

Communication between Parents and Preschool-Aged Children about Tuberculosis Preventive Treatment: A Qualitative Study

Abstract

Background: Communication with preschool-aged children about Tuberculosis Preventive Treatment (TPT) is a challenge for parents. Good communication can encourage children to be involved in their treatment and enhance their adherence to the treatment. This study aimed to explore the experience of parents in communicating with their preschool-aged children about TPT. **Materials and Methods:** This study used a qualitative approach. Participants were 10 parents who were selected using the purposive sampling technique from three community health centers in Bandung City, Indonesia. The inclusion criteria for the study were parents who have a child aged 3–5 years who received or was receiving TPT. Semi-structured interviews were conducted to obtain the data, and when saturation was reached, no further interviews were conducted. Subsequently, the interviews were transcribed and analyzed using thematic analysis. **Results:** The findings revealed three themes with eight categories. The themes were persuading children, lack of understanding, and supporting communication. **Conclusions:** The findings are relevant for nurses and other health professionals who need to provide adequate information related to TPT and to develop media for parents and children during their communication. Nurses can collaborate with other physicians and software engineers to develop interesting media such as game applications to educate children about Tuberculosis (TB) prevention.

Keywords: Communication, child, preschool, tuberculosis

Introduction

Tuberculosis Preventive Treatment (TPT) is recommended for children aged under 5 years who live in a Tuberculosis (TB) household for 6 months.^[1,2] This treatment is highly effective in preventing the progression of TB disease by up to 59%.^[3,4] However, the coverage and adherence of children to TPT is still poor. In 2018, only 10% of 1.3 million children worldwide aged ≤5 years who lived in an active TB household received TPT.^[5] Indonesia has similar experiences related to this poor adherence to TPT. A study conducted in Indonesia reported that 74.4% of 82 children who received TPT were not adherent to it.^[6] This poor level of adherence was caused by the rejection of children due to their emotional reaction to the bitter taste of treatment and the long duration of treatment.^[6-8] Improving adherence to TPT requires collaboration between parents and children through communication. Communication related to health care is different to social communication.

In healthcare communication, there is more concern about private and intimate problems. Effective healthcare communication responds to the needs of parents and their children.^[9] Children should be involved in their treatment and should be given more information about it.^[10,11] Effective communication can enhance an understanding and adherence to treatment.^[12,13] Therefore, encouraging the involvement of children through good communication between parents and their children is essential.

However, children have a limited ability to absorb and understand particular information.^[14] In the developmental stages, children aged 3–5 years are in the preoperational stage which refers to the ability of children to learn about something. Their language ability is highly developed at this stage. However, these children cannot think logically and rationally.^[13] Furthermore, a previous study found that parents did not understand the importance of communicating with their children about

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the treatment and were confused regarding how to involve their children in their treatment.^[15] Therefore, most parents attempted to make their children to take the TPT by forcing the child's mouth open while holding the hands and body of the child. This situation leads to traumatic experiences for children, and one of the principles in pediatric nursing is atraumatic care to minimize the physical and psychological impact of distress in children.^[16] Concerning this issue, parents should manage their communication with their child about TPT based on the child's developmental stage.

A better understanding of communication between parents and preschool children about TPT may improve the adherence of children to TPT. No study has reported on the experience of parents in their communication with their preschool children about TPT. Similar studies have been conducted; however, they focused on cancer disease,^[17,18] which has different characteristics to TPT for children. Moreover, Indonesian culture may contribute to the relationship between parents and children that influences the pattern of communication within the family. Therefore, this study aimed to explore the experience of parents in their communication with their preschool children about TPT.

