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Patient Experience in The Healing Process of Tuberculosis: A Phenomenology Study

Abstract

Background: Indonesia has the third rank of the highest tuberculosis (TB) incidents globally. The complete treatment of the disease could not be more urgent. The duration of TB treatment for at least six months, and other factors can lead to depression. Depression in TB patients is significantly associated with poor adherence to TB treatment, higher rates of treatment failure, and higher mortality rates.

Objective: Exploring the experience of tuberculosis patients during the healing process related to the risk factors that cause depression in patients.

Method: A qualitative study with a phenomenological approach was implemented. The purposive sampling collected nine participants from five public health centers in the Sleman district. They were patients with pulmonary tuberculosis who underwent treatment in the intensive or the continuous phase, presence of depression based on screening with the Beck Depression Inventory-II Questionnaire. Data were collected by conducting in-depth interviews and were analyzed using inductive content analysis.

Result: Five themes were found as the factors causing depression in patients with pulmonary tuberculosis: a) denial of destiny, b) stigma about tuberculosis, c) comorbidities, d) no family support, and e) losing a job.

Conclusion: Factors causing depression in TB patients involved denial of destiny, stigma about tuberculosis, comorbidities, no family support, and losing a job. Health workers must provide health education, counseling, and psychotherapy community-based intervention related to disease, stigma prevention, and family support to reduce depression to help complete treatment.

Keywords: Depression; Experience; Factor; Pulmonary; Patient; Phenomenology; Tuberculosis

INTRODUCTION

Pulmonary tuberculosis (TB) is one of the global infectious diseases. An estimated 10.0 million (8.9-11.0 million) people suffered from TB. In 2020, Indonesia was the third contributor to TB cases (8.4%) after Indians (26%) and then China (8.5%). From 2017-2019 there was a significant increase in the number of new cases of tuberculosis patients from 6.4 million new cases in 2017 to 7.1 million new cases in 2019, then decreased to 5.8 million in 2020. The COVID-19 pandemic has reduced new patients diagnosed worldwide, including in Indonesia, which was reported in 2020. The relatively significant reduction occurred in the Southeast Asia and West Pacific regions. The two areas combined accounted for 84% of the global decrease in new case notifications. Indonesia was the second country that contributed to the reduction in the number of new cases of tuberculosis in 2019, which is 14%, with the first being India (41%) and the third being the Philippines (12%), then China (8%) (World Health Organization, 2020) (WHO, 2021)

This decline in cases deserves special attention because the most direct consequence of the massive decrease in the number of new patients diagnosed with TB in 2020 will be an increase in the number of people who die from TB. By 2020, the global number of deaths was officially classified as caused by TB. TB (1.3 million) in 2020 was almost double that of HIV/AIDS (0.68 million), and deaths from TB were more severely affected by the COVID-19 pandemic than HIV/AIDS. TB was the 13th leading cause of death worldwide and the top single infectious agent. By 2020, TB was estimated to be the second leading cause of death from a single infectious agent after COVID-19 (WHO, 2021). The Director of Infectious Disease Prevention and Control of the Indonesian Ministry of Health said that of the estimated 824 thousand TB patients in Indonesia, only 49% were found and treated, and 500 thousand people have not been treated and risk becoming a source of transmission. TB that is not appropriately treated is also a risk of disease severity and even death. Deaths due to TB in Indonesia reach 93,000 per year, equivalent to 11 deaths per hour (Widyawati, 2022).

Indonesia, as a country with the third largest number of TB cases and the increasing number of deaths due to TB, is undoubtedly a serious concern from the government to overcome it with complete treatment and new issues. The duration of TB treatment for at least six months, and various factors can affect mental health to the occurrence of depression. Based on a study conducted on 4903 participants in seven countries, the prevalence of depression in TB patients was 45.19%. The majority was higher in MDR-TB, 52.34% than in non-MDR-TB patients, 43.47%. Depression is higher among women (51.54%) compared to men (45.25%) (Duko et al., 2020).

Depression in TB patients is significantly associated with poor adherence to TB treatment, higher rates of treatment failure, development of antimicrobial resistance, and higher mortality rates (Ugarte-Gil et al., 2013) (Ruiz-Grosso et al., 2020). Patients with depressive symptoms are likelier to have low adherence than those without depressive symptoms (Yan et al., 2018). Therefore, it is essential to know in-depth factors that influence depression in tuberculosis patients, especially pulmonary tuberculosis; as a result, it can be a reference for health workers, families, and the community to provide support for tuberculosis patients and not fall into depression. It will have implications for increasing drug adherence, treatment success, and the recovery of tuberculosis patients. Moreover, in providing holistic nursing care, it is a philosophy that guides the care received by patients that emerges from the concepts of humanism and holism. It refers to providing care to patients based on a shared understanding of their physical, psychological, emotional, and spiritual dimensions. Therefore, health does not only refer to the biological dimension but also psychological, sociological, and spiritual to achieve a harmony that goes beyond physical health (Jasemi et al., 2017). Patients with tuberculosis are not only seen in the biological aspect of physical complaints or due to Mycobacterium tuberculosis but also in psychological aspects, including depression that can appear in patients with social, spiritual, and social risk factors.

