

THE EXPERIENCE AND PERCEPTION OF TUBERCULOSIS PATIENTS DURING THEIR TREATMENT IN JAKARTA.

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Abstract

Tuberculosis is an infectious disease and remains a significant health problem in Indonesia. Combating TB is paramount as the drop out and relapse of patients are still high. This study aimed to explore the experience of tuberculosis patients who had relapsed. The qualitative method with phenomenological approach was used in this study. Ten participants, with relapse of TB visiting the out patient of pulmonology department in a respiratory hospital in Jakarta were selected using the purposive sampling and interviewed using semi- structured questions. The data were analysed using conventional content analysis. This study found four themes: the perception of tuberculosis, the impact of tuberculosis on patients, the challenge of TB patients during their treatment and the support from family. These results of this study can be used as the information for the healthcare workers to improve TB program such as, increasing health education program, so that the prevalence of the relapse in TB patients can be reduced.

Keywords: TB patients, experience, perception, treatment

BACKGROUND

TB is a contagious disease of lung infection which causes a high mortality rate in Indonesia. The data indicate a reduction in the incidence of TB in Indonesia, from the third rank in the final ten years became the fifth rank in 2009 (WHO, 2012). Nevertheless, the incidence of TB is still really high and has not achieved the expected target of the Millennium Development Goals (MDG's) that half of the incidence of TB in 1990, or approximately 221,000 patients in 2015.

Detection of TB and their recovery in Indonesia is very overrated. Indonesia Health Profile data in 2011 (Kementerian Kesehatan RI, 2012) describe that most of the provinces (31 provinces) have 5-15% of TB cases. There are two provinces which have the percentage of patients with BTA+ more than 15% such as North Maluku province (19%) and Jakarta (16%). For the treatment success target of more than 85%, according to the WHO nine provinces, including Jakarta has not yet achieved the target of TB treatment success. Profil Kesehatan Indonesia shows that DKI Jakarta has the second highest prevalence of TB after West Java.

Tuberculosis requiring long-term treatment to achieve a cure. Rab (2013) explains that TB treatment was given for 6 and 9 months and can be extended based on clinical conditions and resistance tests. Treatment which takes a long time can cause patients to feel tired and do not obey the treatment. This could result in the inability of patients to

complete the treatment of pulmonary tuberculosis, which in turn can lead to treatment failure, drug resistance and will continuously transmit the infection (Vijaj, Balasangeswara, Jagannatha, Saroja & Kumar, 2003). Patient noncompliance in the treatment can cause a high incidence of recurrent pulmonary TB disease (Hutapea, 2008).

The increase in cases of recurrent TB becomes important to explore. Based on the Pedoman Nasional Penanggulangan Tuberkulosis tahun 2011, TB patients who have a recurrence of TB will take in a TB treatment category 2.

The purpose of this study is to get a description about the patient's experience while undergoing TB treatment category 2. Thus, the findings in this study can be used as a basic information to improve health education and prevention program to prevent the recurrence of TB.

METHODS

This qualitative study use a phenomenological approach with conventional analysis methods of content analysis. This design was used to explore the experience of TB patients who receive a recurrent treatment.

Ten participants were selected by purposive method according to the following inclusion criteria: 1) TB patients in category 2, ie recurrent TB patients for drug withdrawal or treatment failures and were mejalani TB treatment category 2, 2) Ability to communicate actively, and agreed to be

interviewed and to participate in the study, 3) TB patients who get a OAT category 2 treatment at the Lung clinic.

Participants were interviewed with a semi-structure questions using an interview guide for 30-40 minutes for each participant. Interview done in a pulmonary polyclinic at the central hospital in Jakarta and performed in a room with good ventilation and circulation as well as separate room with other patients to prevent distraction during the interview.

RESULTS

Characteristics of Respondents. The study involved ten participants of TB patients due to drug withdrawal or treatment failure who are undergoing treatment of pulmonary tuberculosis in the National Lung Hospital Center in Jakarta. The figure of participants by gender has the same number (5 male participants and 5 female participants). The average age of participants is 32.8 where the youngest is 16 years old and the oldest is 56 years of age. The background of the participants in this study varied, 7 participants were educated at the high school, 1 in primary school, 1 D3 and S1. Most of the participants are married (7 people) and 3 participants are not married. The participants who have jobs also varied (1 participant was a student of SMK, 1 a housewife, two people do not work, 1 participants as motor mechanics, 3 private sector employees and 1 teacher and 1 government employee).