Materials and Methods

This study was conducted from February to September 2020. A qualitative approach was used in this study to explore the experience of parents in their communication with their preschool children about TPT. A qualitative descriptive study is able to gain an understanding of life experiences or issues.^[19,20] The participants were recruited using the purposive sampling technique. Of the 25 parents who met the inclusion criteria, 10 parents participated in this study. The inclusion criteria were parents with a child aged 3–5 years who had received or was receiving TPT at three Community Health Centers (CHCs) in Bandung City, Indonesia. We recruited the participants via the TB staff at the three CHCs. The TB staff approached the potential participants who met the criteria and gave them information about this study. Once the potential participants had agreed to participate in this study, we contacted them and provided further information related to the study, such as the purpose and procedure of the study. Subsequently, we obtained written informed consent from each participant.

Data were obtained from semi-structured interviews. The semi-structured interview is useful to maintain the researcher's focus on the purpose of the study as well as to gain systematically and comprehensively the experiences of participants.^[21] Due to the policy relating to social and physical distancing because of the COVID-19 pandemic, we interviewed participants by video call or phone call. The telephone interview is a viable and valuable method for collecting data in a qualitative study.^[22] Even though using a telephone interview may have some disadvantages in a qualitative study, it may also have some advantages

such as allowing participants to feel comfortable and able to disclose sensitive information. Furthermore, there is a lack of evidence, indicating that it yields lower-quality data.^[22]

Each interview lasted 30–40 minutes and was recorded with the participants' permission. The participants were asked to share their stories. The interviewer started with this open question: "Can you tell me what it was like when giving TB preventive treatment to your child?" Other questions were asked to elicit information about what the participants know about TPT, how they communicate with their child about the TPT, their child's reaction to this treatment, barriers in communicating with their child about the treatment, needs of parents to facilitate good communication with their child about the treatment, and nurses' support in facilitating parents' communication with their child about TPT. Data collection and analysis occurred simultaneously. It was considered that saturation was reached, when no new codes or other information were provided in the interview and no further interviews were conducted. Saturation was reached after the tenth participant was interviewed.

Each interview was transcribed and analyzed by using thematic analysis. Thematic analysis is useful for conducting applied research, including health research.^[23] We used thematic analysis, since the researcher considered both latent and manifest content in data analysis by identifying patterns of meaning across a dataset that provides an answer to the research question being addressed.^[24] Furthermore, this analysis can examine different perspectives of participants, highlight similarities and differences in coding, and summarize key findings of a large dataset.^[25] In this study, the thematic analysis process was performed based on Braun and Clarke's method, which includes the following six steps: Familiarizing with data by reading and rereading the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the report.^[23] Table 1 provides an example of the data analysis of one theme.

Lincoln and Guba's four criteria were used to ensure the rigor of findings.^[26] Credibility was ensured by building trust and a rapport with participants; member checking was performed by returning some interview data analysis to the participants to evaluate and validate the findings. Moreover, the research team members discussed the data analysis. To ensure confirmability, the authors reported quotations using the participants' words. Dependability was obtained by documenting the data analysis process. Transferability was ensured by presenting the demographic of the participants.

Ethical considerations

Ethical approval was obtained from the Research Ethics Committee of Universitas Padjadjaran (No. 621/UN6.KEP/EC/2020). This study obtained written consent from the participants through Google Forms. The confidentiality of

Table 1: An example of data analysis process

Meaning unit	Condensed codes	Categories	Theme
<p>"I told my son that these medicines will make him healthy. He was still young; he might not understand. I said, "It is for your health. If you take it, you will be healthy and will not be sick" (P6).</p> <p>"I told to my child, "This treatment will make you stronger" (P4).</p> <p>"I told my child, 'I have TB*... You should take this medicine to prevent my disease transmitting to you. This TB is contagious, from mouth to mouth, through my spoon or glass ... If you take it, you will be healthy" (P5).</p> <p>"If you do not want to take your treatment, you will be sick, your body will become thin, you will feel nauseous, and your skin will darken" (P1).</p> <p>"I persuaded him, I softened my voice and talked to him softly" (P9).</p> <p>"My son received two kinds of medicines, one was a preventive medicine and the other one was a vitamin supplement. Actually, I told my son that all of his medicines were vitamins even though I gave it to him twice a day ... he only knew all of his medicines were vitamins ... I was afraid that if I told him what his medicines were, he would refuse to take them" (P9).</p>	<p>Focusing on the benefits of treatment</p> <p>Focusing on the potential negative impact</p> <p>Speaking in a gentle manner</p> <p>Saying treatment is a vitamin</p>	<p>Constructing meanings of medicine</p> <p>Gentle persuasion</p>	<p>Persuading children</p>

*Tuberculosis

the participants was protected by using anonymous data, and these data can be only accessed by the researchers.