METHODS

This research used a qualitative study with a phenomenological approach. Nine participants

were collected using the purposive sampling technique. The inclusion criteria of this study were patients with pulmonary tuberculosis who underwent treatment in the intensive or continuous phase, depression based on screening with the Beck Depression Inventory-II Questionnaire and could communicate well. The exclusion criteria for this study were extrapulmonary tuberculosis patients and pediatric patients.

This research settings were in five public health centers in the Sleman District. Researchers obtained data on prospective participants based on inclusion and exclusion criteria from the nurse in charge of the tuberculosis program at five public health centers in Sleman. The researcher then contacted the prospective participants to explain the research objectives and procedures. If participants agreed to the process and agreed to be involved in the study, participants were asked to sign an informed consent form and set a time for collection. Thirty-four patients were willing to participate in this quantitative and qualitative study, and nine refused and were then screened using the Beck Depression Inventory-II questionnaire. Based on the screening results, the participants included in the criteria for depression were then carried out further qualitative research. The researcher made an appointment to come to the participant's house to collect data. In this study, nine participants were used. Participants in this study were determined by whether the number had reached data saturation (data saturation) or no new data was found.

Data were collected by conducting in-depth interviews. The interview duration ranged from 30 minutes to 60 minutes. Researchers used an interview guide with several questions. Data analysis used inductive content analysis. The process of analyzing the data involved several steps, including 1) listening to the interview results, writing a transcript of the results, scanning the data, dividing the data, and organizing the data; 2) rereading the entire data set and analyzing and coding it; 3) analyzing the keywords, categories, and themes after coding; and 4) performing data analysis. This data study employed the Atlas.ti program. Interview transcripts were returned to participants to increase the research trust. It was done so that participants could assess how closely the transcript matched their intentions. Many authors independently read the transcripts and held talks to build the conceptual framework. This research has received ethical approval from the Ethics Committee of the Faculty of Medicine and Health Sciences Universitas Muhammadiyah Yogyakarta with the number 030/EP-FKIK-UMY/I/2019. The participants also gave their written informed consent to the researchers.

RESULT
The participants' characteristics in this study can be seen in Table 1. The longest time to undergo tuberculosis treatment in the intensive and continuation phases is eight months. The age range of participants is from 28 to 63 years old. Participants consist of five men and four women. The participant's education backgrounds are elementary school (2 participants), junior high school (1 participant), senior high school (4 participants), and graduate student (1 participant).

(see table 1)

Five themes were obtained based on in-depth interviews conducted with the respondents, which can be summarized into two themes (seen in Figure 1). Internal factors consist of two factors, and external factors consist of three-factor.

(see figure 1)

The factors that cause depression in tuberculosis patients have two themes: internal and external. There are two categories for the theme of internal factors: feelings of disappointment in God for suffering from tuberculosis and comorbidities. While on the external factors, there are three categories: stigma about tuberculosis, no family support, and losing their job. The explanation of each category is as follows.

Theme 1. Denial of Destiny (Feeling disappointed in God)

Based on the finding, the first factor causing depression in tuberculosis patients is denial or not accepting suffering from tuberculosis. The patient feels disappointed in God for his illness, as seen from what was conveyed by the participants.

*"Yes, why do I have this disease, why is it (slow voice)... I often in prayer, **why is it that I am sick like this? I have a disease like this, while my descendants don't have this kind of disease**. Maybe I'm afraid of destiny in my life to have a disease like this"* (Participant 7)

*"I took three medicines once, where the medicine was huge... **Oh my God, what kind of punishment did that come from**.. lately, I've been through it.. yes, in the end, every day I wear the mask, I don't dare to go out of the house, do I)* (Participant 3)

Theme 2. Stigma about Tuberculosis

Another risk factor that causes depression in tuberculosis patients is a misperception about tuberculosis, which adds to the burden on the patient's mind. As stated by the participant from the family or the environment, he should not be close to his family. TB patients were told to stay away from their families, especially their children. Then the participants would have psychological stressors leading to depression, as stated by the following participants.

