

The Perception and Life Experience of Pulmonary Tuberculosis Patients during Treatments in Jakarta, Indonesia: A Qualitative Study

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Abstract - Tuberculosis (TB) is an infectious respiratory disease and still remains a significant health problem in Indonesia. Combating TB is paramount as the drop out and relapse of patients are still high. Generally, there are two types of TB patients, which are: TB patient category I and category II. Someone who never suffered and very first had TB treatment is the characteristic of type I whereas relapsed or have second (or several) times of treatment are the characteristic of category II. The aim of this study is to explore the experience of tuberculosis patients who had relapsed; TB patient category II. This research was conducted in Jakarta, Indonesia for seven months (March – October, 2014). The qualitative method with phenomenological approach was conducted in this study. Ten participants, with relapse case that are usually visiting the outpatient 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 and has been saturated. 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 professional, especially community nurse, to improve TB program such as, increasing health education program, so that the incidence of the relapse in TB patients can be reduced.

Keywords - TB patients; experience; perception; treatment

I. INTRODUCTION

Tuberculosis is a contagious pulmonary infection with a high mortality rate in Indonesia. Data shows a decrease in the number of TB cases in Indonesia; from ranking third in the last ten years down to fourth rank in 2007 and fifth rank in 2009 in terms of patients diagnosed with TB [1]. However, the number of TB cases is still very high and has not reached the target expected in the Millennium Development Goal's (MDG's), which is half of the number of TB cases in 1990 or approximately 221,000 patients in 2015 [1].

There are various findings of TB cases along with its recovery in Indonesia. According to the Indonesian Health Profile Data 2011 (most provinces (31 provinces) have approximately 5-15% TB cases [2]. Provinces with a percentage of over 15% for TB BTA+ patients cover two provinces, which are North Maluku (19%) and the Special Capital City District of Jakarta (16%). According to WHO, nine provinces, including Jakarta has not reached the successful treatment target, which aims to achieve more than 85% of TB successful treatment [1].

The Indonesian Health Profile shows that Jakarta with 0.6 of prevalence has the second highest TB prevalence following West Java.

Tuberculosis requires long-term treatment to achieve full recovery. According to Rab (2013) describes how TB treatments are given for 6 months and 9 months, and it could also be extended based on results of clinical and resistance testing [3]. This form of long-term treatment could cause patients to get bored of the treatment and not comply with the on-going treatment plan. This may lead to a patient's inability to complete the TB treatment and cause treatment failure, drug resistance, and continuous infection transmission [4]. Non-compliance with treatment is one of the factors causing the high number of TB recurrence [5].

The increasing number of recurrent TB cases in the same patients along with the high number of TB relapses in hospitals and community health centres have become a vital issue to study. Based on the National Guidelines of Tuberculosis Treatment 2011, TB patients experiencing a relapse will receive category II TB treatment [6]. For this reason, researchers would like to get an overview of patient's life experiences during their category II treatment. A descriptive output is expected from this research, which will give an overview of the reasons behind a patient's incompletion and an overview of life experiences during the repeated treatment. Results from this research could, therefore, serve as input to help improve the prevention program through regular health education to prevent TB recurrence among patients.

II. METHOD

The method utilized in this research is a qualitative design with a phenomenological approach and conventional content analysis [7],[8]. The selected approach and research design was chosen as the research aims at exploring the life experience of category II TB patients during treatment.

Ten participants of the research were selected through a purposive method which involved selecting participants according to the following inclusive criteria:

- Category II TB patients, who are recurrent TB patients due to discontinuation of medication or treatment failure and are currently undergoing category II TB treatment [9].

- The ability to communicate, and also the willingness to be interviewed and participate in the research.
- Category II TB patients undergoing treatment in Lung Polyclinic (outpatient respiratory clinic).

Data were collected by means of semi structured interview and a guideline for a 30-40 minutes interview of for each participant. Interviews were conducted in the outpatient respiratory clinic in the National Lung Centre Hospital in Jakarta and held in a separate room with good ventilation and circulation, which is to prevent distraction during the interview.

