

“Cough was Extremely Excruciating”: A Qualitative Study of Pre-Diagnosis Experience among Individuals with Tuberculosis in Samarinda, Indonesia

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ABSTRACT

Tuberculosis (TB) is a global public health challenge. It's critical to comprehend how an infected person lives with the disease for TB control initiatives to be successful. Identifying the experiences before being diagnosed with tuberculosis needs to be done. This study aimed to explore the pre-experiences among individual that survive from TB. The qualitative method of descriptive phenomenology was utilized in this study. Purposive sampling was used in the sample process, and 16 tuberculosis survivors were included. This study found two themes that were pre-diagnosis symptoms (cough symptom, nutrition problem, hyperthermia and breathing problem) and health seeking behavior prior to being diagnosed with tuberculosis (visit health services, treatment behavior and ignore the symptoms felt). This study revealed that some individuals were still unable to identify the signs of tuberculosis and seek inappropriate treatment before receiving a diagnosis. Particularly for those who are at high risk, interventions aimed at enhancing the community's capacity to identify tuberculosis symptoms and adopt appropriate treatment-seeking behavior must be refined and implemented.

Keyword: Health seeking behavior, pre-diagnosis, symptom, tuberculosis

ABSTRAK

Tuberkulosis (TB) merupakan tantangan kesehatan global. Mencapai keberhasilan upaya pengendalian TB penting untuk memahami cara hidup penderita TB dari sudut pandang orang yang sudah terinfeksi. Identifikasi pengalaman sebelum didiagnosis tuberkulosis perlu dilakukan. Penelitian ini bertujuan untuk mengeksplorasi pra-diagnosis di antara individu yang pernah mengalami TB. Penelitian ini merupakan penelitian kualitatif dengan pendekatan fenomenologi. Metode pengambilan sampel adalah purposive sampling yang melibatkan 16 orang penyintas tuberkulosis. Penelitian ini menemukan dua tema yaitu gejala yang dirasakan (gejala batuk, gangguan gizi, hipertermia dan gangguan pernafasan) dan perilaku mencari pengobatan sebelum terdiagnosis tuberkulosis (mengunjungi pelayanan kesehatan, perilaku berobat dan mengabaikan gejala yang dirasakan). Penelitian ini mengungkapkan bahwa beberapa individu masih belum mampu mengidentifikasi tanda-tanda tuberkulosis dan mencari pengobatan yang tidak tepat sebelum terdiagnosis. Intervensi yang bertujuan untuk meningkatkan kemampuan masyarakat dalam mengidentifikasi gejala tuberkulosis dan menerapkan perilaku mencari pengobatan yang tepat harus dilakukan dan dilaksanakan khususnya bagi mereka yang berisiko tinggi

Kata Kunci: Gejala tuberkulosis, Perilaku mencari pengobatan, Pradiagnosis, Tuberkulosis

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Introduction:

One major issue for worldwide public health is tuberculosis (TB). With 270 million people living there, Indonesia continues to have the greatest number of tuberculosis cases worldwide. Indonesia is ranked second in the world for TB prevalence and is among the top 10 countries with the greatest prevalence of multidrug-resistant tuberculosis (MDRTB). In Indonesia, there are about 845,000 cases of TB, of which 92,000 result in death and an estimated 24,000 develop MDR-TB (WHO, 2020).

Even with the reported increase in TB cases, there was a substantial difference in the number of reported incident cases (7.0 million) and the predicted number of new cases (10 million) in 2018. Underreporting, underdiagnosis, and underidentification of instances are the causes of this disparity (Arini et al., 2022). Ten percent of this global disparity can be attributed to Indonesia (WHO, 2020).

The World Health Organization (WHO) lists TB as the primary cause of single infections and one of the top 10 causes of mortality (WHO, 2020). According to prior study, Migration from high-to low-prevalence nations has been linked to tuberculosis cases in low-prevalence countries (Aldridge et al., 2016; Pradipta et al., 2019). Therefore, identifying TB problems and strategies in high-prevalence countries is crucial to controlling TB cases at a global level (Pradipta et al., 2021).

Inherent socioeconomic position, sociodemographic, and behavioral factors continue to be significant in the onset and dissemination of TB, as well as in its prevention, treatment, and recovery (Nidoi et al., 2021; Wanahari et al., 2022). Furthermore, those in poverty are less likely to seek medical attention or complete treatment, which exacerbates the failure of TB control efforts (Makgopa et al., 2022). According to previous research, one of the problems in people with tuberculosis was delayed treatment (Christian et al., 2018; Tedla et al., 2020). Delayed treatment will affect to infectiousness, clinical severity and quality of life (Soebroto et al.,

2023; Tedla et al., 2020). Poor knowledge, low level of awareness and poor treatment seeking behavior contribute to delayed treatment in tuberculosis patients (Amanuel & Aregahegn, 2023; Animut et al., 2024; Christian et al., 2018; Noman et al., 2024; Putrie et al., 2015). Hence, research needs to be carried out to explore more deeply how these factors contribute to tuberculosis treatment.