*"In the beginning, **I was confused. I couldn't be near my child... I couldn't be near my family, so I slept separately** (while holding her baby's feet) and **didn't want to be separated from her mother**, so it felt like... Oh my God... having a child, but you can't be near your child... you can't kiss your child... moreover this is asking for a kiss (while chuckling)... this can't be the case, whatever it is, you often give a kiss as a gift, you can't kiss the child... it feels... (didn't continue the words, eyes looked teary)"* (Participant 3)

*"Yeah.. if it's for the family, you have to be careful, **so don't be too close to your wife** so that it doesn't spread like that, right ...."* (Participant 4)

Theme 3. Comorbidities

Comorbidities are the next risk factors leading to depression for tuberculosis patients, which adds to the burden on the patient's mind. Participants said that since they were exposed to tuberculosis, they were more susceptible to other diseases, even though it was not so before, thus making their

hearts more depressed (broken). It is as stated by the following participant:

*"**I keep complaining all the time when my body is tired** (while remembering) oh, the last one is different, sis, suddenly I feel tired here (pointing to the back) **that's what the diagnosis is instead of changing**"* (Participant 3)

*"**Yes, instead, I changed it. Then, after that, it dropped again**... it fell in the urinary tract.. keep checking... check back and forth again, finally, it was said to be cervical cancer. Wow, it was crushed.. **Oh Allah, Ya Robbi.. what do you want, the disease that TB has not finished yet there is another disease**.. this one has no cure, I thought, it was crushed at that time* (Participant 5)

Theme 4. No Family Support

The absence of family support can be a stressor that causes the patient to become depressed. Her husband left a participant to return to his parent's house when he was sick, indicating a lack of family support.

*".. **Now he doesn't live here... he used to live at his parents' house while I was sick. As long as I was sick**... he said he didn't want to be a bother. In the end, when he was here, he never did anything... I mean if I want to eat, so I can't... finally he goes to his parents first... but when the evening comes back here after maghrib or Isha, then, at 10 pm or 11 pm he comes home again... but at least, it just once a week or two weeks hehe (laughing small)...."* (Participant 2)

Theme 5. Losing a Job

Due to tuberculosis, participants may lose their job, which becomes a stressor leading to depression, as stated by the following participants.
*"Well, yes.. there is.. **I can't work, I can't do anything.. I'm just sleeping** like this (answered with a slightly raised tone)"* (Participant 1)

*"**I stopped working,** and now my son is working"(Participant 2)*

DISCUSSION
Depression in tuberculosis patients can worsen the disease because it causes them to drop out of

treatment, leading to complications and even death. Risk factors for depression in infectious diseases such as tuberculosis can be seen from various aspects, especially with the capacity of humans as bio, psycho, socio, spiritual, and cultural beings. On the natural element, previous studies have shown that patients with chronic inflammatory diseases and depression have reduced tryptophan (TRP) circulating levels and increased metabolites of the enzyme Indoleamine 2,3-dioxygenase (IDO), such as kynurenine. IDO is a rate-limiting enzyme in the TRP kynurenine pathway. It converts TRP, a serotonin precursor, to kynurenine resulting in reduced serotonin synthesis. Pro-inflammatory cytokines such as IFN-g and TNF-a regulate IDO expression and activate the kynurenine pathway. It reduces central serotonin levels. A decrease in serotonin synthesis may explain the development of depressive symptoms (Chandra et al., 2019).

Besides the biological aspects of the disease itself, comorbidities in patients can be a risk factor for depression in TB patients. The participants stated that the comorbidities added to the burden on their minds. Other diseases will likely appear when the patient suffers from TB, even though the TB has not been cured. Psychological stress further strengthens the risk factors for depression in TB patients. In addition, the stigma of TB patients further adds to the patient's psychological pressure. Patients are increasingly sad when they are not allowed to be near their children and families. A study in Southern Ethiopia found that patients who experienced TB stigma were about 11 times more likely to experience depression than their counterparts (Duko et al., 2015). Previous studies have shown that perceived stigma is strongly associated with depression. The prevalence of stigma felt by patients with pulmonary tuberculosis reached 57.1%. Stigma is also closely related to feelings of stress and tends to trigger depression (Mohammedhussein et al., 2020). People with chronic illness and a sense of stigmatization may have a low self-image and social isolation, which can predispose them to depression (Perlick et al., 2001). Social factors also increase the burden on tuberculosis patients, becoming a risk factor for depression. Tuberculosis affects the patients' daily abilities, making them unproductive. Tuberculosis causes patients to lie down, so they cannot work like

healthy individuals. The participants said that their children had to replace them to work. This condition, where the patient cannot work nor cannot provide for his family's needs, becomes a stressor for the patient and will cause depression. Previous studies revealed that in Eastern Ethiopia, the case and control group in a study of patients with multi-drug resistance tuberculosis (MDR-TB) had quit their jobs due to physical exhaustion (Roba et al., 2018). The function of social roles is disrupted and causes them to experience severe financial challenges. Low-income and financial patients have an increased risk of anxiety symptoms (Wang et al., 2018). This disorder will psychologically make the patient depressed, ultimately affecting the quality of life for a long time (Kastien-Hilka et al., 2017). The quality of life becomes poor, mainly due to depression and other psychological stresses that can interfere with the immune system response of tuberculosis sufferers, impacting anti-TB medication adherence and, in the worst case leading to death (Duko et al., 2015).