Results

Ten participants were interviewed in this study. Most of the participants were mothers, but one participant was a father. Their ages ranged from 23 to 62 years. The participants' demographic data are given in Table 2. During the thematic analysis, the three main themes with eight categories that emerged in this study and are shown in Table 3 were persuading children, lack of understanding, and supporting communication.

Persuading children

Persuading children refers to the way parents communicate with their children about the TPT to enhance the willingness of children to take their medication. In relation to giving the TPT to their child, most parents did not talk specifically about the TPT to their child due to the child's young age. They perceived that their child might not understand their treatment. Therefore, the parents tried various ways to communicate with their child about the treatment, such as focusing on the benefit of treatment, focusing on the potential negative impact of refusing treatment, saying the treatment is a vitamin supplement, and speaking in a gentle manner.

Most parents prefer to inform their child about the child's treatment by focusing on the benefit of the treatment, which can make the child healthy and strong. For instance, one participant described how she informed her son about the benefit of the treatment to her son: "I told my son that these medicines will make him healthy. He was still young; he might not understand. I said, "It is for your health. If you take it, you will be healthy and will not be sick" (P6).

Another example is: "I told my child that this treatment will make you stronger" (P4).

Similarly, another participant also described how he communicated with his child, focusing on the benefit of treatment for his child. However, the parent tried to relate the benefit of the treatment to the risk of contracting TB from his parent. "I told my child, I have TB ... You should take this medicine to prevent my disease from transmitting to you. This TB is contagious, from mouth to mouth, through my spoon or glass ... if you take it, you will be healthy" (P5).

During the child's treatment, parents sometimes encounter difficulty in giving the medicine to the child as the child rejects the medicine. Therefore, the parents preferred to focus on the potential negative impact of refusing treatment, for example, "If you do not want to take your treatment, you will be sick, your body will become thin, you will feel nauseous, and your skin will darken" (P1).

However, one participant said that she informed her child that the treatment was a vitamin supplement. This was the parent's way to encourage her child to take the treatment. She said: "My son received two kinds of medicines, one was a preventive medicine and the other one was a vitamin supplement. Actually, I told my son that all of his medicines were vitamins even though I gave it to him twice a day ... he only knew all of his medicines were vitamins ... I was afraid that if I told him what his medicines were, he would refuse to take them" (P9).

During communication with the child, this participant also mentioned that the parent should speak gently to persuade the child and to be willing to take the treatment, stating, "I persuaded him, I softened my voice and talked to him softly" (P9).

Table 2: Demographic data of participants (n=10)

Participant case no.	Family position	Age	Occupation	TB* source
P1	Mother	36	Teacher	Mother
P2	Mother	38	Private employee	Father
P3	Mother	29	Housewife	Father
P4	Mother	29	Housewife	Mother
P5	Father	62	Freelancer	Father
P6	Mother	23	Housewife	Aunt
P7	Mother	28	Housewife	Mother
P8	Mother	39	Housewife	Mother
P9	Mother	42	Laundress	Mother
P10	Mother	42	Housewife	Mother

*Tuberculosis

Lack of understanding

During communication between parents and their children about TPT, some parents found that a lack of understanding was a challenge. The lack of understanding refers to a narrow range of information, responses of a child to TPT, and a younger child's understanding.

