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## Original Article

# Moving from fear to realization: Family engagement in tuberculosis prevention in children living in tuberculosis Sundanese households in Indonesia

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## ABSTRACT

**Objective:** Children living in tuberculosis households need protection. However, families need to be engaged to prevent tuberculosis transmission to children. This study aimed to analyze the details of “moving from fear to realization,” which is one category of a substantive theory of family engagement in tuberculosis prevention in children.

**Methods:** Fourteen family caregivers participated as key informants after their families met the criteria. The participants were recruited at a lung clinic in West Java, Indonesia and followed up at their homes. The data were gathered using in-depth interviews and analyzed following the coding procedures of the Straussian grounded theory.

**Findings:** “Moving from fear to realization” was the main category that emerged from the experiences of the Sundanese families to begin engaging in tuberculosis prevention in children living in tuberculosis households. It was composed of four sub-categories, namely, fear of tuberculosis, seeking information, following God's will, and awareness of tuberculosis transmission risks.

**Conclusions:** This study showed how a family moves from fear to the realization of tuberculosis transmission risks. Its findings are useful for nurses to provide optimum care in order to prevent tuberculosis transmission to children with household contact by providing both education and counseling for families.

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## What is known?

- Most studies related to family engagement were on child mental health treatment, child maltreatment or neglect or both, and childhood obesity prevention. All of these studies were conducted in the USA.
- Most studies focused on barriers or influencing factors to successfully prevent tuberculosis in children living in tuberculosis households. Fear of tuberculosis diagnosis was identified as one main barrier. This fear was influenced by the participants' misperceptions associated with tuberculosis.

## What is new?

- This study showed the process of how the families dealt with their fear of tuberculosis. This study also revealed strategies that the family used to overcome their fear and to transform their fear to realization to begin engaging in tuberculosis prevention in children living in tuberculosis households.

## 1. Introduction

Tuberculosis is still a major cause of illness and death in children worldwide. In 2016, the World Health Organization (WHO) estimated that 6.9% of 6.3 million new tuberculosis cases were children, and 210,000 deaths occurred among children. The WHO also estimated that 1.3 million children  $\leq 5$  years old were living in

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households with tuberculosis cases, but only 13% of them received tuberculosis preventive treatment [1]. Most cases of tuberculosis in children occur in tuberculosis-endemic countries, such as Indonesia, which is the second-highest tuberculosis-burden country worldwide in 2016. In that year, the number of new tuberculosis cases in Indonesia was estimated at about 1,020,000 or 391 cases per 100,000 population, and the new tuberculosis cases among children were about 7% of all tuberculosis cases [1].

The most common cause of tuberculosis among children is household contact [2–5], particularly from parents [4,6,7]. Given their immature cellular immunity, children younger than 5 years are at a high risk of infection. Children usually spend ample of time with their parents and sleep in the same bed with them [7,8]. In consideration that children with tuberculosis infection present with non-specific symptoms, many parents are unaware of their child's condition. Tuberculosis can cause mortality or severe conditions (e.g., tuberculosis meningitis) that often result in permanent disability or death [9].

Family engagement is useful in child care or treatment to ensure the child's wellbeing [10]. According to the WHO recommendations, the tuberculosis preventive strategies in children are BCG vaccination, contact screening, and contact management [11]. Successful family engagement in preventing tuberculosis transmission in households is significantly related to the prevalence of tuberculosis disease [12]. Nevertheless, according to earlier study in Indonesia, only 7.8% of the 437 child households contacted were taken by the family to lung clinics for screening [13]. Another study pointed out that 74.4% of the 82 children under study had poor adherence to isoniazid preventive therapy (IPT) [14]. In addition, most Indonesian families did not open the bedroom windows or put the mattresses out in the sun and had high-housing density and poor ventilation [15]. West Java Province has poor engagement in tuberculosis prevention and the highest proportion of child tuberculosis cases among all tuberculosis cases in Indonesia [16]. One study in Indonesia found that 44.71% of 85 families had poor engagement, whereas 37.65% and 17.65% had moderate and good engagement, respectively. According to the aforementioned studies, most of the families did not recognize the family's tuberculosis problem. Furthermore, they failed to follow appropriate strategies or provide care for the tuberculosis patient in their family or modify their household environment [15]. These situations can facilitate tuberculosis transmission among family members, including children, in the home.

