

## Youth perspective on pulmonary tuberculosis parent's care

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### ABSTRACT

When parents have pulmonary tuberculosis (TB), youth can provide attentiveness to parent's physical need and TB treatment. The purpose of this study was to determine the response of youth whose parents suffer from pulmonary TB. This research used descriptive qualitative design. Semi-structured interviews were conducted online and/or face-to-face in November 2020 to June 2021. There were 17 participants contributed to this study consisting of seven youth and seven parents or older siblings with pulmonary TB at Bogor regency. The data obtained were further analyzed using thematic analysis. Four themes were produced from this research. These themes include knowledge of youth and parents with pulmonary TB: the transmission, administration duration, and side effects of TB medication; negative responses of youth to parents with pulmonary TB; youth poor skills in taking care for families; and cooperation between family, and health care workers in supporting the healing of pulmonary TB. Future research could develop and strengthen youth capacity to increase their skills providing care to parents with pulmonary TB.

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## 1. INTRODUCTION

Tuberculosis (TB) is an ancient disease that has been found since 9,000 years ago [1]. This chronic disease can be transmitted between humans through the air [2]. Indonesia is one of the countries with the highest TB cases in the world in which approximately 845,000 people with active TB and 24,000 people with drug-resistant TB. In addition to the high number of cases, the mortality rate of TB in Indonesia is also high, reaching around 98 thousand or equivalent to 11 deaths/hour [3]. Case finding also experienced problems, especially in 2020 where from 845 thousand cases, only 349–350 thousand cases were found, while from an estimated 24 thousand drug-resistant cases, only 860 cases were found [4].

The increasing of TB cases number and mortality rate per hour may occur at any age, especially at the productive age, however many people still underestimate the impact and threats of this disease. This is supported by a study which conducted in China. It reported that TB patients' lack of behavior in managing TB care and preventing TB transmission [5]. This situation also occurred in Indonesia. Unfortunately, when pulmonary TB parents live with other family member in household, it will increase TB transmission that influence physical and psychosocial other family member including youth.

Youth is a period between childhoods and adult, that actually have an important role in increase health development to smallest scope, which is family. Youth always expected to have their daily live with

health parents. In order to adopt with youth growth and development, parents have to fulfill youth need, such as support, love, encouragement and acceptance; however it would not be noticed by parents, especially when parents is sick. When their parents sick, youth have role to increase parent's health such as taking care and give support to parents. Eventhough, some studies have recognize youth as change agents to improve parents life style [6], [7] and literature review also reported that many children in families with cronicallly ill are highly involved in caring [8], but relatively still less of study that identify youth perception and responses about their parents with pulmonary TB. This research was a first phase of study that aimed to determine the perceptions or youth's opinion about parental illness, as well as their responses, and actions towards families, specifically parents/brothers with pulmonary TB. This study result generates to develop nursing model that based on youth capacity strengthening in order to improve parent's adherence to tuberculosis treatment.

## 2. RESEARCH METHOD

This study employed descriptive qualitative design. This study conducted in November 2020–June 2021. The inclusion criteria of participants were youth who have parents/adults with pulmonary TB, pulmonary TB patients and health care workers for TB program in Bojong Gede District and Tajur Halang District, Bogor Regency, Indonesia. Participants were contacted through whatsapp text and phone call about their willingness to participate in online or offline interviews. Semi-structured interviews were conducted for 30 to 60 minutes using a question guideline that prepared prior to data collection. The participants' participation was voluntary, so it did not have any coercion to the participants. Before the implementation of the interview, the research objectives were explained to the participants. Then informed consent from each participant was obtained. Several interviews were conducted at the participant's home, due to network constraints. The data analysis method applied in this research is thematic analysis. In the analysis process, the researcher reading the transcript of the recording repeatedly, finding keywords, compiling the categories, and finally determining the theme to answer the research objectives. The ethical approval of this study was obtained from Ethics Committee of the Faculty of Nursing, Universitas Indonesia with approval number: SK-273/UN2.F12.D1.2.1/Etik 2020 dated August 25, 2020. Discussion between researchers held to ensure that there was no bias in analysing themes. All the researchers were agreed of these findings.

## 3. RESULTS AND DISCUSSION

### 3.1. Results

#### 3.1.1. Characteristic of participants

There were seventeen participants involved in this research consisting of seven pulmonary TB patients, seven youth and three health care workers that have responsibility to TB program at primary health care. Most of the pulmonary TB patients and youth involved are male (64.28%) with the age range of pulmonary TB patients is 25-63 years old, while the age range for the youth is 15-24 years old. Furthermore, most of the participants' parents/families have education background as vocational school graduates or equivalent (57.14%), while youth are students of vocational high school as large as youth graduates from vocational high school or equivalent were 42.85%.

#### 3.1.2. Interpretation of themes

Based on the analysis result, there were four themes obtained and described as:

- The knowledge of youth and parents about the causes, transmission, as well as administration duration, and side effects of pulmonary TB drugs is not adequate.

The majority of adolescent participants showed that they have inadequate knowledge about the causes, transmission, as well as administration duration, and side effects of pulmonary TB drugs.

