ORIGINAL ARTICLE

Experiences of Patients with Tuberculosis Who Underwent Completed TB Treatment during the COVID-19 Pandemic in Indonesia: A Qualitative Study

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Abstract

Background: The scope of tuberculosis (TB) elimination programs, such as case detection, rapid diagnostics, and treatment success, has dramatically worsened because of the COVID-19 pandemic. Therefore, this study aimed to explore the experiences of patients with TB who had completed their treatment during the COVID-19 pandemic.

Methods: This qualitative study was performed using content analysis approach between May–July 2022. A total of 14 patients with TB who agreed to participate in this study were selected using purposive sampling. In-depth interviews were conducted using semi-structured interview guidelines, and the interviews ended after information saturation occurred. Data analysis was carried out concurrently to identify the main themes. The NVIVO software application version 12 was utilized to analyze the data.

Results: Several key themes emerged from the study, shedding light on various aspects of the experiences of TB patients during the COVID-19 pandemic. These themes encompass (1) Barriers to TB Diagnosis during the COVID-19 Pandemic; (2) Challenges in TB Treatment during the COVID-19 Pandemic; and (3) Support Resources during TB Treatment in pandemic era.

Conclusion: Patients have difficulty receiving healthcare because of changes in TB health services brought on by the pandemic. This research advances our knowledge of the effects of the COVID-19 pandemic on patients with TB and lays the groundwork for improved patient support and interventions.

Keywords: Tuberculosis, Treatment, Experiences, COVID-19 pandemic, Qualitative research

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Introduction

Since the coronavirus disease-2019 (COVID-19) was declared a pandemic by World Health Organization (WHO), various aspects of government programs, particularly health development, have been affected.[1, 2] In addition to the increased mortality and morbidity rates caused by COVID-19, utilization of health services has also decreased by about one-third during the pandemic.[3, 4] Health services for tuberculosis (TB) programs have been greatly affected by this pandemic and is a new challenge in efforts to eliminate TB in Indonesia by 2030.[5] The pandemic policy continues to be associated with the low quality of health services and TB treatment. This is illustrated by the declining interest of patients with TB in visiting health services because of social distancing policies.[6-8] Moreover, TB patients had difficulty accessing health services during the COVID-19 pandemic.[9]

Although Indonesia has shown remarkable progress in TB program coverage over the last decade, TB remains one of four leading causes of death in Indonesia.[10] The increasing number of multi-drug resistant cases with TB and unreported TB cases challenges national TB programs,[11] particularly during the pandemic that dramatically worsened the success of TB treatment. All TB services, including case detection and rapid diagnostics, were hampered by the pandemic. Limited operational guidelines during the pandemic in case finding, limited movement of patients to access treatment, concerns about contracting the virus when visiting healthcare facilities, and most hospitals in Indonesia having been designated as COVID-19 hospitals ultimately led to significant delays in diagnosis and TB treatment.[7]

The Global TB Report 2020 states that 1.5 million people died from TB, and an estimated 10 million people fell ill worldwide because of TB. This condition can certainly be an agent of spread to others when someone with active TB is not treated immediately.[12] Indonesia is the third country that accounts for two-thirds of the total high TB burden worldwide after India and China.[12] TB in Indonesia has constantly been increasing in the last five years. In 2017, there were 844,000 TB cases; in 2019, the estimated number of people who fell ill because of TB reached 845,000, with a death rate of 98,000 or equivalent to 11 deaths/hour.[13, 14] This phenomenon is a serious health concern for all of us because the success of treatment is an important indicator to achieve TB elimination in Indonesia by 2030.[15, 16]