Several research studies have reported several barriers to the successful family engagement in tuberculosis prevention for children [17–20]. In addition, a number of other studies have mentioned that misperceptions concerning tuberculosis and the fear of tuberculosis stigma are the main barriers to family engagement in tuberculosis prevention [21–23]. Misperception is related to the lack of knowledge and awareness in families about tuberculosis and its transmission to children [24]. Most families also perceived that their children were healthy and not at risk to catch tuberculosis in their homes. Meanwhile, the fear of tuberculosis stigma stemmed from misperceptions associated with tuberculosis. When one of their family members was diagnosed with tuberculosis, most Indonesian families experienced several negative responses, such as shame, fear of the tuberculosis stigma, and fear of death. This fear of stigma caused the family to hide their disease [24,25]. It also contributed to the rejection of a tuberculosis screening test in the household [22,23,26]. Consequently, it led to the spread of tuberculosis in the household [22].

Most literature in Indonesia focused on the influencing factors and the outcomes of family engagement in tuberculosis prevention. To date, scant research reported on family engagement in tuberculosis prevention in children who live in households with

tuberculosis patients. The majority of research studies on family engagement were on child mental health treatment [27,28], child maltreatment and/or neglect [29], and childhood obesity prevention [30], and all of these studies were conducted in the USA. The findings from these studies may not be applicable in the Indonesian context because of different cultural backgrounds.

Indonesian families, particularly those of Sundanese ethnicity, have adopted the patriarchal system, which means the wives should obey their husbands. The husbands act as the leader and decision-maker in the family, while the wives are expected to respect and obey their husbands and be responsible for taking care of their husbands and children [31]. Moreover, Indonesian families usually have good relationships and social interaction among family members and relatives [32]. These situations might influence tuberculosis prevention in children. The wives as the primary caregivers of children should ask permission or advice from their husband, other family members, or relatives that can delay their response times to child health [33,34]. This condition might lead to the risk of tuberculosis prevention and control delay or failure.

This paper is a part of a larger grounded-theory study aiming to develop a substantive theory of family engagement in the prevention of tuberculosis in children living in tuberculosis households. This study aims to analyze the details of one category of the substantive theory of family engagement in tuberculosis prevention in children, namely, “moving from fear to realization.”

## 2. Methods

### 2.1. Design and study setting

This study is a part of a larger grounded-theory study, of which main findings will be published elsewhere. This study was conducted in Bandung, West Java Province, Indonesia.

### 2.2. Participants

Purposive sampling was used to recruit families, who met the following inclusion criteria: 1) had a child  $\leq 5$  years old living in the same household, 2) the child had received tuberculosis screening and adhered to IPT for 6 months, 3) the household had an adult with a tuberculosis diagnosis during at least the last 3 years before the data collection period, and 4) able to speak the Bahasa Indonesia language or Sundanese. The key participants were the primary caregivers because they are knowledgeable about their families and mainly responsible for taking care of the children and household tasks. Therefore, they could potentially provide rich experiences regarding families engaged in tuberculosis prevention among children.

The recruitment process was conducted at a lung clinic in Bandung. A nurse at that clinic was the first person to contact the potential participants and inform them about this study. They were then asked for their willingness to participate in it. After obtaining their consent, initial meetings between the researcher and the participants were conducted at the homes of the participants to build trust. Furthermore, theoretical sampling was applied to saturate the categories and validate the relationship between them by selecting additional participants. Saturation was accomplished at 14 primary caregivers.