A narrow range of information related to TPT was reported by some participants as a challenge in communicating with their child about the treatment. Some participants stated that they only knew that this treatment is for preventing TB transmission in children as one participant reported: "My son received the treatment to prevent his father's disease being transmitted to him. That's all I knew" (p3).

However, participants did not know about the side effects of this treatment as one participant stated: "I know that this treatment can prevent TB transmission to my son, but I do not know whether there are any side effects of this treatment. This treatment might have various side effects. Based on their experiences, from other mothers, they said that some children had some lumps in their body, and the appetite of some children was poor. But, so far... my son is fine. He does not have any bumps in his body and his appetite is still good ... So, actually, I am not sure whether there will be any side effects of this long treatment for my son?" (P1).

Furthermore, some participants did not know about what kind of medicine would be given to the child and the duration of TPT. One participant said: "The TB staff at the CHC told me that my son's treatment is for preventing TB transmission ... I was surprised when I saw my child's medicine was in tablet form. I thought its form was a liquid ... I am not sure whether my son will receive his treatment for 6 months like me or more than this ... I also thought that his treatment was only given once every two days. I am not sure whether he will continue his treatment or not ... I was confused about how to tell my son about this medicine ... Hopefully, we have a commitment to accomplishing his treatment" (P7).

Another challenge in communication that was also reported by some participants was the responses of the child to TPT, such as anger, crying, being fussy, closing their mouth, and spilling the medicine off the spoon. These responses of the child resulted in the parents experiencing difficulty and confusion regarding how to communicate with their child about the treatment and to encourage the child to take the medicine willingly. For example, one participant described her desperation when her son was fussy while taking his treatment: "Previously, my son did not know the taste of his medicine. After he tried it, he said his medicine was bitter. I told him that it was ok, this medicine was for his health, but he became fussy. Therefore, I could not do or say anything. I forced him to take his medicine ... I held his body and forced the medicine into his mouth" (P6).

Another problem was a younger child's understanding. Some parents perceive that preschool-aged children are still young and have a limited understanding of TPT. This circumstance was perceived as a challenge for parents to communicate with their children about TPT. Therefore, some participants preferred to avoid open communication with their children, and one parent said: "My son is still young ... If I explained in detail to my son, he might not understand ... So, I told him, 'Take this medicine for your health'... and it is better to make my son happy" (P2).

Supporting communication

With regard to facilitating effective communication between parents and children, the participants highlighted that they need support from a health professional, particularly an informational support related to the child's treatment. One parent said: "I think I need support and clear information related to this preventive treatment from a nurse, a midwife, or a doctor at the CHC ... To be honest, I was surprised when I found that my husband had TB disease and that my child should be given the preventive treatment. So, I need further clear information from the health staff at the CHC" (P1).

In terms of obtaining more information about TPT, some participants tried to find information on the Internet such as from Google, YouTube or a health application on a mobile phone. However, they highlighted some disadvantages of searching for information on the Internet. For instance, a parent stated: "Previously, I tried to search for some information on Google but, sometimes ... I think some information on the Internet made me scared ... there's so much information, and this made me confused, as it may be different from the facts" (P7).

Similarly, another participant reported a disadvantage in searching for information on a health application on a mobile phone that was related to the purchase of the application: "Previously, I downloaded a health app on my mobile phone because I wanted to know more about my child's treatment and TB disease if my child was infected with TB. However,

Table 3: Theme, sub-themes, and codes related to communication between parents and preschool-aged children about tuberculosis preventive treatment

Codes	Sub-themes	Themes
Focusing on the benefits of treatment	Constructing meanings of medicine	Persuading children
Focusing on the potential negative impact		
Speaking in a gentle manner	Gentle persuasion	
Saying treatment is a vitamin		
Purpose of treatment	Narrow range of information	Lack of understanding
Side effects		
Duration of treatment		
Type of medicine		
Anger	Child's reactions	
Crying		
Being fussy		
Closing mouth		
Spilling the medicine off the spoon		
Limited understanding	Younger child's understanding	
TB* prevention treatment	Content information	Supporting in communication
TB disease in child		
	Health professional support	
Searching from Internet	Managing digital information	
Disadvantages of digital information		

*Tuberculosis

to access more information in that application, I had to pay more. I thought that after I downloaded it, I could use it without paying any more” (P6).

