

A Qualitative Study Exploring the Experiences of Tuberculosis Patients Who Have Successfully Recovered

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ABSTRACT

Background: Tuberculosis cases in Indonesia occupy the second highest position after India. TB eradication is an important program in the SDGs 2030. Recovering from Tuberculosis is a blessing. This study aimed to explore the experiences of tuberculosis sufferers who have recovered.

Subjects and Method: This qualitative study was conducted in the Yosodadi Community from January to February 2023. A total of 12 patients with tuberculosis who had successfully recovered were selected for this study. The variable of this study was the experiences of tuberculosis patients who have successfully recovered. A depth interview was used to obtain the data. The data were analyzed descriptively.

Results: The study showed the importance of patients knowing their disease, the support of those around them, and health workers who have good empathy towards TB patients. This research also found the importance of health providers and patient families being asked to pay attention to the mental health problems suffered by TB patients.

Conclusion: Vaccine reluctance is a huge problem in the face of a pandemic that is not yet over. Even with to achieve recovery for TB patients, efforts are needed to understand the mental condition of TB patients. Policymakers must consider ongoing health education regarding TB patient assistance by family and health workers.

Keywords: Empathy, family support, health provider, mental health, patient, tuberculosis.

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BACKGROUND

Indonesia is the second country out of 8 (eight) countries that contributes to two-thirds of Tuberculosis cases in the global total (WHO, 2020). According to data from the Ministry of Health of the Republic of Indonesia, it was found that in 2021 there

were 397,377 cases of tuberculosis found in Indonesia and this increased compared to cases of tuberculosis found in 2020, namely 351,936 cases (Kemenkes RI, 2021).

Based on the Lampung Province Health Profile, Tuberculosis cases in Lampung in 2018 recorded 31,462 cases or

44.38%. This number has increased in 2019 to 54% (Dinkes Prov Lampung, 2019), and has decreased in 2020 to 30.6% (Dinkes Prov Lampung, 2020), and has increased again to 40.1% in 2021. Lampung Province consists of 15 regencies/cities, one of which is Metro City. Meanwhile, according to the Health Profile of Metro City, there were around 297 TB cases in 2020, or 30.1% of TB cases in Metro City. This number has increased in 2021 to 37.9% (Dinkes Prov Lampung, 2021).

Metro City with an area of 68.74 Km² has 5 sub-districts with 11 health centers spread across the Metro City area. Metro Timur Subdistrict, with an area of 11.78 km², has 3 health center services, one of which is the Yosodadi Health Center. Based on the data obtained, it is known that the Yosodadi Metro Health Center has 14 TB patients. In 2021 the number of patients receiving treatment at the Yosodadi Metro Health Center is 7 patients and will increase in 2022 (Dinkes Prov Lampung, 2021).

Based on the results of interviews with Yosodadi Metro Lampung Health Centre's staff, it is known that there were no patients with repeated cases of treatment. However, some sufferers were reported to feel insecure, sad, worried, and bored with taking medication. The emergence of discomfort felt by tuberculosis sufferers is feared to be one of the triggers for not completing the tuberculosis treatment period. Previously, there had been no exploratory research regarding the treatment experience of TB patients at the Yosodadi Metro Lampung Health Center, so the researchers were interested in conducting exploratory research regarding the experiences of TB sufferers in the work area of the Yosodadi Metro Lampung Health Center in 2023. This study aimed to find out the experiences of tuberculosis sufferers during TB treatment, as well as know matters relating to the com-

pletion of tuberculosis treatment at the Yosodadi Metro Lampung Health Center. The research will use a qualitative method with a phenomenological design.

SUBJECTS AND METHOD

1. Study Design

This research uses a qualitative case study based on human understanding and behavior based on human opinion. This qualitative study produced descriptive data in the form of words or sentences based on information and experience from the participants or resource persons. The experience is important for a civilized society. Experience can be a foundation for the formation of good behavior in the future. This study was conducted in Yosodadi Community Health Center from January to February 2023.