Treatment adherence is one factor contributing to increasing the cure rate of patients with TB, reducing the transmission rate, and preventing drug resistance.[17, 18] However, the COVID-19 pandemic affected treatment adherence in patients with TB. One of the causes of the decreasing level of treatment adherence during a pandemic is the result of policies such as patients being given TB drugs for 1–2 months during a pandemic to reduce patient visits and the risk of disease transmission. Potentially, this can lead to a lack of control over medication adherence.[19] Meanwhile, some patients with TB during the COVID-19 pandemic stopped rehabilitation services, limited outpatient visits, and avoided access to healthcare facilities for fear of getting more severe symptoms because of COVID-19, which resulted in the risk of death.[20] In addition, the patients' health conditions become difficult to monitor; hence, patients who need treatment and regular follow-up are underserved.[19] Various patients with TB experience repeated incidents because of non-adherence to treatment and experience worsening conditions and even death.[21]

Based on the phenomena described, this qualitative research aimed to explore experiences of patients with TB from the time they were diagnosed with TB until they completed TB treatment, particularly during the COVID-19 pandemic.

Materials and Methods

This is a qualitative conventional content analysis study conducted between May–July 2022. In this

context, we conducted an in-depth exploration of experiences of patients with TB who had completed TB treatment, particularly during the COVID-19 pandemic, and were declared cured by health workers. The pandemic setting was chosen because the COVID-19 pandemic has impacted the provision of TB services in primary health care and hospitals. Lockdown, social distancing, isolation strategies, and public health guidelines to prevent virus transmission greatly affected all aspects of TB treatment.[19]

A total of 14 patients with TB who had completed TB treatment during the COVID-19 pandemic, by considering data saturation, were enrolled in this study. Sampling was done using purposive sampling. The criteria for eligible participants in this study were patients with TB who had completed TB treatment; patients being diagnosed until completion of TB treatment during the COVID-19 pandemic (March 2020–April 2022); ability to speak and understand the Indonesian language; and willingness to participate in this research. Unwillingness to participate in the study after interview was the exclusion criterion.

The location of research interviews was two Community Health Centers, namely Cimanggis Health Center and Pasir Gunung Selatan Health Center, which are located in West Java, Indonesia. Data were collected through in-depth semi-structured interview. An interview guide was prepared in the form of objectives and a list of questions that had been made but did not rule out the possibility that the researcher would expand the questions to obtain more comprehensive data from the experiences of patients with TB. The interview guide includes open-ended questions such as: "What challenges have you encountered while undergoing TB treatment, particularly during the COVID-19 pandemic?" and "What sources and forms of support did you get during TB treatment in the pandemic?". During the interview process, researchers attempted to conduct in-depth interviews with probing techniques to clarify the experiences expressed, such as "What do you mean by this?", "Why?", and "How?". Participants were interviewed individually; each interview lasted approximately 30–45 min and was digitally recorded. Data collection was terminated when data saturation was reached. During the data collection process, none of the participants dropped out.

Data analysis was carried out simultaneously with the data collection process using Graneheim and Lundman's approach.[22] The data was read and understood in preparation, then a coding system was created. We coded the relevant information units. Sub-themes development involved identifying emerging patterns and themes. The interview process and data coding were carried out by the first and second authors, who have backgrounds in community nursing science and experience in interviews and data analysis in qualitative research. The third author reviewed the coding process and its results to ensure the quality and accuracy of the analysis. NVIVO software application version 12 was used to facilitate the process of data analysis, especially when grouping data and formulating sub-themes/themes. The authors also used a consolidated checklist of qualitative research reporting criteria (COREQ) as a guide for writing research results.[23]

In this study, researchers made four efforts to strengthen the validity and trustworthiness of research results based on the Lincoln & Guba framework: credibility, dependability, confirmability, and transferability.[24] To ensure credibility, researchers conducted member checking by confirming the research results to participants through direct meetings and explaining essential aspects that were revealed. Good engagement with participants and internal researchers also ensured credibility. For dependability, the research team reviewed and examined all research steps through discussion and inquiry audits by other researchers who were not involved in the research. Furthermore, for confirmability, the researchers employed an audit trail by transparently explaining and delineating every

research step from inception to conclusion. All research steps were elaborated in detail to facilitate transferability, thus enabling the findings to be applied to other populations with similar characteristics.

