status since TB disease pose a significant impact on their responsibility [22,18,23,24]. An exploratory study of the challenges faced by parents may highlight many problems among them. Hence, an improvement can be made to the national TB services by providing more support to the affected family. This study aims to explore parents' experiences on the challenges to attain TB treatment success for their child in Klang and Petaling districts of Selangor state.

MATERIALS AND METHODS

Setting and participants

This study was conducted in Klang and Petaling Districts in Selangor, Malaysia from January to February 2020. The qualitative phenomenological study design with an in-depth interview (IDI) method was used to explore challenges faced by parents who were looking after a child with TB disease. Participants were identified through the children registration data in

MyTB version 2.1, a national TB surveillance database for Klang and Petaling Districts. The selected cases were children (age must be less than 15 years) who had been successfully treated or still undergoing treatment for the registration year of 2017 until 2019. Participants in this study were the parents or guardian aged above 18 years who were directly involved in taking care of the child during the illness period and the treatment phase. The sample size was estimated at 12 participants using the maximum variation sampling technique to cover participants from a wide socio-demographic background differences and the variation of participants' experience according to the age of the children with TB disease. Based on the previous study, the range of sample size was between 11 to 35 participants [17,25]. Theoretically, a phenomenology study design may achieve saturation within less than ten interviews [26,27]. A list of the MyTB data for children including the contact number of parents or guardians was requested for Klang and Petaling districts. Participants were approached via the WhatsApp application. A few questions were asked to check for eligibility of the participants such as their age must be 18 years old and above, and they were directly involved in looking after the child. The information on rural or urban residence was available in MyTB data.

Data collection

Data was collected using a topic-based interview protocol by a trained researcher. The main questions used in this study were presented in Table 1. The interview protocol was developed after an extensive literature review. Following that, the main interview questions were also reviewed by a panel of expert consisted of three members, two persons from TB stakeholder and a paediatrician. An open-ended question was used in designing the main questions, and the probing questions depended upon participants' answers. The protocol was pre-tested among a few mothers to improve the clarity of the language used. The parents' experiences were explored according to the flow of the child's illness when the parent noticed health changes of their child until TB treatment completion. The IDIs were mainly conducted in a natural setting of the participants' own home. However, some

participants preferred the session to be done in a conducive restaurant. All interviews were conducted in the Malay language. Informed written consent was taken prior to the interview. The average duration of the interviews ranged from 40 minutes to one hour, and the participants were not paid for participating in this study. The interview was conducted one-to-one between the participant and the principal researcher, and they had not met each other in any previous occasions. A tape recorder was used to record each interview session and complemented with a concurrent note-taking by the researcher. A unique identification number (ID) was generated for each participant to maintain anonymity. Data collection was discontinued when the researcher had the evidence of data saturation because there was no new theme detected in the latest IDI sessions [28].

Table 1 Sample of IDI questionnaires

Topic of interview	Main questions
Detecting health changes and TB disease confirmation	1. What are the first health changes of your child at the initial phase? 2. How was your child detected as having TB disease?
TB treatment phase	3. Can you tell me, how was your child underwent the TB treatment? 4. What are the challenges to complete the TB medication?
Perceived benefits and supports	5. How was your child's condition after TB treatment? 6. What kind of support that you received during TB treatment of your child?
Response from community	7. How was the neighbourhood reaction after your child diagnosed as having TB? 8. How was the school acceptance towards your child?

Data analysis

The audio files were transcribed verbatim by the same researcher who conducted the interview. R package for R-based Qualitative Data Analysis (RQDA) version 0.2-8 was used to perform the thematic approach of qualitative data analysis [29]. Deductive and inductive coding were applied to the selected quotes from the participants' data. A few techniques, such as triangulation of participant's quotes, member checking, peer review and reflective notes were implemented to

ensure the validity of the results. Transcribed interview data were reviewed regularly according to the audio files to eliminate glaring errors. Data analysis was conducted concurrently within the data collection phase after each interview session, and constant comparisons with previous interviews were made. Interactive interaction of the data of these interviews allowed for remodeling of the themes until data saturation was achieved. Themes were derived based on two methods. First, a deductive method, where the themes were developed from the previous literature reviews and supported with participants' quotes. Second, the themes can be newly created from the participants' data through the inductive method. The analysis procedures were recorded according to the step to allow reproducibility of this study [27]. This study was reported following the QOREQ-32 item checklist [30].