In this study, all of the primary caregivers were mothers aged 22–43 years. Five participants were infected with tuberculosis while being engaged in tuberculosis prevention for their children, whereas the other nine took care of the sick family members and their children. The general information of the key participants is shown in Table 1.

**Table 1**  
Demographic characteristic of key participants (n = 14).

No.	Family position	Age(year)	Occupation	Ethnicity	Religion	Family structure	Tuberculosis sources
F1	Mother	22	Housewife	Sundanese	Islam	Nuclear	Mother
F2	Mother	33	Shopkeeper	Sundanese	Islam	Extended	Grandma (mother-in-law)
F3	Mother	29	Shopkeeper	Sundanese	Islam	Extended	Grandma (mother-in-law's sister)
F4	Mother	23	Housewife	Sundanese	Islam	Nuclear	Father
F5	Mother	39	Shopkeeper	Sundanese	Islam	Compound	Mother
F6	Mother	42	Housewife	Sundanese	Islam	Compound	Mother
F7	Mother	36	Housewife	Sundanese	Islam	Nuclear	Mother
F8	Mother	27	Housewife	Sundanese	Islam	Nuclear	Father
F9	Mother	43	Housewife	Sundanese	Islam	Compound	Mother
F10	Mother	35	Housewife	Sundanese	Islam	Extended	Mother's sister
F11	Mother	39	Blue-collar labor	Sundanese	Islam	Nuclear	Father
F12	Mother	27	Shopkeeper	Sundanese	Islam	Nuclear	Father
F13	Mother	41	Housewife	Sundanese	Islam	Nuclear	Older child (Adolescent)
F14	Mother	33	Housewife	Sundanese	Islam	Nuclear	Father

### 2.3. Ethical considerations

Ethical approval was obtained from the Ethics Committee of the Faculty of Nursing, Prince of Songkla University, Thailand (No. MOE 0521.1.05/2580). The participants were given detailed information related to this study. After the participants agreed to join, the researchers shared further information related to the study and obtained written informed consents from them. The participants in this study remained anonymous to protect their privacy and ensure the confidentiality of the data. To prevent potential social and emotional repercussions related to tuberculosis stigma, the researchers blended into the environment of the participants using informal dress and public transportation when visiting their homes.

### 2.4. Data collection

Data collection was conducted from December 2016 to July 2017 through in-depth interviews in their homes. The interviews were conducted in Bahasa Indonesia and started with these open-ended questions: "Can you tell me what was it like when you first knew that you or your family member was diagnosed with Tuberculosis?" or "What was in your mind when knowing that someone in your family had Tuberculosis infection?" These questions were followed by probing questions such as "Can you tell me more about your fear?" and "How did you overcome this fear?" The interviews were recorded with the permission of the participants and transcribed verbatim. Each interview was about 40–90 min long. Moreover, follow-up interviews (2–4 interviews depending on the participant) were conducted in their homes to ensure data saturation, and the final number of field visits was 40. Field notes were also taken during the face-to-face interviews by taking notes using keywords. The notes were completed in a different location immediately after the data collection had finished. The researchers conducted an initial analysis of each interview before holding the next one, and if important issues were identified, they were explored further in the next interview. When no new codes, concepts, categories, or other information was provided in the next interview, the data collection process was considered saturated.

### 2.5. Data analysis

The data analysis proceeded continuously and simultaneously with the data collection [35,36]. The data were analyzed using the coding procedures of the Straussian grounded theory approach, which comprises open, axial, and selective coding [35]. A constant comparative method to compare the differences and similarities

between codes and categories was also applied. Following the paradigm model that consists of condition, action, and consequence [35], the researchers explored the relationship between category and four sub-categories. The transcripts, codes, and tapes were reviewed many times until theoretical saturation was reached, i.e., no new sub-categories, properties or dimensions, and theory emerged. In this study, the researchers identified "moving from fear to realization" as the first stage of family engagement in tuberculosis prevention for children living in tuberculosis households.