This research was approved by the research ethics committee of the Faculty of Nursing, the University of Indonesia, with the code number of KET-128/UN2.F12.D1.2.1/PPM.00.02/2022. Participants were given a clear explanation about this study and were not discriminated in treatment between participants and ensured that all participants received the same treatment and opportunities by respecting all agreed considerations. All participants gave informed consent and had the right to withdraw from their cooperation in research at any time without any change in receiving health services. During the interview, researchers carefully tried to see the participants' condition. When participants seemed tired, the researchers considered a break, so that they could rest; or they ended the meeting. Efforts were made to maintain the privacy and confidentiality of the participants by not publishing the identity of research participants.

Results

Participants comprised 14 patients who had completed TB treatment during the COVID-19 pandemic. The participants' age ranged between 33 to 73 years. The majority of the participants (8; 57%) were women. Five participants (36%) had completed their Senior High School education. Nine participants (64%) were married, while most of them (11; 79%) were not working during the interview. All participants successfully completed a six-month treatment period in accordance with the standard TB treatment duration. Table 1 shows the participants' characteristics in this study.

From the interview transcription analysis, we formulated nine sub-themes and three themes resulting from the experiences expressed by the participants starting from the initial diagnosis of TB and from the beginning to completion of TB treatment during COVID-19 pandemic (Table 2).

1. Barriers to TB Diagnosis during the COVID-19 Pandemic

This theme refers to a series of challenges and obstacles that hinder the process of identification and confirmation of tuberculosis (TB) cases during the COVID-19 pandemic. This theme is composed of three subthemes that are explained in-depth.

1.a. Overlapping Symptom Limitations

In this subtheme, it is highlighted that the early symptoms of TB often overlap with COVID-19 symptoms. Patients who

Table 1: Characteristics of the Participants

No.	Age (years)	Sex	Level of Education	Marital status	Occupation at the time of the interviews	Start and finish of treatment
P1	50	Female	Senior HS[a]	Widowed	Unemployed	2020 August–2021 February
P2	53	Female	Senior HS	Widowed	Unemployed	2020 June–2021 December
P3	55	Female	Junior HS	Married	Unemployed	2021 January–2021 July
P4	42	Male	Junior HS	Married	Unemployed	2021 September–2022 March
P5	47	Male	Senior HS	Married	Unemployed	2021 January–2021 July
P6	47	Female	Elementary	Married	Unemployed	2021 November–2022 April
P7	64	Male	Junior HS	Widowed	Unemployed	2021 October–2022 April
P8	73	Female	Elementary	Widowed	Unemployed	2021 November–2022 April
P9	39	Male	Junior HS	Married	Driver	2021 September–2022 March
P10	33	Female	Junior HS	Married	Housemaid	2021 September–2022 March
P11	60	Male	Elementary	Married	Unemployed	2021 August–2022 February
P12	58	Male	Elementary	Married	Driver	2021 April–2021 October
P13	45	Female	Senior HS	Married	Unemployed	2020 April–2020 October
P14	59	Female	Senior HS	Widowed	Unemployed	2021 October–2022 April

[a]High school

Table 2: Sub-themes and themes generated from the data

Sub-Themes	Themes
Overlapping Symptom Limitations Fear of Medical Referrals Difficulties in Obtaining TB Tests	Barriers to TB Diagnosis during the COVID-19 Pandemic
Access to healthcare during the Pandemic Difficulties and obstacles during TB treatment during the Pandemic Stigma and Discrimination patients with TB face during treatment	Challenges in TB Treatment during the COVID-19 Pandemic
Support of family and friends in undergoing TB treatment The Role of health workers in Supporting TB Patients during the Pandemic Resources and information received during TB treatment	Support Resources during TB Treatment in pandemic era

experienced cough, fever, and shortness of breath become confused in distinguishing between TB manifestations and COVID-19 symptoms. This situation creates ambiguity that hinders early detection and appropriate interventions. As mentioned by one participant: *"At first, I was utterly confused. I had cough and fever, and with the presence of COVID-19, I wasn't sure if these were TB symptoms. I was worried that I might have contracted the COVID-19 virus and was concerned about not receiving timely treatment."* (P5)