Ethical approval

This study obtained approval from the Research Ethics Committee (REC) UiTM and the Medical Research and Ethics Committee (MREC), Ministry of Health Malaysia, and was registered under NMRR-19-1201-47959.

RESULTS

A total of 43 registered parents of children with TB were approached via the available contact number in MyTB version 2.1 database; however, only fifteen mothers agreed to participate in this study. The mothers' age ranged from 25 to 52 years old. The level of education for the participants was nearly similar in both groups of those with secondary education and those with tertiary education. All the participants were of Malay ethnicity. Of the total participants, eight (53.3%) participants had children with TB disease aged 5 to 14 years old, and the remaining were mothers with children aged 1 to 4 years. Eleven of the TB cases were pulmonary TB, and the other four cases were extrapulmonary TB. Twelve (80%) of the cases had achieved TB treatment success, while only three children were continuing their TB treatment. There were six subthemes emerged from the data after exploring the challenges faced by participants in this study, as shown in Figure 1.

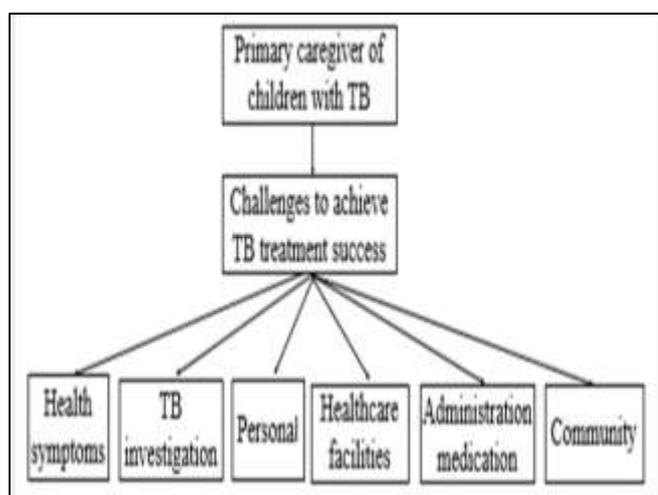


Figure 1 Thematic diagram for the challenges faced by participants in this study

Theme 1: Health symptoms challenges

Generally, parents claimed that TB symptoms were mild at the initial phase and can resolve after some symptomatic treatment. However, they discovered that TB symptoms had recurrent episodes. There was some uncertainty experienced by the mothers whether the child was at risk of contracting TB even though the child had been exposed to adult sputum-positive TB due to inadequate knowledge of TB symptoms.

“At first, he lost his appetite; after that, he had a fever. He had intermittent fever for a month, but the fever only came at night.” (ID10)

Mother of children with TB disease in this study brought their child to the clinic promptly, but the doctor told the mother that it was just a cough and common cold problem. Mother claimed that the episodes of mild illness happened for a prolonged period, and the child went to school as usual despite the mild symptoms. Parents never expected that it was a TB disease.

“Initially, she coughed and had an intermittent fever for quite a long duration. We went to see a doctor in the clinic. Her fever has resolved, and the problem was getting better, but the symptoms returned. It took about two months, as we did not expect a child of her age will contract TB disease. I have heard about TB a long time ago and had never expected the TB germs could infect a child. She still went to school during that time on days when she felt better”. (ID11)

Another mother suspected that her child was having an asthmatic attack as the child had the attack regularly during the last time.

“I thought that he had his asthmatic attack as he had it before. I did not expect that he will get TB disease as the symptoms were mild” (ID9)

Theme 2: TB investigation challenges

TB patient needed to undergo several specific TB investigations such as blood test, Mantoux test, providing three consecutive sputum samples for acid-fast bacilli examination, chest x-ray, and more advanced tests including ultrasound, computed tomography (CT) scan, magnetic resonance imaging, bone x-ray, biopsy, sputum/fluid/tissue culture and sensitivity test.

“My child underwent a test at her forearm skin. It showed a big red mark. She was admitted to the hospital for further investigation of lungs, eyes, and bone. I was told that her lungs contained a minimal amount of fluid, but they cannot proceed for sample collection.” (ID1)

The investigative procedure took some time and might induce some anxious feelings among the mothers. The doctor informed them of a broad range of illnesses such as a tumour, appendicitis, blood cancer, and dengue fever. The doctors could not come up with a definite diagnosis at the initial phase of the disease. The mother expressed her frustration regarding many blood samples taken from her child but was not informed regarding their child’s illness. While, other mothers feared of the possible issues listed by the doctors.