### 2.6. Trustworthiness

This study ensured trustworthiness by following the four criteria proposed by Lincoln and Guba [37]. Credibility was ensured by prolonged engagement to build trust and rapport, and member checking was performed by returning the analyzed data to the participants with the purpose of checking and validating the findings. Furthermore, peer debriefing was conducted by discussing and sharing the data with co-researchers. Confirmability was gained by adequately reporting quotations using the participants' words. Dependability was maintained by documenting the analytic process sufficiently to allow auditability. Finally, transferability was ensured by providing thorough descriptions of the participants. All of the transcriptions were translated into English by the researcher. An Indonesian English translator familiar with the Indonesian and Sundanese cultures was consulted to avoid any misunderstandings regarding the meaning of the data.

## 3. Findings

"Moving from fear to realization" was identified as the main theme based on the experiences of the Sundanese families, who became engaged in tuberculosis prevention for their children. Their journey began after one of the adult family members was diagnosed with tuberculosis disease. This main category comprised four sub-categories: fear of tuberculosis, seeking information, following God's will, and awareness of risk for tuberculosis transmission. These sub-categories were interrelated.

### 3.1. Fear of tuberculosis

When the diagnosis of tuberculosis was first known, most participants experienced the fear of tuberculosis transmission and the stigma associated with tuberculosis. They feared that tuberculosis would be transmitted to other family members, particularly their children. The participants were concerned about the impact of

tuberculosis on their children's development and health. Their fear of transmission was influenced by their perceptions of tuberculosis. One participant accompanied her mother-in-law's sister to the Community Health Centre. She described her feelings when knowing that her mother-in-law's sister developed tuberculosis.

*"At that time, I felt fear. There are many people living in our household. What will happen if her Tuberculosis transmits to us, particularly to my children, who are still young? I felt fear because I know Tuberculosis can be transmitted through the air or something ... we live in the same house. I felt fear that it (her Tuberculosis) would infect my family, particularly my children ... I have heard that Tuberculosis can lead to death. It is dangerous. Thus, it brought many bad thoughts to my mind. It was the fear that made me cry."* (F3)

This participant lived in the same household with a tuberculosis patient, and she perceived tuberculosis as a dangerous disease that can be transmitted to others and could affect her children. In addition, some participants also reported the fear of tuberculosis stigma as their first reaction to the tuberculosis diagnosis in their family. They feared being blamed by others as the cause of tuberculosis transmission in their community and, consequently, ostracized. One participant (F6) was the mother of three children and infected by tuberculosis. She expressed her fear of being blamed by her neighbors.

*"I was afraid that I would transmit it (Tuberculosis) to them (neighbors) and be blamed as the source of the disease. I feared they would say something like 'because of you, the disease will transmit to the others.'" (F6)*

Similarly, another participant shared her fear. She was worried and feared that her neighbors would become aware of the tuberculosis diagnosis within her family from changes in physical appearance, such as weight loss and coughing.

*"I felt fear... if everybody knows about it (Tuberculosis diagnosis), they will avoid us, and we will be isolated ... If people know, they may not want to get close to us."* (F7)

### 3.2. Seeking information

Seeking information served as a mean to reduce fear among the participants. Most of them reported seeking information from nurses. They also tried to find further information on the risk of tuberculosis transmission, tuberculosis screening, and how to control tuberculosis transmission in the household from several sources, such as brochures, leaflets, and books. The information helped them understand the risk of tuberculosis transmission and tuberculosis prevention in children.