III. RESULTS

The research involves ten participants with category II TB due to discontinuation of medication or treatment in the National Lung Centre Hospital in Jakarta. There are five male participants and five female participants involved in this research with an average age of 32.8 with the youngest age being 16 years old and the oldest, 56 years old. The participants' educational backgrounds vary, with seven participants with a high school education, one participant with elementary school education, one participant with a diploma, and one participant with university education. Most of the participants are married, i.e. seven married participants are only three are not married. The participants' occupation also vary; one vocational high school student, one housewife, two unemployed, one mechanic, three employees of private companies, one teacher, and one governmental employee.

IV. THEMATIC ANALYSIS RESULTS

Four themes emerged from the experiences of category II TB participants, who underwent recurring TB treatment. Analysis of themes in this research are based on the life experiences of the participants during their initial treatment, the impact of treatment, and also challenges faced by participants during their initial treatment which have caused participants to discontinue the TB treatment. Data saturated has been achieved and the four themes include as following:

A. Patient Perception of TB

This is the first theme identified by researchers before exploring other themes. The theme provides an overview of the participant's perception of TB, which covers their perception on what TB is, what causes it, and its symptoms. From this initial theme, emerged the following sub themes:

I) Patient's perception of TB

The sub theme describes the participant's perception regarding the diagnosis of the disease. Interview results show that most of the participants understand the diagnosis of TB disease, as reflected in the following statements:

"After that I had my X-ray test, and similar to a recent test here, I also had a sputum culture. I was then diagnosed with TB which was followed by 6-month treatment" (p.9)

Not every participant stated his or her current disease as TB. Two participants describe their existing TB with the term lung spots, as shown in the following statement:

"At first the doctor said it was spots on the lungs" (p.3)

"I went here and got my X-ray, and it turns out I was positive with symptoms of lung spots" (p.6)

II) Patient perception of the causes of TB

Based on interview results, participants have different perceptions on what causes TB. Participants of the research stated that TB is caused by stress, lack of rest, environmental factors, smoking, junk food, and pollution. This is reflected in the following participants' statement:

"My guess is, I caught the disease because of the food I ate and.. well,, maybe.. Because I had too much on my mind.. And even though I do not smoke, I hang out with people who do. So many of my friends do smoke, and I can't tell them to not to smoke." (p.9)

"We run a canteen in the general hospital. It turns out that behind this house of ours there is a morgue, and next to it there is a pulmonary care unit. And as children, well, we usually played around and go near the room. It's a general hospital which is, you know, not very strict about people entering the premises, so probably it was because of that as well" (p.7)

"Probably the relapse was also caused by fatigue, and I also had an operation and miscarriage recently, so it affected me and my health condition dropped" (p.7)

"I think it was probably because of my diet, since I usually eat irregularly during work" (p.5)

"Maybe the cause is, well since it is a relapse and I already caught the disease in the past and because of the pollution too" (p.4)

III) Participant's perception on the symptoms of TB

This sub theme describes the participants' perception of TB symptoms, which include a persistent cough that lasts more than three weeks, weight loss, nausea, and vomiting, as reflected in the following statement:

"At first I started to cough for more than three weeks and it didn't go away..." (p.2)

B. Impact of Suffering from TB

This theme emerged after researchers identified categories, which had similarities with the impact of TB. This theme describes both the physical and psychosocial experiences felt by participants during their on-going TB treatment. The theme has the following sub-theme:

I) Psychosocial impact when suffering from TB

The sub theme describes feelings experienced by TB patients when they were diagnosed with recurrent TB and also

during their TB treatment. Most of the respondents expressed feelings of sadness, shock, and embarrassment when they realized that had a relapse of TB, as reflected in the following statement:

“I cried and worried whether I could recover or not” (p.7)

“What a shame. I felt embarrassed with my friends, afraid they wouldn’t want to come near me” (p.1)

Participants of the research also described their feelings after having to go through recurring TB treatment. Three participants stated their boredom with the treatment they received.