“They took blood samples from my child for more than ten times but still did not detect any illness [.]. The doctor gave so many causes for my daughter’s illness. She was admitted to the hospital after the second clinic appointment to undergo a CT scan, where the team noted “something” in her chest. They consulted the specialist team in another hospital to review her case. She was admitted for more than three weeks in Hospital A. Her blood samples were taken frequently, but no diagnosis was made within the first three weeks of admission” (ID2)

“My child had a very high fever. He was investigated and found to have low haemoglobin. The doctor suspected my child as having cancer of the blood.” (ID10)

“I asked for an x-ray examination for my daughter at the nearest clinic. However, I was told that nothing was wrong with her. My daughter’s condition still has no improvement. The unsatisfied mother, like me, brought her to another government clinic. Later, I went back to the first clinic and requested for further examination. The doctor looked puzzled with my daughter’s symptoms as she presented with stomach-ache recently. The doctor suspected that my daughter is having appendicitis and explained further to me that she might need an operation. This news made me shocked. Then, the doctor referred my daughter to the Hospital S for further evaluation.” (ID4)

TB investigations include probing for the source of infection; however, many participants were unsure about the origin of the disease.

“I ask the doctor on how my daughter was infected by TB disease. I have no family history of TB disease. I also never heard of TB disease in my daughter’s school hostel. The doctor said the infection may occur during a shopping mall visit or visiting crowded places with the presence of foreigners.” (ID3)

Theme 3: Personal challenges

Personal challenges are any problems related to the mothers’ personal commitment as a wife or a worker and also involving their financial status and emotions. Mothers from low socio-economic backgrounds mentioned that TB disease increased the financial cost of their daily expenses in terms of transportation costs. Three participants expressed their difficulty and stress while taking care of their child with TB disease because two of them were pregnant when the doctor made the TB diagnosis, and one mother just had a new baby and stayed apart from her husband. Participants also had to face time constraints if both parents were working and need to apply unpaid leave to look after their child. The critical phase leads to more personal problems or arguments between the mothers and their husbands. Personal challenges also involved participants’ fear regarding TB disease and its complication.

“I am becoming an overprotective mother. I will not allow people to come close to my son as I thought his illness would get worse. He got the infection from others. I am afraid that the germs will infect his lung, as for now, it just involved bone. I am scared if it happened to him. He would get a runny nose easily following an exposure if I sent him to the nursery.” (ID7)

“I am afraid as TB can cause death. I also did not know how was I being infected? How was the TB treatment? Can it be cured?” (ID13)

Mothers expressed their lack of knowledge and awareness of TB disease. There were also many misconceptions on the symptoms of TB, although TB is quite prevalent in Malaysia. The participants’ quotes were as below:

“I do not know that TB disease may infect other organs besides lungs. This is the first time I heard about TB spine.” (ID3)

“Her grandfather was admitted to the hospital for TB disease at that time as we thought that the disease would not infect other household members. I did not have any idea how the disease can spread, although I already knew that TB is an infectious disease. [...]. TB is also related to foreign persons. [...]. I am not sure what were exactly the TB symptoms. Besides that, we thought that TB disease affects only the older age group. I never thought of TB disease affecting my daughter.” (ID8)

“As far as I know, a person with TB disease will have a severe cough, some with blood as I heard a few people have TB disease in my area. I did not know that symptoms of swelling are also related to TB disease. It seems that TB diseases have many types and not only cough.” (ID6)

Theme 4: Healthcare facilities challenges

Participants reported that they went to multiple health facilities because the health problem of their child was still unresolved despite receiving various medications. They also said that the child needs to be sent to the hospital to seek advice from the specialist for further evaluation.

“They took a lot of blood samples frequently. I brought my daughter to the hospital many times, but the doctor did not tell me about the disease which affecting my daughter.” (ID2).

“I went to the nearest clinic; they took blood samples and told me that my child was not having dengue fever. After a few weeks, I found that my child was getting weaker and refused to play at all. Later, I brought him to the hospital. They said that he was suspected of having dengue fever and needed a hospital admission at that time.” (ID12)

Besides that, a few mothers had mentioned personal experiences of being scolded by HCWs and, to a lesser extent, received a confusing statement regarding their child’s illness. This created anger among the parents for the change in their child’s diagnosis and many uncertainties.