*"I got that information from the nurse at the DOT (Direct Observation Treatment) unit. She said that I should keep the children away from the Tuberculosis patient and separate my husband's cutlery from those of the other family members ... She explained what we should do at home. She asked how many masks we had, and she said that my husband should wear a mask ... I thought that was the best for us as it could help us prevent Tuberculosis transmission in my home, particularly to our children. ... and she also suggested that I and my children be checked to find out whether we were infected by Tuberculosis."* (F11)

However, some participants also mentioned some unfriendly manners they observed in nurses when talking to them. This made

the participants feel upset and uncomfortable. As a result, the participants did not gain sufficient information about tuberculosis prevention.

*"When the nurse was giving information to me, she made me upset. So, I cried ..., she was unlike the other two nurses... They both were ok. They made me feel more relaxed, calm and ready to accept the information... 'oh iya..ya... so, I now understand this disease, and what I should do and how to take this medicine ... It was different with the first person (nurse), who spoke tactlessly to me. I cried and felt annoyed by her ... the way she informed me scared me."* (F6)

### 3.3. Following God's will

All of our participants were Muslim. They perceived the tuberculosis problem in their family as the will and a test from Allah (God). Therefore, they had to pass this test by following God's will and attempting to seek health care for their family, preventing tuberculosis transmission to their children, and praying to Allah (God) for the health of their family. One tuberculosis participant shared her faith story.

*"To me, Tuberculosis diagnosis was given by God. He will also give the cure for it. Before I prayed to God, I took Wudhu or Tayamum (ways to purify oneself before praying) ... I felt the fear of death, and I wanted to be cured. I was thinking about my son. I was worried my disease would be transmitted to my son. As a Muslim, when we get sick, the main thing is to go and receive medical treatment. The problem with Tuberculosis is the need to get the treatment."* (F5)

### 3.4. Awareness of tuberculosis transmission risks

The consequence of the family's action in this stage was their awareness of the risks of tuberculosis transmission and control. Such awareness reflected their understanding of the risk of tuberculosis transmission from tuberculosis patients in the household to their children, particularly to young children ( $\leq 5$  years old), and the importance of preventing tuberculosis transmission in the household.

Most participants reported that the first family member who knew and realized the risk of tuberculosis transmission to their children was the family caregiver, namely, the mother. One participant described that she became aware of this after receiving information from the nurse on the risk of transmitting tuberculosis to her child.

*"I got information from a nurse at the lung clinic. She (nurse) said, 'if you have a family member who has been infected with Tuberculosis, it (Tuberculosis) may transmit to your family members and your children.' Then she said, 'please come here and bring your children for a Tuberculosis screening test . ... She was right, if my children were infected with Tuberculosis and did not receive any treatment, I worried that the virus would become stronger ... I thought it was good that I knew this information early....'" (F2)*

## 4. Discussion

This study revealed the uniqueness of the Muslim Sundanese family where a senior female family member is assigned the role of the family caregiver that involves both taking care of sick persons in

family and rearing children [31]. Therefore, they are typically the first family members who realized the risk of tuberculosis transmission to their children. As the primary family caregivers, these female family members tend to be more caring than the other family members; even when they are sick (e.g., contact tuberculosis), they continue their role as caretakers of their children [38].

“Moving from fear to realization” was the main theme that emerged from this study. It was categorized into four subthemes, namely, tuberculosis, seeking information, following God's will, and awareness of the risk of tuberculosis transmission and the importance of Tuberculosis prevention.

The findings of this study revealed that fear of tuberculosis transmission was a common response to tuberculosis diagnosis in the households we investigated. Living with tuberculosis in their households made the participants worried about their children's health. They were especially afraid of tuberculosis transmission to their children because they thought that tuberculosis infection could lead to the impairment of their child's health and possibly death. Their fear stemmed from their misperceptions concerning tuberculosis. The participants perceived that tuberculosis is a dangerous disease, which is communicable and can be transmitted through the air or by chatting with an infected person. However, they did not know how to prevent its transmission or keep other family members safe. In addition, their previous experiences of hearing that someone had died from tuberculosis made them conclude that tuberculosis is a dangerous disease. This finding was similar to those of previous studies from India, Ethiopia, and China, which have reported that most people understand that tuberculosis can spread to others, but they lack the knowledge about the basic tuberculosis prevention measures [39–41]. This lack of knowledge contributes to the feelings of fear regarding tuberculosis transmission to other family members, particularly to children, and anxiety about their children's future [19,42].

