

Conference Paper

Family Experiences of Getting Tuberculosis Diagnosis

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Abstract

Background: Children who living in tuberculosis (TB) household have a high risk to be transmitted by TB, that become the main reason for those children to be given TB prevention. Diagnosed by TB, is an entry point of the families to be aware of the risk of TB transmission and the need of TB prevention, especially for their children. **Objectives:** This study aimed to explore the family experiences of living with patients diagnosed with tuberculosis. **Methods:** A qualitative study was conducted from December 2016 to July 2017, among fourteen family caregivers whose a previous adult active-TB and have children living in same households. The key participants were recruited from a lung clinic Bandung-Indonesia and followed up to their home. Data were gathered by in-depth interview. Each interview took 40-90 minutes in the informant's home. Data were analysed by content analysis. **Results:** Most families experienced TB diagnosis delayed. They did not notice initial TB symptoms, felt inconvenience with the health care services, and travelled around for the right diagnosis. **Conclusions/Importance:** This study highlighted important early getting TB diagnosis, therefore nurses and other health care professionals should enhance family's knowledge and awareness to TB symptoms and the health care services system, in order to improve family awareness to the risk of TB transmission. Moreover, strengthening of the health care services system is needed to improve the effectiveness and quality of TB diagnosis.

Keywords: children, experiences, family, indonesia, tuberculosis diagnosis

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1. Introduction

Children ≤ 5 years old who living in households with active tuberculosis (TB) were reported as the highest risk population to be infected by TB. This situation was related to the frequency of spending more time at home or sleeping in the same bed or room with the TB-positive (Nevita, Sutomo, & Triasih, 2016; Rutherford et al., 2012). Moreover, it was also related to their immaturity of immune system. Therefore, when they have been exposed to TB disease, they will be infected by TB and developing the TB disease easier than adult (Kartasasmita, 2009).

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However, most families did not aware to the risk of TB transmission from the adult active TB in households and the need of TB prevention. One of reasons was they did not recognized with TB symptoms, and the consequence was delayed TB diagnosis (Rakhmawati, Nilmanat, & Hatthakit, 2019). The delayed getting a TB diagnosis lead to delay of the families to engage in TB prevention for their children (Cai et al., 2015). Developing of TB disease among older children is within one year, while among young children is shorter than older children (World Health Organization, 2014). Therefore, getting a TB diagnosis is an entry point of the families to be aware of the risk of TB transmission and engage to TB prevention for their children.

Several studies in worldwide had reported about delayed of TB patients to get TB diagnosis such as most TB patients in Kenya got TB diagnosis ranged 3 weeks-9 years from initial symptoms of TB (Ayisi et al., 2011), and most TB patients in Nigeria were more than 2 months (Christopher & Bosede, 2010). These conditions were reported due to misperception of TB symptoms, financial problem, and stigma. When the families realized with the TB diagnosis in households, the family will protect their children by screening of TB infection among their children, giving and adhere to tuberculosis prevention treatment (Getahun, Sculier, Sismanidis, Grzemska, & Raviglione, 2012; Zelnor et al., 2014), and controlling TB infection such as TB patient should use mask and sleep in different room with children (Lule et al., 2015).

This condition may also occur in Indonesia. However, the information related to the onset of TB symptoms to TB diagnosis is limited. Moreover, Indonesian context may influence on their experience in getting TB diagnosis. An understanding of what is going on among family to get TB diagnosis is needed. Realizing TB diagnosis within family, lead to the awareness of family to the risk of TB transmission for their children. It will determine their awareness to prevent TB transmission to their children. Whereas household contact between active TB and children had a significant correlation. Children who have TB contacts with active TB in their households had 6.378 times the chance of having TB than those who did not have household contacts (Yulistyaningrum & Rejeki, 2010). Therefore, this study aim to explore how were the experiences of families to get TB diagnosis. This study is useful for nurses in nursing practice as a guidance to develop the nursing interventions in order to enhance the family's awareness to the risk of TB transmission and the need of engagement in TB prevention for their children.

2. Methods

A qualitative study was used to conduct this study, which provided an understanding and exploration in particular context or issue (Creswell, 2013; Polit & Beck, 2012; Strauss & Corbin, 1998). This study was conducted in Bandung, Indonesia from December 2016 to July 2017.

The participants were families who were recruited by purposive sampling technique with inclusion criteria; had a previous adult active-TB and had children living in same households. The key participants were family caregivers of families. They were one of family members who have more knowledge about their family, and voluntarily participated in this study. They were recruited from a lung clinic Bandung, Indonesia, who has been approached and given the information about this study by a nurse at the lung clinic. Then, after they agreed to be the participant of study, the researcher conducted an initial meeting with the participants at their home to create trust, inform further about this study, and asked their sign in an informed consent. Data saturation was obtained at fourteen key participants.