“...yes sometimes I do, like I feel bored taking medicines...” (p.5)

Although a large number of participants expressed sadness and boredom during TB treatment, three participants stated that they could accept their condition when diagnosed with recurrent TB, as reflected in the following statement:

“And then the doctor explained that I was going to get a 6-month treatment and I thought that I had to go through with it. At the time I was able to get treatment from the community health centre, and there were many other patients too. It turns out that I wasn’t the only one with this condition” (p.10)

II) *Physical impact during treatment*

The sub theme describes physical impact that patients experience during their treatment. These include pain from injections, nausea, and headache, as stated in the following statement:

“Yes there were. When I first took my medicine I always felt nauseated, dizzy, and a little feverish. When I shook hands with my friend, my hand was very warm. And I definitely felt weak. Since I was sick, and I had only started to take medicine, I could feel everything; the nausea, the headaches, the fever. I experienced this for about two weeks. I think it has only been in the past four days that I feel less nausea and fewer headaches though I still feel it sometimes” (p.9)

C. *Challenges during TB Treatment*

The theme describes obstacles and challenges faced by participants during their TB treatment, which caused them to discontinue their treatment. Participants stated that the challenges faced were financial problems and lack of knowledge concerning the length of treatment, as stated by the following participant:

“I remember that I have to take my medicine and I did take it, but then after a while I stopped, because I felt better and due to money problems since I previously had to pay for my treatment” (p.3)

“I had my check up in the community health centre, and I went there regularly for 30 days. After 30 days I had my treatment for over a month, around two months, maybe, and then after that I stopped. I only followed the procedure. I didn’t know how long the treatment was going to be” (p.8)

D. *Support and Expectations of TB Patients*

The kind of support referred to in this research is family support, which is greatly needed to help the patient to comply with the medication program and the success of his or her TB treatment. Family support during treatment is that given by close family members, or members of the nuclear family. The support given is in the form of encouragement throughout the treatment and constant reminders to always take their medicines on time. Results from the interviews conducted between five participants stated their families gave them support during TB treatment, as expressed by one of the participant in the following statement:

“...my mum always gives me support, that I will recover, and that I’ve been an extraordinary person since I was little. I always got sick easily since I was kid. And my mum always gives me her support” (p.5)

IV) ANALYSIS

Patients’ perceptions of TB are a part of the initial themes brought up in this research. The theme describes the participants’ perceptions on what exactly TB is, what causes it, and also its symptoms. Based on this research, most of the participants do not have a correct perception about the disease. As previously stated, several of the participants considered their illness is a type of pulmonary disease or merely lung spots and not and contagious disease. Ultimately, the same applies to the participants’ perceptions of what causes TB, with every single participant having inaccurate perceptions of what causes TB. The research participants stated that their TB was caused by pollution, smoking, environmental factors, and junk food. Similar perception also applied to the duration of the treatment. Participants mentioned their lack of understanding of how long a treatment should be. These themes correspond to a research conducted by Lima Dias (2013) which discusses the life experience of TB patients who succeeded in completing their treatments [10]. The research identified themes related to healthcare professional support and the lack of cultural and knowledge. Participants of the research had the perception that the cause of TB covers a wide range of factors, including: environment, workplace, lifestyle, quality of diet, and contaminated objects. Themes brought up in this research also correspond to those of a research conducted by Bam, et al (2014) which aims to identify perceptions of TB and identify the obstacles and facilities required to search for medical treatment aid for people living in the slum area of Dhalka, Bangladesh [11]. Results of the research perception of TB as one of its theme, which shows that there, still misperceptions about the causes of TB.

TB treatment that is relatively long requires patient compliance in order for them to be able to complete the treatment. Compliance plays a very crucial role in the attempt to decrease the number of relapses, contagion, bacteria resistance, and to avoid defects [12]. The existence of such compliance is also affected by various factors, one of them being related to a patient’s perception of their illness, as perception is also shaped by the knowledge a person has. This research shows how participants reflect a patient’s misperception about TB on what TB is and or what causes it, and its symptoms, although there are

a large number of participants with the correct perception of the symptoms of TB. Researchers assume that the misperceptions found among participants could be an indicator of insufficient information or knowledge among new TB patients regarding the disease itself, the causes, and the symptoms. Regular and continuous information or a structured health education for TB patients and their families, the society, community, health centres or hospitals are urgently needed in order to provide patients with the proper knowledge and thus create the right perception of TB [13], [14], [15].