Results of Thematic Analysis. There are four themes resulting from experience of the participants with pulmonary tuberculosis category 2, which is experiencing recurrent pulmonary tuberculosis. The analysis produced a theme based on the experience of the participants when the first treatment, the effects of TB treatment and constraints faced by participants at first treatment that cause participants do not continue their TB treatment. Themes include:

Patient perception about pulmonary tuberculosis. This theme is a theme that is identified by the researchers beginning before getting into the themes further. This theme describes the participants' perceptions of pulmonary TB include perceptions of what is pulmonary tuberculosis, causes and symptoms of pulmonary tuberculosis. Interviews showed most participants know diagnoses of pulmonary TB. This is showed from the following statement:

"After my x-ray and sputum test, then I in the diagnosis of TB so I underwent 6 months treatment" (p.9)

Not all participants stated that they have

experienced pulmonary TB, two participant said they experienced flex, such as the following statement:

"The doctor told me that I have flex" (p.3)

"I go to hospital, doing x-rays, the symptoms of flex were positive" (p.6)

Based on the patient's perception of the causes of pulmonary tuberculosis from the interviews, the participants have heterogeneous perceptions about the causes of pulmonary tuberculosis. Participants stated causes of pulmonary tuberculosis caused by the stress, lack of rest, environmental factors, smoking, unhealthy diet and pollution. It is delivered by the following participants:

"I guess, I was sick because I eat unhealthy food and also I think because my mind. Because I am smoker, and I usually hang out with smokers. I can not prohibit them from smoking" (p.9)

"I lived near public hospitals, there we have the cafeteria. There are morgue behind my house and next to the morgue was room lungs. As children we we used to play there. Maybe that's the reason" (p.7)

"Maybe recurrence because I was so tired then I also done operation miscarriage, this affect my health condition become weak" (p.7)

"I think of a diet as well, because I like to eat it if the work carelessly" (p.5)

"The cause is still probably because pollution" (p.4)

Perceptions of symptoms of pulmonary TB describes the perceptions of participants about the symptoms of pulmonary tuberculosis. The participants stated that the main symptoms of pulmonary TB are a cough that they had experienced more than three weeks. Other symptoms are perceived as pulmonary symptoms are weight loss, nausea and vomiting. As stated by the following participants:

"Initially the first cough lasting more than 3 weeks and not heal ..." (p.2)

"my weight dropped from 56 to nearly 30.. like the same elementary school children living skin of the skull" (p.5)

Impact experiencing pulmonary tuberculosis. This theme emerged after researchers identified the categories that have the same experience with the impact of pulmonary tuberculosis. This theme describes the experience of perceived physical and psychosocial experienced by participants during the

treatment of pulmonary tuberculosis. Psychosocial impact while experiencing feelings experienced TB patients experienced when diagnosed with pulmonary tuberculosis and feeling back for the treatment. Most of participant reported feeling sad, shocked, embarrassed and worried again while knowing unaccompanied experienced recurrent pulmonary tuberculosis, such as the following statements.

"I was crying, can I heal?" (p.7)

"Shame. Shame with the friend, I fear having no friend"(p.1)

The volunteers also expressed feelings that must undergo TB treatment again. Three people partisan say bored to treatment that is being lived

"... Well sometimes anyway, really tired of taking medication ..." (p.5)

Although most participants expressed feeling sad and tired during treatment of pulmonary tuberculosis, but three participants said that they could receive when they diagnosed again in pulmonary tuberculosis. As the following statement:

" I get the explanation of 6 months treatment from the doctor, I can indeed it must be in run it. And the time that I go to the tuberculosis treatment clinic, it turns out a lot too. It turns out, not only me who feel this disease "(p.10)

Physical impact was experienced during treatment illustrates the impact of the physical conditions experienced during treatment program, the pain experienced when injecting medication, nausea and dizziness that is felt during treatment, as stated the following participants.