*"as usual, well I don't know anything." (p6, p12)*

*"I think it is different (flek and TB). TB is scarier, right? It is more severe, while flek is not that severe." (p14)*

*"It is confusing. Every time my mother takes medicine, she always vomits." (p2)*

Furthermore, parents/families with pulmonary TB participants also have lack of knowldege about TB eventhough participants were undergoing pulmonary TB treatment.

*"I am confused. If I do not take the medicine, I will not heal. But if I take the medicine, it becomes more severe (vomitting-red), so what should I done then." (p1)*

*"It is because I like to sleep on the floow and I rarely wear jacket and mask. I think the wind causes it, in addition to dust as well."(p1)*

*" yes...That's it; the possible cause is because I take a long ride home by motorcycle, that's all."*(p5)

*"in my opinion, it is caused by virus, so it is normal. TBC is severe, so every thing must be separated, like plate and glass."* (p11)

*"This is actually not a transmitted disease."* (p13)

- Youth' negative response towards their pulmonary TB parents

The majority of youth gave negative responses to parents/families with pulmonary TB through emotional responses, such as ignorance, sad and shock. Hence, there was physical response that showed by adolescent participant that getting nausea response when he saw his parents vomiting after taking pulmonary TB medication.

*"It will be as usual. Just ignore it."* (p6)

*"I don't want to ask either. I don't want to mind my parent's business. I have my own world, he."*(p12)

*"It is so sad." When my mother vomits, I also feel nauseous because I have gastritis." Yes, it is because*

*I smell weird odor, so I vomit to."* (p2)

*"Well, I am still worried for my father's disease; sometimes it is scary, because he has TB."* (p8)

*"At first, I was surprised at first."* (p10, p14)

- Youth' skills in taking care for their parents or family member with pulmonary TB are poor.

Youth' poor skills in taking care for their families were stated by the youth, parents/families with pulmonary TB, and health care workers. Adolescent participants showed their reluctance to take care of their family with pulmonary TB by saying, "Just ignore it" and their desire not to interfere in their parents' life. There was also one adolescent participant who showed a silent reaction or just watching his parents vomiting every time they took medication, while another another participant relied more on healthy parents/mothers who took care of TB parents.

*"...it was just as usual, well it is because I know nothing, so I just ignore it..."*( p6)

*"They did not tell me. I was at my room all the time. I also never asked them, I do not want to know my parents' business."* (p12)

*"I will just look at my mom when she was vomiting."* (p2)

*"...I do not really know about the medication, but I always check it up, my mom takes me to the doctor."*(p14)

Youth' poor skills were also expressed by the parents with pulmonary TB and health care workers in charge of TB program. Based on the perspective of the parents, participants expressed their fear if the youth were sad when they were informed about their disease; youth only prayed and did not show concern because of their own activities and work.

*"I do not want to tell my children, I am afraid that they will be sad and overthink."* (p11)

*"Well he only prays to be healed quickly."* (p13)

*"well... I take my medicine by myself; he could not do it (reminding me to take my medicine-red)." (p5)*

*"my son always goes out, while his father always sleeps, there was no one."* (p1)

*"the youngest work (adolescent-red), but sometimes he helps me to take the medicine."* (p7)

Meanwhile, health care workers also viewed that the youth rarely taking care of their parents/families with pulmonary TB. In this case, the youth usually have a role of accompanying them only to get medication at primary health care, and they were usually taken care of by their healthy partner (husband/wife).

*"It is usually my wife who reminded me to take my medicine."* (p15, p16, p17)

*"Youth rarely take it (medicine-red)." (p16)*

*"If it is male patient, he will be accompanied by his wife. Patient sometimes also take it all by himself. When it is a female patient, she is usually accompanied by her husband, but if her husband is working, then her children will accompany her."* (p15, p17)

- Cooperation between families and health care workers in supporting the recovery of pulmonary TB patients.

This theme showed pulmonary TB patients' expectation in undergoing treatment. TB patients hope that there is cooperation from all family members and health care workers so that they can recover from TB. They also hope that the health care workers have more time in providing explanations, especially when experiencing the medication side effects. In addition to the expectations from health care workers, TB parents/families received support from the youth to accompany themselves in completing their treatment apart from the participants' own motivation or intention to recover.