2. Population and Sample

A total of 12 patients at the Yosodadi Community Health Center who had recovered from tuberculosis were selected for this study using a purposive sampling technique. With the criteria of tuberculosis patients who have recovered, are willing to be interviewed, and are over 18 years old.

3. Study Variables

The variable of this study was the experiences of tuberculosis patients who have successfully recovered which is described from the results of in-depth interviews with informants.

4. Conceptual Definition

the experiences of tuberculosis patients are defined as the experience of how patients learn about their disease, how the people around them support them, and whether health workers have good empathy for tuberculosis patients.

5. Study Instruments

Data collection in this study used In-Depth Interviews with informants. Interviews were conducted face-to-face with participants to obtain and explore participants' experiences

regarding tuberculosis. At the time of the interview, the researcher used a tool in the form of a voice recorder to assist in obtaining clearer information. Retrieval of secondary data as supporting data, such as tuberculosis data at the Yosodadi Metro Health Center which functions to complement the discussion report.

6. Data Analysis

The in-depth interviews used were directly with TB patients who had recovered without including health workers who had accompanied the patient when he/she was sick. The principal investigator and research assistants recorded all the interviews and then transcribed them. The transcripts were printed and then reviewed to determine themes that emerged from the in-depth interviews. Two researchers plus one expert in the qualitative field examined the themes and sub-themes obtained based on the similarity of the keywords (codes) obtained. This review was carried out several times so that it could be agreed upon by all researchers.

7. Research Ethics

Ethical approval has been obtained from the ethical bureau, Faculty of Health Sciences, Universitas Esa Unggul in 2022. A copy will be provided if necessary.

RESULTS

1. Participant Characteristics

This study involved 12 participants who had passed the inclusion criteria of 14 tuberculosis sufferers at the Yosodadi Metro Lampung Health Center who had completed the tuberculosis treatment period of less than one year. Each participant was interviewed once, using the Indonesian language and Javanese language. There were 3 female participants with 9 male participants. The age of the participants varied from 15 (fifteen) years to 78 (seven eight) years. All participants resided in the East Metro sub-district.

Based on the data obtained, it is known that of the 12 participants, there were seven participants with an age range of 15-64 years were included in the productive productivity category with a percentage of 58.30%. The other five participants who fall into the category of non-productive with an age range of 65-78 years are already old, with a large percentage of 41.70%.

2. Theme Analysis

From the results of the analysis, eleven themes were obtained namely knowledge of preventive behavior by TB sufferers, Participant experience of taking TB drugs, Family support, Health center's staff support, Friends and neighbor support, Distance to the health center is not a problem, Emotional burden on Tuberculosis sufferers during the treatment period, Treatment Free tuberculosis, good pharmacy services at the Health Center (Community Health Center), good flow of services at the Community Health Center, good medical staff services.

a. Theme 1: Knowledge of preventive behavior by tuberculosis patients

Participants stated that when they communicate with other family members, participants will keep their distance when communicating to avoid transmitting it to other people.

"Yes, here. So, if we talk now, we are not as close as we used to be when we didn't know each other, now we are farther away" (Participant One).

"If we talk now, there's some distance, ma'am, but, it's not too far away" (Participant Two).

"Most far away ma'am, if previously the one seat was closer, now it's a bit of dragging the chair so it's not too close" (Participant Four).

"When I talk, I try to stay away and wear a mask" (Participant Five).

"When you chat or talk to people at home you are a bit distant, it's not like

before if you just talk freely whether there's distance or not" (Participant Seven).

Patients were kept wearing masks to decrease the spread of TB infection.

"Thank God, now we were wearing a mask, so we were still can communicate with others" (Participant Two).

"Yes, ma'am, keep on wearing a mask" (Participant Six).

"Keep the distance away when talking or wearing a mask" (Participant Seven).

Participants maintain distance when communicating with neighbors around the house.

"If I did not wear a mask, I rarely talk" (Participant Two).

"It's a bit far away when talking or wearing a mask" (Participant Seven).

There were participants who stated that preventing transmission, is carried out by reducing communication with neighbors.