In Indonesia, there is still a lack of research that identifies the experiences before diagnosis in people with tuberculosis. Hence, there was not enough evidence how people with tuberculosis behave before they start treatment. Identifying the experiences before being diagnosed with tuberculosis is very important and needs to be done through a qualitative approach. Their experiences will give ideas of how their behavior and perceived symptoms before they decide to start treatment. Their experiences will provide information on how to educate the community about the importance of recognizing the symptoms of tuberculosis and what to do if they experience symptoms of tuberculosis. This study aimed to explore the pre-experiences among individual that survive from TB.

Methods:

Design

The qualitative method of descriptive phenomenology was used to understand the phenomena experienced by research participants. This research methodology was chosen because can explore phenomena related to behavior, motivation perceptions and actions before people with tuberculosis start their treatment. This study adhered to the Standards for Reporting Qualitative Research (SRQR) (O'Brien et al., 2014).

Sample

Purposive sampling was the sample technique used involving 16 tuberculosis survivors. Population in this study is survivors of tuberculosis disease that lives in the region of Samarinda City. The criteria for inclusion of

participants are: (1) over 18 years old; (2) willing to be respondents in this study.

Data collection

The interview was conducted between August and September 2023. Participants in this study were chosen through purposive sampling procedures because the researcher looked at different viewpoints in order to obtain "rich" data. Then, a recorder was employed to gather data. The researchers used interview guidelines with nine questions and developed questions based on participants' statements.

Semi-structured interviewing methods are applied in-depth interviews. Depending on the participants' responses and how they answered the questions, the researchers conducting the interviews did not ask the questions to each participant in the same order. Interview protocols were followed, however participants were free to share their experiences with the researchers. Interviews with researchers lasted an estimated 45 to 60 minutes.

Statistical Analysis

The Collaizi technique steps are applied to process and analyze data (Streubert & Carpenter, 2003). The researchers carefully examined the transcript of the interviews to

Results:

There are two sections in the findings. Table 1 lists the participant characteristics in the first segment. Table 2 lists the topics, categories, and coding.

understand the overall significance of participant experiences. The interviewer then conducted a give-back transcription of the interview and noted any interesting statements. Transcript reviews were conducted in order to interpret remarks and classify them into codings, categories and themes. Data analysis using a variety of techniques, including peer debriefing with peers, member checking of the outcome, and inquiry audit, was done to perform the trustworthiness and credibility technique. Ultimately, the interviewer presented the descriptive findings. The Atlas.Ti program was also utilized in the study to assist in organizing, analyzing, visualizing, and presenting the research findings.

Ethics

The Mulawarman University Faculty of Medicine Health Research Ethics Committee has approved this study ethically (number: 213/KEPK-FK/XI/2023). Participants were informed of withdrawal decisions without any explanation, and the researcher obtained their informed consent while maintaining participant anonymity. The Helsinki Declaration of the study was put into practice (as revised in Brazil, 2013).

Tabel 1. Characteristic of participants

Participants code	Age	Gender	Religion	Education	Job
P1	55	Man	Islam	Senior high school	Self-employed
P2	54	Woman	Islam	Senior high school	Housewife
P3	37	Man	Islam	Junior high school	Driver
P4	54	Man	Cristian	Junior high school	Self-employed
P5	46	Man	Cristian	Senior high school	Self-employed
P6	67	Man	Islam	Elementary school	Farmer
P7	66	Woman	Islam	Illiterate	Self-employed
P8	23	Man	Islam	Junior high school	Driver
P9	30	Man	Islam	Diploma	Self-employed

Participants code	Age	Gender	Religion	Education	Job
P10	49	Man	Islam	Senior high school	Laborer
P11	27	Man	Islam	Senior high school	Laborer
P12	25	Man	Islam	Senior high school	Employee
P13	29	Woman	Islam	Senior high school	Employee
P14	22	Man	Islam	Senior high school	Driver
P15	35	Woman	Islam	Illiterate	Housewife
P16	40	Man	Islam	Junior high school	Parking attendants

Characteristic of participants are aged 22 until 66. Participants' levels of education varied from Illiterate until diploma. Participants

of this research have various types of job, Then, participants dominantly are muslim

Table 2. Themes, Categories, and Codings

Theme	Categories	Codings
Pre-diagnosis symptoms	Cough symptom	Persistent cough Blood cough Hurtfull cough
	Nutrition problems and Hypertermia	Anorexia Weight loss Hypertermia
	Perceived breathing problems	Hard to breath Sore throat Chest Pain
Health seeking behaviour prior to being diagnosed with tuberculosis	Visit health services	Visit hospital Seek treatment immediately Visit public health center
	Treatment behavior	Take regular cough medicine Not taking treatment
	Ignore the symptoms felt	Ignore cough symptoms not having a health check

Theme 1 : Pre-diagnosis symptoms

Cough symptom

"Because this disease is very dangerous and I experienced it and felt it, it was very painful because at that time I was coughing and it was consecutive, prolonged coughing ". (P4)

"So in the past, I coughed for 3 months until my voice stopped".(P11)

"Before I took the medicine my cough really tormented me every night. (P1)

"The coughing would not stop until I was peeing, and when the coughing started, it was really scary and very painful". (P7)