Theme on the impact of experiencing TB puts forward the experiences felt by TB participants, both psychosocial and physical experiences. Examples of psychosocial life experiences are the sorrow, shock, and embarrassment felt by participants. Participants go through sorrow and grief because they have to bear the same disease for the second time. Such life experiences are also found among participants in a research conducted by Lima Dias, et al (2013) [10]. The research, which was conducted in Brazil, aims to explore life experiences of TB patients who have completed their TB treatment successfully, and it corresponds with the general theme found in this research. However, the research conducted in Brazil identifies its themes as an impact found among families and between their social environments. Similarities of experiences found in this research lies specifically in its sub theme about psychosocial impact. Physical impact, on the other hand, is not analysed in the research.

Suffering from TB, especially recurrent TB could certainly lead to feelings of sadness and disbelief. Participants of TB mostly feel these feelings. However, there are also participants who expressed their acceptance of the fact that they had recurrent TB. Feelings of boredom also occurred among a large number of participants during their long period of TB treatment. Support from various parties, both from families and healthcare workers, are greatly needed to anticipate the development of such feelings during treatment [15, 16]. The right support is needed for the continuance and completion of the treatment. Other efforts, which could help anticipate such conditions, are group discussions or meetings between TB patients.

Physical experiences felt by several participants are physical pain caused by medication in the form of injections that extended throughout the medication program. Similar experience was also found among participants in the research conducted by Lima Dias, et al (2013) who mentioned pain that they had during the treatment [10]. However, a note of distinction from the research is how it places pain experiences on a different theme. In the research, experiencing pain is included as part of suffering caused by the disease, while in this research it is categorized as an impact of the TB treatment in the physical impact sub theme. These pain experiences could also lead to feelings of anxiety and fear among participants. An attempt to overcome this situation is by improving the relationship between healthcare workers and TB patients that could give participants the opportunity to express their pain and lower their levels of anxiety and fear.

Challenges of TB treatment include obstacles faced by participants during treatment, which have caused them to discontinue the medication process, which consists of: financial issues and lack of information provided concerning the duration

of the treatment. These results correspond with the research conducted by Bam, et al (2014) that states that the greatest challenges faced by participants in TB treatment are financial conditions, and the lack of support and knowledge [11]. Financial issues as the primary obstacle were also found in the research by Xu, et al (2013) [17].

A successful medication process among TB patients cannot be achieved without the support and active participation of families in constantly reminding and motivating TB patients. The theme on family support participants identifies an overview on the participants' experiences related to support given by families as they receive treatment. Many family members gave their support during the treatment process in various forms; from reminding patients to take their medicines to accompanying participants during medication. This corresponds with the statement expressed in a research conducted by Paz-Soldah, et al (2013) which aims to explore a patient's perspective on the role of social support throughout the treatment process [18]. It is stated that most participants receive a large amount of attention and support from their family during treatment, which ranges from affection, financial support, motivation, and other psychosocial support.

Aside from support during treatment, health education or providing comprehensive information on TB for participants is strongly needed. This is indicated in the first theme which discusses a patient's perception about TB, where it was found the most of the participants have an inaccurate perception about TB; especially about its causes and its symptoms. This corresponds to the research conducted by Paz-Soldah, et al (2013), concerning the need of competent health education for TB patients and also for their families and the society [18]

V) CONCLUSION

An overview on the life experiences of TB patients is reflected through the emerging themes. Most of the participants' perception about TB, specifically about what it is and its causes, is still inaccurate, though a few of the participants were able to identify the correct symptoms of TB. Impacts which occur during treatment, both psychosocial and physical, are experienced by participants as they receive recurrent TB treatment. Challenges faced by TB patients are financial issues and the lack of knowledge on the duration of the treatment. Family support is greatly needed by participants during the treatment process. An improvement in continuous health education for both patients and the society is a crucial program required to improve the knowledge of patients who are currently undergoing treatment, which could ultimately lower the number of TB relapse.

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