"If you talk to your neighbors, it's clear that there has been a change, I'm afraid that the neighbors will be informed later, it's not good, it's coming from me. Somewhat reduce the activity of chatting with neighbors" (Participant One).

The respondents said that they were wearing masks when communicating with others.

"If I'm wearing a mask now, I'll still wear the mask in class" (Participant Ten).

"The difference is maybe if now you wear a mask more often" (Participant Eight).

"It's still the same, it's just that now you're wearing a mask, so sometimes when you talk, you often wear a mask, but when you take off your mask, you talk without wearing a mask" (Participant 12).

Personal hygiene is done by cleaning yourself after leaving the house.

"Maybe the difference now is that the house is cleaned more diligently. Wash

my hands frequently, especially after coughing" (Participant Nine).

"When I came home from school, I immediately cleaned up, washed my hands, and changed my clothes" (Participant Ten).

"When I arrived from outside, I changed my clothes and washed my hands" (Eleventh participant).

Open all the home windows to improve air circulation in the home environment.

Participants opened the windows of their house/ room so that air exchange continued.

"In the early morning the window was often opened to let air in or so let the air change" (Participant Four).

"In the room, the window is often opened. Let the air in" (Participant Ten).

b. Theme 2: Participants experience side effects of taking tuberculosis drugs

They all experienced side effects of the TB drugs, such as nausea, itching, and uncomfortable feelings. Participant Two, Participant Nine, and Participant Eleven found that there were side effects from taking tuberculosis drugs in the form of nausea.

"Oh yes there is ma'am if I feel it. So sometimes after taking medicine I feel nauseous. It feels like I'm going to vomit" (Participant Two).

"You felt a side effect the first time you took the medicine, it was nausea, but over time it went away on its own" (Participant Nine).

"Several times after taking the medicine I usually feel nauseous" (Participant 11).

c. Theme 3: Family support

Participants get support by being reminded to take medication.

"Yes, ma'am, if that's the case, you're often asked if you've taken the medicine or not with you yet" (Participant Two).

"Usually, my medicine is prepared and reminded to bring medicine" (Participant Three).

"You were asked if you have taken the medicine yet, if you haven't then take the medicine and the water" (Participant Four)

"I was often reminded and asked if I had taken the medicine or not when it was time" (Participant Seven).

Participants received support from their families by being taken to the Puskesmas (Health Center) by family members.

"Then sometimes the child was brought to the health center" (Participant One).

"If a patient has to be re-examined by the doctor, I accompanied him to the health center" (Participant Two).

"We usually take them to the Community Health Center to pick up medicine and meet the doctor" (Participant Six).

d. Theme 4: Support from Health Center staff

The health center officers came to the patients' home.

Participants received support from health center staff by coming to the participant's house.

"Several times the midwife came to the house, asking how I was doing" (Participant Two).

"Health Center staff had come to our home to provide advice and information" (Participant Five).

"Yes ma'am, they came to my house and gave information about my illness" (Participant Seven).

e. Theme 5: Support of friends and neighbors

Sub-theme: Motivation to continue treatment.

Participants also received support from friends and neighbors in the form of motivational support to complete treatment.

"There is one friend of mine who often gives encouraging stories to get well soon" (Participant Four).

"When we met on the street when we wanted to go to the community health centers, we were told that we would get well soon, given words of encouragement" (Participant Nine).

"They also encouraged when they came to bring fruit to the house" (participant 11).

"What is it is, they just seem to be encouraging" (participants 12).

f. Theme 6: Emotional burden on Tuberculosis sufferers during the treatment period

Experiencing mental stress and dealing with it. Several participants experienced psychological burden barriers, including:

"I was confused, I was afraid because I did not understand, how come I got the disease and affected family members" (Participant One).

"I thought I was depressed" (Participant Four).

"In the early days, I thought how come I could be infected by this disease. I was worried about my future" (Participant Seven).

Dealing with mental health. Participants began to accept their condition as one effort to overcome the problems.

"I accepted it, I was willing to undergo treatment" (Participant Seven).