"There it is. So the first time to take medicine I always feel nausea, headache, chills-fever is not clear so, warm body. So when my friend shook hands with me, they said that my hand so warm. Anyway fatigue, so the beginning it was because I was sick, had to take medication, that's all I taste, nausea, dizziness I still Serves for 2 weeks. I think the last 4 day I feel nausea, dizziness already started less though but sometimes still "(p.9)

Challenges while undergoing treatment of pulmonary tuberculosis. This theme describes the constraints faced by the participants during the treatment of pulmonary tuberculosis so that patients do not continue treatment of pulmonary tuberculosis previously. Challenges expressed by the participants are financial constraints and lack of knowledge about the length of TB knowledge. Partisipan reveals the challenges faced during the treatment of

pulmonary tuberculosis financial problems and lack of information about the duration of treatment, such as that delivered by the following participants:

"I always taking medicine but when I feel better I just stop the medicationbeside that because it used the money to pay the medication "(p.3)

"I controlled to the clinic for 30 days continues. Up to 30 completed treatment then roughly a month. after it I already stop. I don't understand how long the treatment should be done "(P8)

Support from family. The support is the support of the family is much needed for compliance and treatment success of pulmonary TB patients. Support given by the family during the treatment process is the support provided by those closest to the family nucleus and the pulmonary TB patients in treatment. Support is provided in the form of support for always giving spirit in the treatment and reminded to always take medication appropriate time. The results of most of the interview participants expressed the family to provide support in the treatment of pulmonary tuberculosis, as told by one of the following participants:

"... Mama always supporting me, you must be cured, you the great people, she said. From the little I like sickly. Then mama support me "(p.5)

DISCUSSION

Patient's perception of pulmonary tuberculosis are the first themes o in this study. This theme describes the participants' perceptions of definition and cause of the symptoms of pulmonary tuberculosis. In this study, most of the participants have the wrong perception of the disease. Participants perceive the disease as lung disease or flex, they didn't know that TB is the infectious disease that can infect other people. Similarly, all participants had inaccurate perceptions about the causes of pulmonary tuberculosis. The participants stated that pulmonary tuberculosis is experienced due to the pollution, smoking, environmental factors and unhealthy foods. However, a different thing with symptoms of pulmonary tuberculosis. The participants have a better perception in this theme. It happens because they have these symptoms so it can provide the right perception. The first theme has similarities with supporting a research carried out by Dias Lima, De Oliveria, Turato and Figueire do (2013) about the experience of pulmonary tuberculosis patients who successfully completed treatment. This study also raised about the theme of support from health workers and patient low of knowledge. The patisipan in the study perceived that causes of pulmonary tuberculosis caused by various factors include: the environment, workplace, lifestyle, water quality and contaminated objects.

The themes of this research also have a similarity to the research conducted by the Bam, Prasda Bhatt, Thapa, Dossajee and Angdembe (2014) aimed to identify the patient's perceptions about TB and identify barriers and treatment facility to seek assistance on slum area in Dhalka, Bangladesh. The results of this study also state perception about TB as one of its themes that also shows there are still misperceptions about the causes of pulmonary tuberculosis.

Treatment of pulmonary tuberculosis requires a relatively long adherence of patients to be able to complete the treatment. Adherence is very important to reduce the recurrence rate, transmission, reducing the resistance of germs and prevent disability (Murtiwi, 2006). Adherence is also influenced by various factors such as the patient's perception of the disease, perception also formed of one's own knowledge. In this study, the participants have a misperceptions of pulmonary tuberculosis especially about definition, the cause of the symptoms of pulmonary tuberculosis, however most participants has the right perception about the symptoms of pulmonary tuberculosis. This is due to the symptoms of an experience that is felt by partisipan. Researcher assumed that misperception of these participants may be an indicator of the low information or knowledge about pulmonary TB. Development program for the TB prevention needs to be done especially for providing structured health education and information for pulmonary TB patients and their families both in the community, health center or hospital. Information is required to provide the right knowledge so that patients have the right perceptions about pulmonary TB.