“The doctor scolded me for bringing a child with no illness to the clinic. “Your child is not sick. The blood sample’s results came back as normal,” said the doctor. I replied to the doctor, “I do not simply bring her to the clinic if she did not fall sick.” I felt angry at the doctor. I understood her workload and pressure, but she should conduct a proper examination for my daughter.” (ID2)

My son’s hospital card was missing during the appointment day. I was asked to return home and came back later. I insisted my son be seen on that day as I have been waiting for so long. The doctor had to ask a similar history, repeatedly. [...]. Another episode during the fasting month, I was scolded by the nurse since I forgot to bring the monitoring book. I burst into tears at that time. She did not need to scream at me as I can bring the book later. (ID 9)

“He was admitted to Hospital A and was given treatment for his fever, which includes five types of antibiotics; subsequently, the fever resolved. He was noticed to have low haemoglobin and needed a blood transfusion. Later, he was found to have swelling of the lymph node over his body. They put us into the isolation room for a month because he was diagnosed as TB. At first, I was informed that my child is having cancer of blood” (ID10)

TB disease among children has caused parents to stay in the hospital ward. Some mothers mentioned that the hospital admission took less than a week, while other mothers said it took more than a month depending upon the type of TB disease. Upon discharge from the hospital ward or after confirming TB disease in the paediatric clinic, mothers were instructed to come to the nearest clinic for DOT. Participants found that DOT at the nearest clinic was challenging due to time

constraints and transportation issues.

“I went to multiple facilities to complete two weeks of DOT. I take grab services every day. It caused a huge burden to me.” (ID4)

Participants complained that there was no one-stop center for TB disease in the paediatric clinic or the primary care clinic. They had to face unfriendly and crowded health facilities for a clinic appointment.

“I am tired of the parking lot in the hospital compound; it always full. [...]. It should be a specific place to be a TB one-stop centre. All the TB investigations should be conducted there. [...]. As per my experience, I had to go to Hospital A to bring my children, then to Clinic P for TB screening. Unfortunately, Clinic P did not have an x-ray facility where I had to go to another clinic, Clinic PK. Can you imagine, I always bring my children, including the four months old baby with me for any follow-up. Thank God for ease my things, anyway.” (ID9)

Theme 5: Administration of medication challenges

TB treatment success can only be achieved when the child completed the course of TB medication. Giving medication to children with TB disease was a big challenge for some mothers. For instance, the younger or, the older children have specific behaviours towards taking medication because TB medication is large in amount, either in liquid or tablet form. Participants mentioned that they received medication in a liquid preparation as well as tablet form. They needed to crush the pills and mix them with some syrups. The children always complained about the difficulty of swallowing the medicine because of the big size and unpleasant taste. The younger children gave refusal reaction and needed to be restrained while administering the medication.

“He made a sound like to vomit the medication, but I persuaded him to swallow it, or I threatened him to give another dose. I also prepared some sweet juice or drinks for him to reduce the bitter taste. He was able to adapt with the situation until he completed the treatment course, but his sister needed to be restraint at each time of medication.” (ID9)

Theme 6: Community challenges

Participants mentioned that they sought religious opinion and tried some traditional tips in the earlier phase. They did not know the exact cause of their child's illness until they were informed by the doctor. Participants also informed that there was lack of information on TB disease in electronic media. They compared TB disease with dengue disease, which they perceived had more coverage on television. Participants had heard that TB could cause death, TB is related to a foreigner, and TB is infectious; but they still have a lack of understanding regarding the disease. Participants also felt that the TB awareness in the community was low as pictured in this quote:

“There are some ignorant people who do not care about TB disease. They refuse to read the TB pamphlet, although it has been put on the display rack in the clinic. It depends on us; we search for more information if we have contracted the disease. Those who are not involved in TB disease they will not search for more information. They just hear about TB disease and are not aware of the seriousness of the illness. [...] People might think that the symptoms are mild, and the disease will not spread in the community. The doctor can only give advice but, the most important are those who are having symptoms should self-quarantine, avoid the crowded public area, wear a mask if necessary, and do not be selfish. It is difficult to spread TB awareness in the community.” (ID9)

Due to the lack of information and awareness on TB disease in the community, the stigma on TB disease still exists to date. Participants refused to disclose their child's illness to other than their family members or close friends. They were afraid of their child being left out and losing friends in school.