"Now I should accept it, Miss. I believed that my parts will recover" (Participant Ten).

Some participants overcome their problems by praying.

"Yes, just diligently taking medicine, while trying and praying. Optimists can recover" (Participant Four).

"It's more about prayer, miss, usually if you don't miss it, every prayer asks for

healing the same as above" (Eleventh participant).

Some participants overcame the method by adding information and knowledge about the disease both from themselves and others.

"Yes ma'am, the doctor gave a lot of information explaining, so it's calmer" (Participant One).

g. Theme 7: Responsive medical services

Health center staff who are friendly and informative are very important for successful treatment. Participants said that the officers at the Yosodadi Metro Lampung Health Center were friendly and informative in serving patients who came.

"All right ma'am, they gave us beneficial information. So far I haven't met anything that is not good" (Participant One).

"The officers are good, ma'am, when I went there they served me well. In my opinion, the facilities are also sufficient (Participant Two).

"During treatment there, the officers helped me, Ma'am, directed me where to go, then when I asked questions and they answered and gave information" (Participant Three).

DISCUSSION

The main factor in the successful cure of tuberculosis is patient compliance with drug consumption during the treatment period (Sumiati et al., 2021). Compliance is the level of a person's attitude in carrying out a medical regulation by instructions prescriptions and usage rules according to the recommended time (Yulisetyaningrum et al., 2019).

The drug consumption period is quite long, often causing boredom for regular drug consumption in tuberculosis patients, and can be one of the triggers for non-adherence

of tuberculosis patients in taking drugs during the treatment period (Mientarini et al., 2018). Consumption of drugs in tuberculosis patients who are incomplete and complete during the treatment period can make patients resistant to tuberculosis drugs (Mando et al., 2018). Non-adherence to taking tuberculosis drugs is one of the factors for the failure of treatment in tuberculosis patients (Sadipun and Letmau, 2022).

The treatment period for TB patients, which takes a long time, can also have an impact on the patient's mental health. The mental health of tuberculosis sufferers who are not good during the treatment period will result in a decrease in the patient's quality of life which will affect the quality of the treatment being undertaken (Athiutama et al., 2022). The negative views received by sufferers from the surrounding environment, as well as the long duration of treatment that must be passed by sufferers, further exacerbate the mental health conditions experienced by tuberculosis sufferers (Endria and Yona, 2019). According to (Widakdo and Besral, 2013), individuals with chronic illnesses or who are undergoing treatment for chronic illnesses, will have problems with their mental health which will also have an impact on a person's quality of life.

The poor mental health of tuberculosis sufferers can affect the success of the treatment being carried out by tuberculosis sufferers. The World Health Organization (WHO) created a program called Sustainable Development Goals (SDGs). The SDGs program is a substitute for the previous program, namely the Millennium Development Goals (MDGs) program, which is also a program that has the goal of reducing the number of repeated TB treatments and new incidences of tuberculosis (Nurussolehah et al., 2021).

1. Theme 1: Knowledge of preventive behavior to reduce the spread of TB infection.

Participants stated that there were differences in the way of communicating with family members by keeping a distance when communicating. This was done by the participant to reduce the possibility of transmission to other people who were in the participant's house. Based on research that has been conducted by (Tristiana et al., 2019), reveals the same thing in previous studies, namely tuberculosis patients keep their distance when communicating with other family members. According to (Suryani and Efendi, 2020) several TB participants unconsciously kept their distance when communicating with other people because of decreased self-confidence and a feeling of fear of infecting others.

a. Sub-theme: Separating cutlery from other family members

Participants stated that the change in habits that occurred in the family environment was by separating cutlery at home from the cutlery of other family members, as stated by Participant One that separating cutlery was done to avoid transmission to other healthy family members. This is the same as what has been done beforehand by (Amelia et al., 2020) that family members who live with tuberculosis sufferers already know there is a risk of contracting the disease, and take precautions by separating cutlery for tuberculosis sufferers from other family members. According to another study by (Mbuthia et al., 2018) also states that one of the prevention measures is to separate cutlery for tuberculosis sufferers from healthy individuals.

b. Sub-theme: The tradition of eating with family is still being continued

Participants stated, they still eat together with other family members, although this is not always done every day at mealtime due

to the busyness of each family member. This is in line with research conducted by (Fris-tanti et al., 2020) that there are participants who still carry out joint habits with their family members at home. However, this is contrary to research that has been conducted by (Teofilus et al., 2018) tuberculosis sufferers are not advised to continue to eat together with healthy individuals.