Discussion

This study revealed how the parents communicated with their children about TPT. Most parents experienced difficulty in communicating openly with their children due to the challenges they faced, particularly the young age of the children. This finding is similar to that of a study on the disclosure of antiretroviral therapy treatment to children with Human Immunodeficiency Virus (HIV). The parents preferred to not disclose to their children about what the medications were for due to the children's age maturity and readiness.^[27] Therefore, the parents preferred to persuade their children by focusing on the benefit of treatment or the potential negative impact of refusing treatment, saying the treatment was a vitamin supplement, and speaking in a gentle manner to the child. Young children may have negative responses to their treatment due to the bitter taste and long duration of treatment.^[6,7] Parents need to adopt a motivational approach by persuading children, which will enhance their children's willingness to take their medication.^[17]

In this study, a lack of understanding among parents and children was revealed. The lack of understanding among parents is related to the narrow range of information. Therefore, some parents tried to gather further information from health professionals and through the Internet. This finding is congruent with that of a study conducted in a

Massachusetts suburb about health communication within the family. When the caregivers had limited information, it was difficult for them to discuss the health topic with their children. They found more health information from other sources, including the Internet.^[28]

The lack of understanding among children perceived by parents was related to young children's cognitive development. This made it challenging for the parents to communicate openly with their child. However, children have a right to be informed of the truth and to be cared for with respect and dignity.^[12] Furthermore, communication with children can encourage them to be involved in taking their medication, which, in turn, has an influence on their adherence to medication.^[9] A previous study conducted in the United States also reported that even if children had limited understanding about their medications, they could be involved in communication about their medications based on their different age level.^[29] According to the cognitive development of children from Piaget's child development stages, children at 3 years of age can start to be involved in communication about their health care or medicines. Parents can begin communication by building a rapport with the child and giving information related to the medications, such as the taste, duration, benefit, and time to take it, in a way that the child can understand.^[13] However, parents should be careful in selecting an appropriate language when communicating with this age-group.^[10]

Finally, this study found that support, particularly informational support, was needed to facilitate communication between the parents and children about

TPT. This finding is consistent with that of a study conducted in Australia regarding the need of mothers in communicating with their children about maternal breast cancer. Mothers need informational support related to type of disease, treatment, and children's developmental stage. It is needed as a parental guidance to anticipate, manage, and respond to children.^[30] Parents may need support media that provide any information needed. Some parents tried to obtain digital information. Health digital information can be obtained through the Internet and a mobile phone. It is effective to facilitate communication among caregivers, children, and also healthcare providers.^[13,31] Furthermore, children may also need simple and creative media that can be used as a model of responsive caregiving for parents. However, the most important aspect is having a positive interaction between parents and children.^[14]

This study was conducted in Indonesia, which may have a different culture to other countries or areas. Therefore, this finding may have limited transferability to other settings. Furthermore, some of the data collected in this study were obtained via a phone call, which may have a limitation in assessing the participants' nonverbal cues during the interviews. In our study, the parents' participation was voluntary, and they provided rich information during the interviews. However, most of the participants were mothers. It should be taken into consideration that information from fathers or other family members may differ.

Conclusion

Communication between parents and preschool children about TPT may be difficult due to some of the challenges that parents face. This finding identified the lack of understanding of parents and children that led the parents to find out more information from digital media to enhance the effectiveness of their communication. Health digital information may be needed for parents to be skillful enough in delivering TPT information to their children and in communicating with their children. This situation means that nurses and other health professionals need to facilitate communication. Nurses can collaborate with physicians and software engineers to develop interesting media such as game applications or videos to educate children about TB prevention.

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Conflicts of interest

Nothing to declare.

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