1.b. Fear of Medical Referrals

This subtheme focuses on the feelings experienced by TB patients regarding medical referrals during the pandemic. Patients feel reluctant or fearful to visit medical facilities due to concerns about contracting COVID-19. This fear can hinder their access to appropriate care and slow down the crucial diagnostic process. As expressed by one participant: *"I felt hesitant to visit the health centre or hospital when the pandemic began. I feared that by going there, I might get infected with COVID-19. This caused me to postpone my visits to the Hospital or Health Centre, which ultimately worsened my condition."* (P7)

1.c. Difficulties in Obtaining TB Tests

This final subtheme highlights the difficulties related to TB testing and examination. With the primary focus on COVID-19 testing, healthcare facilities struggle to provide sufficient access and attention to TB tests. This results in delays in TB testing, ultimately impeding early case detection. One of the participants explained: *"I really wanted to undergo a TB test, but the health centre was swamped with COVID-19 examinations. This caused me to believe that COVID-19 testing was considered more important than TB testing."* (P11)

2. Challenges in TB Treatment during the COVID-19 Pandemic

This theme illustrates the challenges faced by patients with TB in treatment phase during the COVID-19 pandemic. In this theme, three sub-themes will be explained in depth.

2.a. Access to Healthcare during the Pandemic

This sub-theme highlights the challenges of access to healthcare faced by patients with TB during the COVID-19 pandemic. A participant stated: *"I found it difficult to get regular treatment due to travel restrictions during the COVID-19 pandemic."* (P3). Another participant said: *"In the early months of COVID-19, several health facilities were closed or had strict rules, so it was difficult for me to find alternative treatment places for the disease I was experiencing."* (P8)

2.b. Difficulties and Obstacles during TB Treatment in the Pandemic

This sub-theme covers the difficulties and obstacles patients with TB faced during their treatment in the COVID-19 pandemic. Some quotes that represent this sub-theme are:

"I feel nauseous, vomit, have a headache, feel weak, even my child told me to stop the medicine because the effects are not good, but I cannot go to healthcare services and ask

about the symptoms due to COVID-19..."(P14). *"It is like there is a feeling of boredom inside to take medicine. Sometimes, there is a feeling to stop because the duration of the treatment is quite long..."*(P1)

2.c. Stigma and Discrimination Patients with TB Face during Treatment

This sub-theme covers the stigma and discrimination experienced by patients with TB from their surroundings during treatment. A patient said: *"I was shunned by my neighbors; they said they were afraid of contracting it due to the symptoms I felt, which were the same as those of Covid-19, such as coughing."*(P2). Another participant stated: *"Many people assume that everyone with cough symptoms is COVID-19 positive and do not consider the possibility of TB disease. Some people still consider TB a shameful disease, especially during this pandemic."*(P13). One of the participants who was a driver implied: *"So, when I was sick, I rested because the owner of the car did not want to see me; he said he was afraid of infection, so I lost my job when they found out that I had TB… ."*(P9). A patient stated: *"I faced discrimination in my community during COVID-19. People looked at me differently and treated me differently because I had TB."*(P12)

3. Support Resources during TB Treatment in Pandemic Era

This theme describes the support received by patients with TB during the treatment process. Three sub-themes in this theme will be elaborated in depth.