*"at least the doctor should be more give information. His explanation is not clear enough regarding the pulmonary TB."* (p5)

*"I want to wake up.I wanto to go out to recite the Al Quran and healed."* (p1)

*"My husband and my children give me support."* (p3)

### 3.2. Discussion

Behavior is the combination of experiences and activities of someone as the results of internal and external factors covering three areas of knowledge, attitudes, and actions [9]. Lack of TB patient to adhere TB treatment influence TB transmission, especially in the family. Moreover, if family member did not recognize about pulmonary TB. Youth and parent's knowledge regarding the causes, transmission and duration of TB treatment that is not adequate became one of the factor that can cause incomplete of TB treatment and medication. It can lead to drug resistance and death. Knowledge is an information that could be provide by training and education. Lack of knowledge from TB patients is accordance with research that held in Africa, including in Indonesia. From these qualitative research found that TB patients have poor knowledge regarding the causes, transmission, and duration of TB treatment [10]. In Indonesia, knowledge and perception of TB treatment became barriers to succesfull TB treatment that identified through qualitative study [11]. Meanwhile, youth as part of family also had poor knowledge regarding TB. This is accordance with previous reviews and research that reported poor knowledge of youth about TB is also one of the inhibiting factors in the completion of TB treatment [12]–[14]. If youth health literacy skills are not balanced with the development of information and technology, there will be poorer health outcomes , including lack of information [15] and it lead to an incorrect understanding of TB disease. Beside that, increase of smoking behavior in youth, other house hold with TB that did not adhere the treatment and unhealthy TB individual behavior will affect the higher incidence and transmission of TB.

Individuals will give a response when they encounter a stimulus. When a member or head of household is sick, it will affect other family members, including youth. The second theme describes youth response to situation that faced by parents or families with pulmonary TB. Most of them showed negative response. Beside negative emotional responses, youth also give physical responses especially when they saw their parents vomited after taking medication. This negative emotional responses include ignorance, worried, sad that developed by youth are accordance with research that reported youth responses when their parents suffered from life-threatening diseases such as cancer or other diseases that can cause disabilities such as multiple sclerosis and low parental mood [16], [17]. Then, youth also will develop other responses when their parents have chronically disease such as cancer. The responses are anxious and depression [18]–[20]. This significantly depends on the severity of parents' disease and stress due to parental illness. Other responses developed by children who have parents with TB and human immunodeficiency virus (HIV) in Zambia, Hunleth reported that children will get closer with their ill guardian and provide attentiveness [21].

The third theme is the youth' poor skills in taking care of their pulmonary TB parents. This situation was also expressed by parents and health care workers. This theme is not accordance with the actions taken by youth when taking care of the elderly, especially parents with life-threatening diseases such as advanced cancer. Several studies and reviews reported that youth develop a coping that focuses on solving problems such as parentification, helping each other in the family, giving help in taking care of their parents including personal care [19], [20], [22]. Hunleth also reported that children who have parents with TB and HIV will providing good care and give attentiveness to adults or parents physical needs and medication program [21]. Before youth provide care to parents, youth must have self awareness including factors related to communication, so that they can understand their parents condition [23]. A child, especially those in the late adolescence stage or youth, should be able to develop a "caring" behavior or activity as they grow up since the characteristics of this age are better, more realistic, and more mature psychological responses in dealing with problems [24], [25]. This can positively affect the children's social skills, including youth, and the ability to control their perceptions from uncontrollable external factors [16].

The fourth theme is the cooperation between families and health care workers to support the recovery of TB patients. Patients expect well recovery of their illness and being able to carry out daily activities including religious activities. The recovery of TB patients influence by internal factors such as

patients' self-motivation and intention, and also external factors such as support from families and health care workers, including the management of psychological stress [26], [27] as well as support from peers/fellow TB patients [28]. There was an advance change of TB management due to COVID-19 pandemic, including TB patients and caregivers that have responsibility of their self care. Through COVID-19 pandemic situation, youth in UK consider on their role as recipients rather than participants; providing them with appropriate accessible information will increase youth concern about family that consistent with a high level of moral development [29]. From this youth' view of pandemic situation, health professional can empower youth by optimizing youth role and function as caregiver or providing care for TB parents as an implementation of youth' caring and obligation activities to their sick parents.

These convey the implication of nursing practice in Indonesia. Eventhough, there were limitation on research that related with youth' perception on taking caring of parents with pulmonary TB in Indonesia, nurses can play an important role to promote health and prevent the transmission of pulmonary TB by encourage youth role and function. Nurse as a leader need to develop family model and intervention to decrease the transmission of pulmonary TB by provide youth' awareness of parental disease and optimizing youth' role as family member since this age need to participate with their meaningfull way. The model and nursing intervention should encourage and empower youth' capacity and provide opportunity to learn and strengthen their capacity. The acceptance of parental disease to children and youth must facilitate, so it can reduce the negative effects of youth development [30]. Research and reviews have been done by increasing youth' role and bring impact to parents, such as changing parents health behaviour to decrease degenerative and non infectious disease [6], [7], also improve parents quality life. Beside that, the impact also affect to their self such as improving coping skills, social support, knowledge about the disease and reduce their emotional stress [31]. When providing empowerment and develop youth opportunities until they are engaged, there will be multiple benefits for society.

#### 4. CONCLUSION

Youth behavior in terms of their knowledge, response, or action in taking care of their parents or families with pulmonary TB has not optimal yet. Therefore, it is necessary for nurse, as one of health professional to develop a model in the form of a series of structured interventions for late adolescence to improve the health behavior of parents or families with pulmonary TB. It is because late adolescent period is the most appropriate time to become a change agent in the family. The role of youth as change agent in the health sector can help the parents or families with pulmonary TB to complete their treatment and prevent pulmonary TB transmission.

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