In-depth interview was applied in the family's homes to obtain data of family experiences by using an interview guide. This guide was developed from a literature review. The interview was started by the general questions and followed by the specific questions. Interviews were applied 2-4 times for each participants and spent time 40-90 minutes for each interview. The data of interviews were recorded by a tape recorder and continued to transcribe verbatim. Content analysis was used to analyse the data, which comprises read each transcription line by line, identified words, phrases, and sentences that have meaning, and coded them, then, categorized them by their similarity meaning to determine categories and themes (Bengtsson, 2016). Concerning to achieve the trustworthiness of study, this study also applied member checking technique.

An ethical approval was obtained from by the Ethical Committee of the Faculty of Nursing, Prince of Songkla University, Thailand with No. MOE 0521.1.05/2580, whereas informed consent was also obtained from all participants to protect confidentiality of the data.

3. Results

In this study, all of the family caregivers were mothers and most of their educational attainment was at a senior high school level. The majority of them were housewives,

and only five of them were employed as a shopkeeper or other blue-collar jobs. They ranged in age from 22 to 43 years old, and all of them were Muslim. There were 8 nuclear families, while another three lived as an extended family, and three others lived as a compound family. Five participants were sick with TB infection while being engaged in TB prevention for their children, whereas the other nine took care of the sick family members and their children. The family were coded from F1 to F14.

Getting a TB diagnosis was a condition of the first stage that as an entry point of the families to engage in TB prevention for their children. The TB diagnosis within the family made families aware of the risk of TB transmission from the adult family member with active TB to the children in the household. The TB adult of the families were diagnosed at any health services including at a hospital, a Community Health Center (CHC), and a lung clinic which most families called as *Cibadak* because that lung clinic is located on *Cibadak* Road. The period of being diagnosed with TB from symptoms varied, which was about 2 days to > 1 year. The findings revealed that some families getting a TB diagnosis delayed. During the period of being diagnosed with TB, the families expressed their experiences including did not noticing with TB symptoms, felt inconvenience with health care services, and traveled around for getting the right diagnosis.

3.1. Not Noticing TB symptoms

Most key participants reported that their family did not notice the TB symptoms within their family because they thought that their health problem's symptom was only a common cough. Therefore, they ignored their health problems and tried to treat themselves by buying some medicines from a drug store or a pharmacy. They became aware and sought a health care services after their condition was getting worst. For example, Mrs. WN from F4 described that her family did not concern about her husband's symptoms. Initially, her husband tried to do self-treatment, and began to seek a health care services after his condition became severe.

He (husband) ignored his illness. He often coughs and usually took some medicines from a drug store (to reduce his cough). Over the time, because he ignored his illness, he had bloody vomit. So, after I forced him (to visit a doctor), he was willing to go to a doctor clinic. But, the doctor said he should go to the *Cibadak* (lung clinic) because he should be Rontgen. After that, we knew it (TB diagnosis) and he should be treated for 9 months (F4; L4-7)

3.2. Inconvenience with health care services

Some key participants reported that they felt inconvenience with health care services system such as taking long queues and confusing with the working area responsibility of the CHC. As Mrs. AS from F4 reported that her husband took a treatment at 2 weeks after he had a persistent cough, because he did not want to take a long queue at a clinic.

Another instance, Mrs. HH from F13 had a daughter (19 years old) who had some symptoms of TB, she expressed her confusing with the working area responsibility of the CHC. Concerning to seek the health care for treating her daughter, they had to travel around to some CHCs to seek the right CHC that responsible for the area where her family lived.

At that time, my relative worked there (lung clinic), she asked me to check my daughter condition to the CHC, but it made me traveled around to many CHCs ... Initially, I visited this CHC, then, a health staff said, "Mam, you should not come here, you should go to that area!" But, when I visited that CHC, they also said "Mam, you should not come here!" I did not know where the right CHC for my family was. Finally, I found the CHC at Sukahaji road. I just knew that my family included in the working area of Sukahaji CHC ... At the Sukahaji CHC, they asked me to bring the Rontgen test of my daughter. I said, "I don't understand". Then, (the health staff said) "you check your daughter to the lung clinic to get Rontgen test." They should do that (explain clearly), so, I can understand it (F13; L182-189)

3.3. Traveled around for getting the right diagnosis

Failed to detect of TB diagnosis early was reported by seven of 14 key participants. They expressed their experience when the family decided to seek care at the health service, they traveled around to several health services for getting the right diagnosis. For instance, Mrs. AS from F2 reported that her mother in-law was a TB patient in her household. Initially, her mother in-law often coughs. Since her mother in-law's illness was not getting better, her family bring her mother in-law to several health services until found out the right diagnosis. Their traveling for getting TB diagnosis spent more than one year.