Participants stated that participants wore masks when communicating with neighbors around the house. This is done to anticipate the transmission of TB bacteria to neighbors around the house. Research conducted by (Mbuthia et al., 2018) states that it is important for tuberculosis sufferers to wear masks in carrying out communication activities with others to prevent transmission to others.

It is known that participants who suffer from tuberculosis will keep their distance when communicating with neighbors around the house. Research conducted by (Behzadifar et al., 2015) said that there are individuals who are undergoing treatment for tuberculosis will experience changes in their habits of communication or interaction with others to take care to minimize the risk of transmission to others.

The next discussion is about changes in participants' communication habits with neighbors around the house that happened to Participant One. Based on research that was previously carried out by (Tristiana et al., 2019), changes in communication habits are carried out by reducing communication activities with neighbors. prevent the risk of tuberculosis transmission in the neighborhood by reducing communication activities.

In the participants, there were changes in the way of communication with colleagues and school friends. The difference is the use of masks when carrying out communication activities in the work environment. According to research that was pre-

viously carried out (Maulana, 2020) regarding recommendations for the use of masks that are good for people with tuberculosis in the family, work, and school environment, when the patient is within three feet of other people. This is a preventive measure that sufferers can take to limit the spread of the virus to others. This is also in line with research conducted by (Saputri et al., 2020), that wearing a mask when leaving the house can be an effort to prevent TB transmission.

c. Cleaning well when coming home from outside in the home environment

Participants revealed that the changes that occurred after they were diagnosed with Tuberculosis were by maintaining personal hygiene.

Based on research that has been done by (Lestari et al., 2019), washing hands and cleaning ourselves is one way to prevent transmission of the disease. This finding is similar to the narrative conveyed by (Purba et al., 2021) in their research, that one of the precautions that can be taken to prevent transmission of tuberculosis is by providing handwashing materials.

d. Open windows to improve air circulation in the home environment

The participants often opened the windows and doors of the house to allow air exchange so that the air circulation in the house was better.

Based on Research that has been carried out by (Simatupang et al., 2019), reveals that poor air exchange and closed rooms can lead to increased exposure to bacteria and disease development. Research conducted by (Yunita et al., 2022), also states that houses or residences with less ventilation and windows can increase humidity and create a high risk of spreading and growing bacteria.

2. Theme 2: Participants experience side effects when taking tuberculosis drugs

Based on the experiences felt by the participants, all participants felt any side effects caused by taking tuberculosis drugs. According to research that has been carried out by (Abdulkadir et al., 2022) the side effect of nausea arises because of the drug Rifampisin contained in anti-tuberculosis drugs. Another study conducted by (Reviono et al., 2014) showed that the most common side effect experienced by tuberculosis sufferers was nausea.

The itching was another side effect. This was stated by previous research by Abdulkadir et al (2022) that, the side effects of nausea and the appearance of a reddish rash on the skin trigger itching, which arises due to the content of Isoniazid. Isoniazid is one of the main components or ingredients of anti-tuberculosis drug ingredients. Based on research conducted by Abbas (2017) one of the most common side effects felt by tuberculosis sufferers is the side effect of itching.

3. Theme 3: Family support Reminding to take medicines

Participants said that family members in the home environment provided support in the form of being reminded to take medication. According to previous research by (Pameswari et al., 2016), it was revealed that providing family support by being reminded to take medication can be one of the supporting factors in the adherence of tuberculosis sufferers to taking medication. This is different from the opinion expressed by (Murtiwi, 2006), that PMO does not affect adherence to taking medication in tuberculosis patients.