The theme of the impact of experiencing pulmonary tuberculosis expressed about the perceived experience of the current participants experienced either psychologically and physically experienced. Experience perceived by participants as a psychosocial treatment for lung is the experiences of psychological as well as social experience. Psychological experiences described by unpleasant sad, shocked and embarrassed and afraid to make friend, because they was worry no one wants accompany. This experience is felt, because the participants had to undergo back of pulmonary tuberculosis. Feeling sad because they have experienced the same pain again. Feeling embarrassment suffered pulmonary tuberculosis, fearful friends do not want to be friends anymore. These experiences are also experienced by the participants in the study conducted five yag Dias et al. , 2013). The research aims to explore the experiences of patients with pulmonary tuberculosis who have completed and successfully undergo treatment of pulmonary tuberculosis in Brazil also has similarities with the general theme of this study.

However, the research themes indentified the impact on the family and social environment. The similarity of experiences found in this study, especially with the sub-themes of psychosocial impact. As for the impact on the physical are not included in the study.

Experiencing pulmonary tuberculosis, especially pulmonary tuberculosis recurring certainly cause feelings of sadness and shock. These experiences experienced by the majority of participants who experienced pulmonary tuberculosis. However, there are also acknowledge the participants to learn to get recurrent pulmonary tuberculosis. Feeling bored while undergoing treatment in the long term also experienced a large part of the participants. Support from various parties, both families and health professionals are needed in order to anticipate the feeling during treatment with the right support to continue and complete treatment (Lewis & Newwel, 2009; Lima Dias et al., 2013). Efforts else can be done to anticipate these feelings is a meeting or discussion groups of patients with pulmonary tuberculosis.

Experience physically experienced by the majority of participants were pain caused largely participant take injectable medications, it is experienced by participants during the period of time during a given injections of medication. It is also felt by the participants in the study conducted by Lima Dias et al. (2013) that elevates the experience of pain during treatment. But differences of this study is that study participants incorporate the experience of pain as a different theme. In the study, pain experience incorporated into the theme of the suffering caused by disease, while in this study included pain as a result of treatment of pulmonary tuberculosis with a physical impact. The experience of pain experienced by these participants can also cause participants to feel anxious and afraid. Improving the relationship between health workers and patients with pulmonary TB is one of the efforts to provide opportunities for participants to be able to express their feeling about and to reduce anxiety pain and fear.

The current challenge is the treatment of pulmonary tuberculosis constraints faced by participants during treatment that causes participants did not continue their treatment; finance and the lack of information about the duration of treatment should be undertaken. These results are consistent with research conducted by Bam et al. (2014) which states that the biggest challenge while undergoing treatment of pulmonary tuberculosis is the financial, lack of support, lack of time and knowledge. Financial constraints are the main problem, which is also presented as well as the study of Xu et al. (2013).

The success of the treatment of patients with

pulmonary tuberculosis can not be separated from the support and active participation of the family in reminding and motivating patients with pulmonary TB. Theme support from family of the participants were identified describing the experiences of the participants related to the support given from the family in the treatment. Most families provide support for the treatment of pulmonary tuberculosis began reminding to take medication and accompany participants to treatment. As stated by Paz-Soldah et al. (2013) on his research that aims to explore the patient's perspective, the role of social support during treatment. It said most of the participants get the attention and support of the family during treatment ranging from affection, finance, support, and other psychosocial support.

Aside from the support for the treatment of pulmonary tuberculosis, the health education or providing complete information to the participants of pulmonary tuberculosis is needed. So obtained in the first theme about perception of pulmonary tuberculosis patients in which the majority of participants had inaccurate perceptions of pulmonary TB, its causes and symptoms of pulmonary tuberculosis. This is in line with research by Paz-sSoldah et al. (2013), about the need for better health education for patients with pulmonary tuberculosis and health education to the family and society.

CONCLUSION

Experience of pulmonary TB patients who are treated identified in the themes that emerged. As a major participant perception of pulmonary tuberculosis, especially about definition and causes of pulmonary tuberculosis remains uncertain, although there are some participants who can identify exact symptoms of pulmonary tuberculosis. The effects of treatment affect both psychosocial and physical participants felt while undergoing repeated treatment of pulmonary tuberculosis. The challenges faced by patients with pulmonary TB are financial problems and a lack of understanding of the long treatment of pulmonary tuberculosis. Family support is desperately needed by the participants during the treatment. Development of comprehensive health education programs and sustainable given by health personnel is a recommendation of this study.

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