She (mother in-law) had been checked to the health clinic at X road, near the *tupperware* shop. There is a health clinic. They (health professionals) said that "it (her

illness) is only common cough.” Then, we stopped her treatment and changed to the Y hospital. They (health professionals) said that my mother in-law had a lung cancer, so, they referred my mother in-law to the Z hospital (General hospital). But, they (health professionals at the Z hospital) said that it (mother in-law’s disease) was not a cancer. Then, she was referred again to the lung clinic. In the lung clinic, we knew that she was infected TB. Therefore, she got treatment for 6 months. (F2; L7-12)

Another example, Mrs. LN from F6 described that she was a TB patient in her household. Initially, she noticed her illness was as a common cough but since her illness was not getting better, she traveled around to look for the right diagnosis.

Initially, I had a cough. But, it never cured although I went to the CHC many times. I have been given some medicines, but there was no reaction at all ... I went back and forth to the CHC for 2 months ... at the CHC, the diagnosis was only a common cough. From the first until the third visit, I received the same medicines. So, after the third time, I asked to be referred to a hospital. Then, a doctor said “ok, let’s try to the hospital that more complete (facilities) than in here!” Then, I asked to go to Cibadak ... A doctor (at Cibadak) who told me (about my TB diagnosis). (F6; L4-30)

According to interview data, most key participants reported that the first family member who knew more about TB diagnosis was a mother (wife) as a main family caregiver either as a TB patient or not. Therefore, the caregivers were the first family member who realized to the risk of TB transmission from the active TB households to their children. In this stage, once the caregivers knew about TB diagnosis within their family, they applied three actions comprised of responding to TB, seeking and receiving information, and believing in God’s will.

4. Discussion

Realizing the risk of TB transmission is an important point as the initial engagement stage of the family engagement process in TB prevention for children. According to the findings of the study, getting a TB diagnosis among one of the adult family members was the point in time when the families began their journey to engage in TB prevention for their children. Missing a TB diagnosis caused the family to not realize the problem in their family. Another study related to child mental health also described that in the beginning of the engagement process of youth and families in mental health care was the recognition of a child mental health problem by parents, teachers, or other adults

within a child's context (Gopalan et al., 2010; McKay & Bannon, 2004). However, the finding of this study revealed that the wives were the first family members who realized the risk of TB transmission to their children. It may be influenced by the Indonesian view that the mother is the family caregiver who plays the main role in taking care of a child (Piercy, Soekandar, Limansubroto, & Davis, 2005).

Some families reported a delayed TB diagnosis because of a delay in seeking care and a delay in health services to detect an early TB diagnosis. Most families misinterpreted the symptoms of TB as a common cough. Misinterpretation of TB symptoms led the family did not realize that their one of family members has been got TB, which in turn they did not try to seek any help or treatment from health (Ayisi et al., 2011; Christopher & Bosede, 2010). Therefore, the family did not also realize that this condition led their children were exposed and infected by the infectious adult family members (Getahun et al., 2012).

Additionally, some families felt uncomfortable with the health care services because they had to travel around to find the location of the right health care service. These conditions led the family to a delay in seeking treatment early. Moreover, delayed TB diagnosis and care were also caused by failure of the health care services to consider an early TB diagnosis, and also led the family to unnecessary traveling to get the right diagnosis. Late detection of a TB diagnosis led to late engagement of the family to prevent TB transmission from the TB patient in the household to the children. The patient and provider delays in a TB diagnosis in Asia were associated with TB prevention and control (Cai et al., 2015). Therefore, early detection of TB is needed and it was suggested that health care professionals and providers improve the knowledge in the populace on TB symptoms. The health care system also needs to provide better procedures to diagnose TB.

5. Conclusion

This study highlighted important early getting TB diagnosis. The family experiences included not notice initial TB symptoms, felt inconvenience with the health care services, and travelled around for the right diagnosis. Their experiences contributed to the delayed TB diagnosis, which in turn influenced on delayed of family to engage in TB prevention for their children who living in active TB in household. Therefore, those children will be placed in the high risk to be infected by TB. Concerning this situation,

nurses or other should be the consideration for nurses or other health care professionals should enhance knowledge of TB symptoms and better procedures to diagnose TB.

6. Recommendation

A delay in getting a TB diagnosis among adult family members in the family was experienced by some families when the families first become engaged in TB prevention for children. The intervention program in the first stage should focus on developing family awareness to the risk of TB transmission. Nurses or health care professionals and providers should help the family to improve the family's understanding of TB symptoms, TB prevention, and the health care system. Providing better procedures to diagnose TB and good communication to the families should also be a concern in developing an intervention program in this stage, which in turn enhances the awareness of family caregivers.

Another recommendation is for health policy. The findings suggested that the health system needs strengthening at both the primary (the CHC) and secondary levels (the lung clinic) in improving the effectiveness and quality of TB diagnosis for adults and children. Another suggestion was improving accessibility to the health services for childhood TB control, such as increasing the number of adequate facilities for primary health care (the CHC) and ensuring coverage of subsidized health insurance for the poor and nearly poor families.

Disclosure

There is no conflict of interest related to this study

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