DISCUSSION

This study explored challenges faced by parents in two districts of an urbanised state in Malaysia according to the HBM construct of perceived barriers [31]. HBM explained a theory exploring community behaviour on a disease prevention activities which also includes other constructs such as perceived susceptibility, perceived severity, self-efficacy, perceived benefits and cues to action [32]. Among the children with TB disease who their parents participated in this study, twelve (80%) of

the cases had achieved TB treatment success, while only three children were continuing their TB treatment. Parents reported that the important key for their child treatment success was their trust towards the healthcare system. The theme emerged from self-efficacy and perceived benefits of HBM constructs. Trust to the healthcare system has sub-themes such as acceptance, self-efficacy, holistic care and perceived benefits. In addition, another factor contributed to TB treatment success was when parents are motivated to take or continue treatment by receiving adequate support from family, HCWs and community together with a convenient healthcare service.

This article focused on the aspect of perceived barrier construct of HBM or in other terms can be reworded as parents' challenges while taking care of the child with TB disease. The challenges faced by participants in this study ranged from health symptoms, TB investigations, personal problems, healthcare facilities, and difficulty in administering the medication. TB disease among children presents with non-specific symptoms mimicking the signs of common cold [5]. Participants in this study mentioned a delay in their child's diagnosis but they did not mention the specific duration for the delay. A previous study reported that the median parents' delay in bringing the child to seek treatment was around three days (IQR 1-14.5) [9]. Four out of fifteen children were detected as having TB disease through active case detection activity after becoming contact to the adult with sputum-positive PTB. Participants who aware of the health symptoms changes for their child confessed that they never thought of TB disease. They assumed that the symptoms were due to common cold or asthmatic attack. Parents in this study sought treatment for their children as soon as they detected the health changes.

A doctor who has a high suspicion of TB disease following a child with repetitive visits of a similar problem will arrange the child to undergo a set of TB investigations. It involves blood and respiratory sample tests, Mantoux test, and other advanced examinations. The tests are time-consuming and may induce an anxious feeling and also frustration among participants. The investigations might take a long time and require frequent visits to healthcare facilities. Caregivers who are working need to adjust their time

management to meet this requirement. Parents claimed they accepted the procedure as long as their child was given the right treatment. This situation was also observed in the previous studies exploring the acceptance of caregivers on the diagnostic test of TB [17].

Parents of children with TB disease also reported on the psychological burden during their child's illness. They were also stressed about their financial and personal problems [10]. Similar findings were noted among caregivers in China concerning TB cure status, disease sequela, the in-direct complication of their child education status, which induced psychological stress [18]. Participants from low socio-economic backgrounds reported some financial constraint due to frequent transportation fees. Numerous appointments and an extended stay in the ward, prevent them from earning money as shared in the previous study [10]. However, parents' perspective on fear of TB disease and its complications demanded them to adhere with the scheduled follow-up and treatment for their child.

Although Malaysia has set up an early national TB control program and implementing a holistic approach in managing TB disease [4], the participants were experiencing difficulties in bringing their child for an early diagnosis and treatment in this study. Participants were told that their child had no illness, although the child's symptoms persist. This problem reflects the need for improvement on TB management among children in our primary healthcare setting in terms of early recognition of TB disease despite the known diagnostic challenges [33–35]. With regards to DOT at the health facility for the first two weeks of the intensive treatment phase, some participants complied with the requirement, while others experienced a problem. In order to ensure effective DOT, it should be conducted at the nearest health facility. HCWs should understand the social problems among caregivers and offer flexibility to maintain treatment adherence and good relationship. The challenges regarding DOT at the health facility were time constraints and cost for transportation which were burdensome to the participants. Other studies found a similar problem concerning DOT at the health facility, which interferes with their work commitment and daily routine [10,11].

Caregivers prefer the community-based treatment compares to DOT at the health facility in a study conducted in Botswana [11]. The mothers showed a higher commitment in getting the right treatment for their child, as observed in another study [10].

Participants in this study experienced a wide range of HCWs' attitudes. Participants also experienced low-quality services from HCWs, which might cause demotivation in continuing TB treatment. Another study observed a similar event in which talking to HCWs was described as hurtful and demoralising [36]. HCW with poor attitudes can cause a negative impact on TB treatment success for TB patients. A mutual relationship between HCWs and caregivers is needed to ensure treatment adherence among children.