Our findings showed that the fear of tuberculosis transmission to other family members, particularly to young children, and the concern about their children's health drove or motivated the participants to seek information regarding tuberculosis prevention in the household. This was in line with the findings of another study on other diseases that reported a strong relationship between the fear of a dreadful disease such as cancer and information-seeking behaviors [43]. Seeking information through reading books or other printed materials such as brochures and talking to health professionals can help families make the right decisions for their children's health [44]. In consideration that families need information to cope with their fear of the disease, the way the nurses educate the family can contribute to the family's adherence to the treatment [45]. The participants in this study suggested that the tactfulness and friendliness of the health professionals were comforting and encouraged them to ask questions, which improved their understanding of the risk of tuberculosis transmission and the importance of tuberculosis prevention in their children. Good open communication with healthcare providers is considered as the key factor in increasing the success of treatment [17,19,20,46].

This study also highlighted the role of religion in helping its participants cope with fear. Our participants believed that having tuberculosis in the family was God's will and a test from Him. God (Allah) states in the holy Qur'an (2:155–156): “And certainly, we shall test you with something of fear, hunger, loss of wealth, lives, and fruits (of your toil), but give glad tidings to those who *As-Saabireen* (patiently) persevere, who say, when afflicted with calamity: Truly! To Allah we belong, and truly, to Him, we shall return” [47]. The participants believed that their tuberculosis disease should be accepted with faith and patience. The participants believed that if they adhered to His words and successfully passed this test from God, He would grant them His love (cure) as Allah states in the holy Qur'an (3:146): “Allah surely loves those who are

the *Saabireen* (patient ones).” Consequently, our participants expressed that they strived to follow God's will.

Even though the fear of tuberculosis made their minds unstable, their firm faith in God calmed their minds and reduced their fear of tuberculosis, which led them to be conscious and realize the potential of tuberculosis transmission. Therefore, they were able to seek treatment for their family. This finding is consistent with those of other studies, which have reported that faith in God is essential in coping with disease and dealing with all suffering by accepting one's situation and believing that God will help [19,48].

The realization of the risk for tuberculosis transmission reflected the participants' awareness of the risk of tuberculosis transmission from tuberculosis patients to children in their households and their willingness to prevent it. Adequate information helped with this realization because it heightened their knowledge and improved their perceptions of the disease, its treatment, and prevention in the family [20,46,49]. Furthermore, religious beliefs and practices also helped them realize the risk of tuberculosis transmission. They facilitated the participants' understanding of the disease and provided meaning to the disease [50,51] and hope to deal with their fear associated with it [51]. Therefore, religion played an important role in disease prevention [50].

## 5. Conclusion

The fear of tuberculosis transmission and the stigma attached to tuberculosis are common responses to having a person with a tuberculosis diagnosis in Sundanese families in Indonesia. This fear may inhibit the family's willingness to engage in tuberculosis prevention measures among children living in a tuberculosis household. However, realization is an important starting point in order for families to begin their journey of tuberculosis prevention engagement. Therefore, nurses should provide adequate information employing the necessary tactfulness and being sensitive to both the personal needs and cultural aspects of the patients and their loved ones in order to improve their understanding of tuberculosis, the risks of its transmission, and prevention. They also need to consider the religious beliefs and practices of the families, which can serve to calm their mind. These approaches can bring the family to the realization of the risks concerning tuberculosis transmission and enhance their willingness to prevent tuberculosis transmission to their children.

## Conflicts of interest

The authors declare there is no conflict of interest related to this study.

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## Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.ijnss.2019.06.002>.

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