Participants said that the support provided by their family members was in the form of support delivered to the district health center. Based on research that has

been conducted by (Pitoy et al., 2022) states that family support is provided by family members to TB participants by taking participants to the community health centers as a form of attention and one of the supporting factors in medication adherence in TB patients. According to research that has been conducted by (Chen et al., 2020), support from people around tuberculosis sufferers is something important and can be one of the influential factors in the successful treatment of a tuberculosis patient until the end of the treatment period.

4. Theme 4: Support from Health Center staff

Health center workers come to the house. The participant stated that Yosodadi Metro Lampung Health Center staff had visited the participant's house to pay a visit and see the development of the participant's Tuberculosis health. Based on research that has been conducted by (Rumimpunu et al., 2018) visiting the homes of tuberculosis participants is one of the efforts to monitor and supervise tuberculosis participants who are currently on treatment. This is contrary to the opinion of research conducted by (Herawati et al., 2020), that health center staff do not visit the homes of tuberculosis participants.

5. Theme 5: Support of friends and neighbors

Sub-theme: Given motivation to continue treatment. Participants stated that they received motivational support to continue treatment. Based on research that has been done previously by (Fitri et al., 2018) states that support in the form of motivation given to tuberculosis participants can increase participant compliance and willingness to take drugs during the treatment period until the end and completion of treatment. According to research conducted by (Prihantana and Wahyuningsih, 2016), the absence of

motivation in tuberculosis sufferers will affect the treatment process.

6. Theme 6: Emotional burden on Tuberculosis sufferers during the treatment period

Experiencing mental stress and dealing with it. Participants felt the obstacle of treatment, namely the emotional burden. Some participants often felt the fear of not being able to recover from their illness, the fear of forgetting to take medication, as well as feelings of anxiety, fear, and surrender to their condition.

Based on research conducted by (Chrisnawati et al., 2017), a decrease in the quality of life of tuberculosis participants can occur due to the psychological burden experienced by tuberculosis sufferers. The psychological burden on Tuberculosis sufferers is influenced by anxiety and fear that arises in Tuberculosis participants. According to WHO data, tuberculosis in 2021 has a Case Fatality Rate (CFR) of 15%. A case fatality rate that is quite high will affect the increased anxiety of TB sufferers while undergoing treatment and will have an impact on the success of treatment (Sitorus and Barus, 2018).

Several participants who experienced the burden of undergoing TB treatment had their way of dealing with the burden that occurred, such as: being more accepting of the participant's condition, praying, and adding information and knowledge about the disease they were experiencing. In the opinion of (Sumarsih et al., 2019), through previous research, it was said that activities to get closer to God, or all activities that involve God, can reduce the level of anxiety, and stress that sufferers have during the treatment period. Another opinion according to (Kusnanto et al., 2016), states that the method of getting closer to God such as praying in tuberculosis sufferers can im-

prove the quality of life of tuberculosis sufferers during the treatment period.

7. Theme 7: Responsiveness of Health Center Staffs

Friendly and informative staff are the important findings of this study. Participants stated that Yosodadi Health Center staff provided services to patients who came to the Health Center in a friendly, kind, and informative manner. Based on research that was previously carried out by (Handayani et al., 2019) and (Gebreweld et al., 2018) the level of friendliness and behavior of health workers is one of the factors that influence the level of patient compliance in completing the treatment period.

The conclusions and suggestions from this study are that TB patients need to understand clearly about their disease. Patients also have to be convinced that Tuberculosis can be cured. Mental health problems that occur during the treatment also require assistance from health workers at the community health centers. Health providers who are friendly and able to answer patient questions are needed. Family and community support need to be encouraged as a form of participation in efforts to eradicate Tuberculosis in Indonesia.

AUTHOR CONTRIBUTION

Contributions as the main author are research ideas, analyzing data and bringing this article to completion. The 2nd contributor worked on data collection and helped analyze the data. the 3rd contributor reviewed sentences in English, checked the bibliography and provided funding assistance.

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CONFLICT OF INTEREST

The authors declare no conflict of interest.

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