TB medication is provided either in a loose tablet or a fixed-dose combination (FDC) tablet. A syrup is only prepared following doctor's request and usually has a short expiry date of two weeks. TB medication has a bitter taste and is unpleasant to children. Despite the challenges, participants administered the TB medication or ensured the older children to take the medication consistently. The stock of TB medication was always available according to the participants in this study. Administration medication challenges were also observed in previous studies such as having a bad taste and the pills need to be crushed [22,37] while another study mentioned the out-of-stock problem [11].

Lack of TB information and TB awareness in the community explained the parents' perspectives that TB disease is an adult only disease and does not infect children. Participants agreed that they were not aware of TB disease and how the disease spreads among household members. This problem might be due to a lack of educational material on TB disease on the main television channel. They also agreed that they allocated some effort to search for more information on TB disease after their child contracted the disease. Lack of TB awareness in the community remained as a problem in this study, and in previous studies [11,17,18].

As a result of a lack of TB awareness in the community, TB stigma still exists until today. In combating this stigma, participants practise selective disclosures regarding their child's illness to prevent discrimination towards their child in the community.

Participants confessed that many people still believe that TB patients need total isolation; TB disease cannot be cured and will end up with death. TB stigma were reported in various studies exploring challenges among TB patients [10,12,13,25].

Lastly, a few of participants tried various traditional tips at the early stage of symptoms, after being told by HCWs that the child's symptoms were mild. It was an effort to relieve the symptoms of fever or swelling. As a long duration was taken by the HCWs to confirm the diagnosis, some of them might think that the disease was caused by black magic. The belief is temporary and resolved after their child responded well to TB treatment. The misunderstanding of TB disease as related to black magic or transgression of the social norm has also been discussed in previous studies [17,38].

This study observed that mother exhibited a warm response towards invitation to participate in this study although invitations were given through WhatsApp application. Mother of children with TB disease in this study able to share positive and negative experiences during their child illness period. A similar reaction to the mother's commitment was reported in another study [10]. An invitation to participate in this study were also given to father of other children with TB disease, however their responses were late and showed a lesser interest. The possible reason for this situation is father may have commitment with their job and often passed the household management issues to their wife. Parents may also had been told that their children were successfully treated and parents thought that they had no more appointments with health clinic.

Strength and limitations

The strength of this study includes being an exploratory primary research which had offered a rich type of data. The challenges were examined from the early stage of health changes occurring until the completion of TB treatment. Some limitations were encountered during this research. First, the participants in this study were only among mothers; thus, the viewpoints of father or other guardians were not explored. Second, the participants came from Malay ethnicity only, and it limits the experiences of different ethnicities. The

participants were mostly those who have a child with completed treatment. Thus, views expressed in this study may not reflect the parents of the child who were having unsuccessful treatment.

CONCLUSION

Parents of children with TB disease shared important themes describing their challenges in achieving TB treatment success for their child. The challenges ranged from TB symptoms, TB investigations, personal problems, health facilities, HCWs' attitude, and administering medication challenges. Understanding the challenges faced by parents of children with TB disease is essential to improve TB services in the community.

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Conflict of Interest

Authors declare none.

Authors' contributions

SMA, NI, SMY, YZ, NMZ and FK contributed in the designing the study, data cleaning, data analysis, interpretation of the findings and drafted the manuscript. SMA conducted IDI and transcription. Finally, the paper has been reviewed thoroughly by MASM and AR. All the authors approved the final version.

Reflexive statement

"I conducted this study with my background as a medical doctor for 18 years and had previously contracted TB disease from my husband five years ago. I was diagnosed as having sputum-negative PTB slightly later from my husband and had completed six months of TB treatment. I experienced the situation of being a TB patient and also a caregiver to my children who were diagnosed as Latent TB. I faced multiple

challenges during completing TB treatment for myself and while getting an early diagnosis for my children. I am not involved in the clinical management of TB patients in this study. This is my first time conducting a qualitative research. I introduced myself as medical personnel working in the government public health sector to the participants, although it may introduce information bias to this study. Participants may choose to keep their bad experiences because of my job status. Surprisingly, they still shared their experiences with me openly, including their problems during TB treatment phase of their child. Probing questions were used to highlighted participants meaning more clearly.”

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