Another social factor that causes depression in tuberculosis patients is the absence of family support. Participants who get lousy behavior from their families feel more burdened in undergoing treatment. The impact of lack of support from the family causes participants to feel uncared for by their families when they are sick. They will have low spirits in undergoing the disease and its treatment. A study in Southern Ethiopia showed that poor social support is significantly associated with depression (Duko et al., 2015). Lack of (imperfect) social support and somatic illness can lead to increased psychological distress. On the other hand, good social support is essential for those with good health in depression prevention (Bøen et al., 2010). Positive social support from the surrounding environment, such as family, colleagues, and the community, tends to give patients a better quality of life (Zarova et al., 2018).

Tuberculosis patients who do not get family support also suffer from changes in family behavior towards them. One of these behavioral changes is the family's attitude away from the patient. As described above, patients with poor social support risk feeling alienated and isolated from the environment, manifested by the family's refusal to

share equipment and food with the patient (Tadesse, 2016). This condition can also trigger depression. This avoidance behavior is social discrimination against people with tuberculosis. Datiko et al.found severe discrimination with shunned manifestations, explaining that tuberculosis sufferers in Ethiopia are often experienced not only in the home environment but in all work and society activities. They may suffer from diseases easily transmitted through air droplets (Datiko et al., 2020a, 2020b).

Another factor is spiritual factors. Generally, patients cannot accept reality and feel disappointed with God's destiny because of the disease. A study in Ghana reported that denial behavior was manifested by feelings of hopelessness and worry about symptoms and the long duration of treatment (Gyimah & Dako-Gyeke, 2019). Tuberculosis patients often feel stressed and pressured to come to treatment facilities. Febi et al. in India reported that about 24% of patients experienced anxiety symptoms at the beginning of their diagnosis of tuberculosis, accounting for 20.9% of patients experiencing depression. Anxiety was common among people with tuberculosis and negatively impacted the patient's quality of life (Febi et al., 2021).

CONCLUSION

The study found five categories causing depression in tuberculosis patients. The feelings of disappointment and rejection by God, because they were diagnosed with tuberculosis and comorbidities are the trigger factors for depression. In addition, the absence of family support, the stigma for patients with tuberculosis, and losing a job may have led to depression in patients with pulmonary tuberculosis. Health workers need to provide health education, counseling, and psychotherapy community-based intervention related to disease, stigma prevention, and family support to reduce the incidence of depression in tuberculosis patients so that they can help complete treatment. Suggestions for further research are to conduct intervention research to overcome depression in tuberculosis patients by considering the risk factors for depression in patients.

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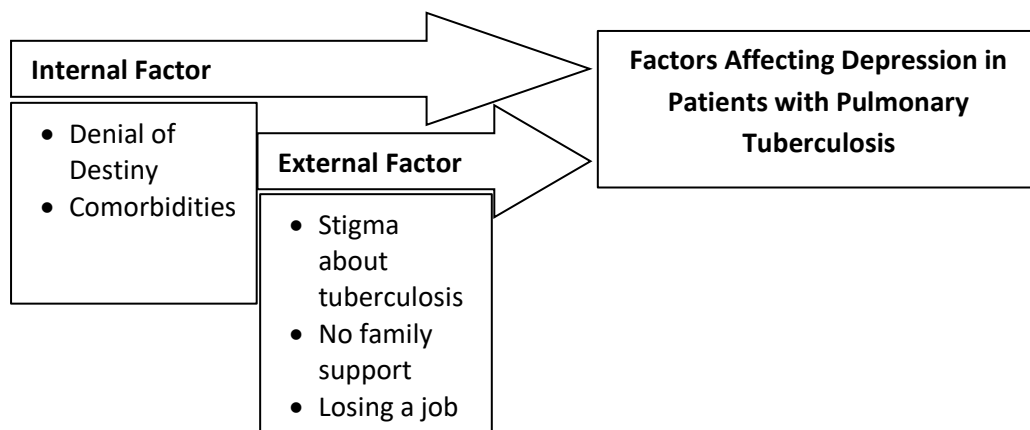
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Table 1. Characteristics of participants

Category	P1	P2	P3	P4	P5	P6	P7	P8	P9
Age	50	50	39	42	40	63	43	28	50
Gender	M	F	F	M	M	M	F	F	M
Education	Senior High School	Senior High School	Vocational	Senior High School	Bachelor	Elementary School	Elementary School	Junior High School	Senior High School
Treatment (month)	2	5	3	4	6	2	3	8	1

Figure 1. The Main Findings