3.a. Support of Family and Friends when Undergoing TB Treatment

This sub-theme covers the important role of family and friends in supporting patients with TB during treatment in COVID-19 pandemic. Quote representing this sub-theme is as follows:

"I am grateful to my family and friends who have supported me. They always remind me to take medicine and take me to the Puskesmas for check-ups even during COVID-19 outbreak." (P6)

3.b. The role of Health Workers in Supporting TB Patients during the Pandemic

This sub-theme highlights the role of health workers in providing support to patients with TB during the pandemic. A patient told:

"Because I am old, the nurse will deliver the medicine to my house because I cannot walk to the Puskesmas anymore. So, every two weeks, the nurse comes to the house to bring me medicine while checking my blood pressure, measuring my weight, and asking about my condition."(P8)

3.c. Resources and Information Received during TB Treatment

This sub-theme includes resources and information received by patients with TB during their treatment. One of the participants said:

"I went to the Puskesmas to have a consultation. I received brochures and informative materials about TB and COVID-19 from the Puskesmas that helped me understand about the diseases and treatments."(P4)

Discussion

This study reveals the experiences of patients with TB who had completed treatment, especially during the COVID-19 pandemic in Indonesia. This is important because COVID-19 affects TB services and programs, including TB prevention, surveillance, and treatment programs.[7] The first findings of this research describe the obstacles faced by TB patients during the COVID-19 pandemic. In the context of the pandemic, TB patients seeking diagnosis encountered more complex challenges due to the overlapping symptoms with COVID-19, fear of medical referrals, and difficulties in obtaining TB tests. The study indicates that symptoms such as cough, shortness of breath, and fever, which can be clinical signs of TB,

are also common symptoms of COVID-19.[25] Consequently, patients and healthcare workers might struggle to differentiate symptoms originating from TB or COVID-19, impeding timely diagnosis.[26]

Another barrier is the patients' concerns regarding medical referrals during the pandemic. These findings reveal that many patients are reluctant or afraid to seek medical care or refer to healthcare facilities due to concerns about COVID-19 exposure in those places. This fear could slow down TB diagnosis and treatment efforts, given the importance of healthcare interaction in the process. Studies stated that the sudden and global occurrence of the COVID-19 disease outbreak caused widespread worries due to its potential impacts.[27, 28] As a result, the increased prevalence of COVID-19 has significantly reduced hospital admissions and referrals.[29]

Another obstacle is that participants faced challenges in obtaining TB tests during the pandemic. Mobility restrictions and operational adjustments in healthcare services due to COVID-19 have led to reduced accessibility to TB tests. The patients in this study described difficulties in planning, arranging, and undergoing TB tests due to travel restrictions and COVID-19 control policies. This is in the same line with the result of a study in Peru which stated that the presence of the Covid-19 pandemic, coupled with various travel restriction policies, affected TB patient behaviour in accessing TB diagnostic services, resulting in delayed TB diagnosis.[26] These findings underscore the complexity of challenges in TB diagnosis during the COVID-19 pandemic. By understanding the obstacles with which TB patients are faced, healthcare providers can direct their efforts to ensure that patients continue to receive necessary care. These findings have significant implications for the management of TB patients during the COVID-19 pandemic. The emphasis on COVID-19 prevention and control must be balanced with strong efforts to ensure the availability and affordability of TB diagnosis and treatment services.

During treatment, participants encountered challenges in TB treatment, especially during the COVID-19 pandemic. These findings illustrate various challenges faced by patients with TB during the pandemic. Participants experienced challenges in accessing healthcare during the COVID-19 pandemic. Some patients had difficulty getting regular care due to travel restrictions during the pandemic. Health facilities also experienced closures or strict rules at the beginning of the pandemic, making it difficult for patients to find alternative treatment places. This challenge is also felt in various countries, such as Turkey, Brazil, and Ethiopia, where the impact of the COVID-19 pandemic on TB patients includes delays in diagnosis and decreased access to TB health services during the pandemic.[30-32]