"I have been ill for almost a year, and after 12 months I am still coughing, and the phlegm is mixed with blood". (P15)

Nutrition problems and Hypertermia

"At that time my appetite continued to decrease until my weight dropped drastically and I do not know why that was?" (P4)

"My weight has decreased a lot, initially 72 kg, down to 52 kg within a month." (P1)

"I have lost a lot of weight, initially, 55 kg fell to 46 kg. My body was getting worse, that is why I went there (Community Health Center) to get checked" (P2)

"Before taking tuberculosis medication, my appetite decreased and my weight dropped drastically to 30 kg. (P5)

"I have had a fever and cough for 3 weeks" (P14)

"At the beginning of the illness, I felt fever every night. 2 am I had a fever, then in the early morning I had a fever again, so I don't know why I had a sudden fever" (P13)

Perceived breathing problems

"Because this disease is very dangerous and I experienced it and felt it, it really hurt because if I coughed, my chest would get tight. The cough was continuous and persistent, my chest and my throat hurt". (P4)

Theme 2 : Health seeking behaviour prior to being diagnosed with tuberculosis

Visit health services

So the first time I got it was at night, so I was immediately rushed to the hospital, I was examined there, immediately x-rayed. So he was told to go to the Community Health Center for treatment so he was given a referral letter. (P6)

I was sure that the symptoms pointed to tuberculosis, because I knew when my husband had tuberculosis. Well, the result was positive but it's not bad for me (P2)

Early in the morning at 3 o'clock I suddenly woke up and immediately coughed up blood. In the morning I went to a pulmonary specialist and was given a referral letter to the community health center (P9).

Treatment behaviour

"One month the cough didn't stop, then I took regular cough medicine first, but the cough

didn't stop, after that I just went to the community health center to be checked" (P7)

"I took medicine from the shop without a prescription. I waited 3 months, but the cough still didn't go away" (P9).

"I coughed until my voice disappeared. For 2-3 months I didn't get treatment because I thought it was just a normal cough" (P11).

Ignore the symptoms felt

I was late; before I was diagnosed with TB, I ignored my cough for more than a month. (P1) I started having a cough while I was working, but I didn't pay attention to it, and I never checked (P10).

Discussion:

The outcome of this study has highlighted how symptoms are felt and treatment-seeking behavior is carried out before being diagnosed with tuberculosis. A large portion of TB prevention centers on increasing awareness by identifying symptoms (Craig et al., 2014). The patients noted that because the majority of them misdiagnosed their symptoms as other illnesses and spent a considerable amount of time in the community self-medicating, the diagnosis and subsequent start of therapy were delayed. Treatment was not started right away in some of the hospitals due to misdiagnosis reports (Dodor, 2012).

Historically, Awareness-raising and control campaigns for tuberculosis have focused on the hallmark symptoms associated with pulmonary TB. In this study participants reported symptoms they had experienced included shortness of breath, weight loss, loss of appetite, and cough. Based on 25 studies, a thorough examination of research done worldwide produced the following estimations of symptom frequency: sweating 35%, blood in sputum 25%, weariness 55%, fever 65%, weight loss 62%, cough 85%, and chest symptoms 50% (Storla et al., 2008). Previous study showed participants listed a variety of symptoms they have encountered, most of

which are connected to a tuberculosis diagnosis (Craig et al., 2014).

Participants in this study self-treated with regular cough medicine, saw private doctors, visit public health center and hospital when they experienced the symptoms. On the other hand, some people said that when they felt symptoms, they ignored the symptoms and did not undergo examination or treatment. Previous studies showed prior to accessing healthcare facilities, participants have also reported self-treating or seeking care from non-medical sources (Asres et al., 2017; Chiposi et al., 2021; Ngwira et al., 2018). Numerous research participants also mentioned delaying the start of their treatments. The duration of stay at a medical facility, which can vary from three weeks to twelve months, much surpassed the time frame within which TB treatment must be started after the onset of symptoms. Treatment delays can be attributed to a number of factors, such as patients self-medicating, seeking assistance from non-medical sources initially, and attributing the illness to reasons other than tuberculosis (Biya et al., 2014). Delayed treatment will have an impact on the transmission of tuberculosis. Therefore the number of tuberculosis cases will increase (Tedla et al., 2020). Apart from the impact of this delayed treatment is a high level of severity and low quality of life (Soebroto et al., 2023; Tedla et al., 2020).

The limitation of the study is the participants used in this study had already passed the treatment period. Hence, there was a possibility of recall bias. Then, the researchers were having trouble getting in touch with the participants again, therefore member checking required additional time to get feedback.

Conclusions:

This study found two themes that pre-diagnosis symptoms (cough symptom, nutrition problem, hyperthermia and breathing problem) and health seeking behaviour prior to being diagnosed with tuberculosis (visit health services, treatment behaviour and ignore the symptoms felt). This research showed that there were still participants who were unable to

recognize TB symptoms and seek inappropriate treatment before diagnosed with TB. Interventions to improve the community's ability to recognize TB symptoms and appropriate treatment-seeking behavior need to be improved and carried out especially for high risk individuals.

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