In the treatment process, some patients experience side effects from the treatment program, such as nausea, vomiting, headaches, and weakness while taking TB drugs. Some feel tempted to stop treatment because the duration of treatment is quite long. These findings are in the same line with those of previous studies where the most common side effects were found in patients undergoing TB treatment, such as nausea, vomiting, headaches, and weakness.[33] These side effects can affect the treatment success, requiring close monitoring during treatment.[34] In addition, participants also received unpleasant treatment and negative views from the public because they had TB, and many people assumed that everyone with cough symptoms was a case of COVID-19, so they were considered to have the potential to spread COVID-19 because of the symptoms they experienced. Participants also experienced discrimination in their communication and even threat to lose job.

Studies indicate that during the COVID-19 pandemic, TB-related stigma has been on the rise due to concerns about transmission as TB patients are often perceived as carriers of two

contagious diseases.[35] The intersection of TB and COVID-19 can result in double stigma for patients, creating complex emotional effects and reinforcing feelings of shame and discrimination that can hinder seeking testing and treatment for both diseases.[36] Addressing stigma and discrimination in TB patients requires multifaceted interventions. These interventions should encompass public awareness campaigns to dispel myths, education for healthcare providers to adopt stigma-free practices, and creation of safe spaces for patients to share their experiences. A comprehensive approach that integrates mental health support with medical care is crucial in mitigating the negative impact of stigma on patients.[37]

Although participants faced challenges in treatment, the support of resources during treatment in COVID-19 pandemic played an essential role in maintaining the participants' motivation to remain consistent in undergoing treatment. Full support from family and friends emerged as a crucial pillar in the journey of TB patients. Studies indicate that family support, peer support, and healthcare provider support are forms of social support that contribute to motivation and treatment adherence in TB patients.[38, 39]

It turns out that health workers also play a role in supporting TB patients during the pandemic. The results of this study showed that during the pandemic health workers actively provided support and care to patients. The results of this study indicate that health workers help deliver medicines to patients' homes and conduct periodic checks for those who have difficulty accessing health facilities. In addition, health officials also provide information support using brochures and informative materials about TB and COVID-19. It can help the participants better understand these diseases and the stages of treatment they are undergoing. The World Health Organization has defined that Primary Health Care in Indonesia, known as Puskesmas, is a holistic approach to providing health services according to the needs of individuals and communities by prioritizing health promotion and disease prevention without neglecting treatment and rehabilitative services that the community can reach.[40] Studies have mentioned the importance of integrating tuberculosis (TB) control strategies with the response to COVID-19. This integration can be achieved by strengthening human resource capacities, integrating disease surveillance systems, and aligning field management systems vertically.[41]

The limitation of this study is that we did not conduct interviews with healthcare providers engaged in the treatment of TB patients and their families. This could constrain a deeper understanding of the perspectives and experiences of those directly involved in TB management. Although we conducted a comprehensive content analysis of the available data, this limitation might impact the depth of insight into the dynamics of interactions between TB patients, their families, and healthcare providers. For future research, incorporating these perspectives would be beneficial to create a more comprehensive and balanced portrayal. However, this study also has strengths in that the focus of this research is to explore the experiences of patients with TB during the COVID-19 pandemic. That is, the findings of this study can provide a foundation for developing better interventions and programs in TB management during the pandemics.

Conclusion

This study reveals various findings that provide a profound insight into the experiences of patients with TB during the COVID-19 pandemic. The identified themes encompass barriers in TB diagnosis, challenges in TB treatment, and support resources during treatment. These findings offer a crucial foundation for the development of improved interventions in TB management during the pandemic, while also advocating for enhanced access to services, stigma reduction, and the pivotal roles of family,

friends and healthcare providers in supporting patients. The findings have significant implications for improving health services for patients with TB during the pandemics. With the insights gained from this research, efforts to control and handle TB during the pandemics are hoped to be further improved. Future studies could consider broader aspects of the issue in terms of family and health providers' opinion to gain a more comprehensive understanding.

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