

THE EXPERIENCE OF TUBERCULOSIS PATIENTS WHO DISCONTINUE TREATMENT: A PHENOMENOLOGICAL STUDY IN BANDUNG REGENCY

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Abstract

Loss to follow-up threatens tuberculosis (TB) control in Bandung Regency, where 18 patients in six districts discontinued treatment in 2023. Previous studies have mostly identified factors associated with loss to follow-up; this study instead describes the experience as a continuous process, from the initial treatment phase and the decision to stop, through its consequences, to the motivation to resume treatment. The aim was to analyze the experiences of TB patients in Bandung Regency regarding treatment discontinuation. A qualitative study with a phenomenological approach was conducted. Five participants (two men and three women) were selected purposively and interviewed in depth using a semi-structured guide. Data were analyzed using Colaizzi's method, and trustworthiness was ensured through credibility, dependability, confirmability, and transferability. Four themes emerged: the duration of the initial treatment, reasons for treatment discontinuation, the consequences of discontinuing treatment, and the motivation to resume treatment. The themes are interconnected, running from patient-related and economic factors and their physical and psychological impacts to the role of family and health worker support. Addressing treatment discontinuation in Bandung Regency requires a comprehensive approach that goes beyond providing free medication to include strengthening family support, educating patients on completing treatment, and empowering health volunteers to monitor patients in their service areas. These findings matter because they show local TB programs where, along the patient's treatment journey, targeted support can keep patients in care.

Keywords: Bandung Regency; Lived Experiences; Lost to Follow-Up; Patients; Tuberculosis

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1. INTRODUCTION

Tuberculosis (TB) is an infectious disease that poses a global health problem. TB is one of the top 10 causes of death worldwide (1,2). Although is a preventable and curable disease, successful TB control continues to face challenges across all aspects of disease management ranging from case detection and treatment adherence to the completion of treatment. The burden of

tuberculosis (TB) remains concentrated in low and middle income countries or developing nations including Indonesia, which is among the countries with the highest TB disease burden in the world, second only to India (3).

TB transmission is exacerbated by incomplete treatment or patients being lost to follow-up. Lost to follow-up refers to the failure of TB patients to complete their

treatment specifically, failing to continue treatment for two consecutive months thereby necessitating a restart of the treatment regimen from the beginning. Lost to follow-up is a serious issue because it can compromise treatment, increase the risk of disease progression or recurrence, heighten the potential for transmission, and raise the risk of developing drug resistance (4,5).

Treatment discontinuation among TB patients can result from non-adherence to the medication prescribed by the doctor, which increases the risk of morbidity, mortality, and drug resistance. Discontinuing TB treatment leads to resistance against anti-TB drugs and results in the development of multidrug-resistant TB (MDR-TB). Discontinuation of TB treatment cannot be viewed solely as an individual patient's failure to adhere to therapy; rather, it must be understood as a complex phenomenon involving the interaction of personal factors, treatment conditions, family dynamics, socioeconomic factors, and the healthcare system.

In Indonesia, the issue of the continuity of TB treatment also still requires attention from all parties. A qualitative study in Indonesia highlights the importance of understanding the firsthand experiences of patients and their families, as the TB treatment process unfolds within the context of the patient's daily life, rather than solely within the healthcare setting (6).

Successful TB treatment is a process

involving physical, psychological, and social experiences, as well as the patient's interaction with the healthcare system. Therefore, the treatment experience needs to be understood more deeply, particularly among patients who have previously discontinued treatment. An approach focusing solely on quantitative data such as the number of patients who discontinue treatment or the factors associated with such occurrences cannot fully explain how patients interpret the decision to stop treatment, what they experienced prior to discontinuation, the impact of stopping treatment on their lives, and the factors that drive them to either resume or not resume treatment (7).

Indonesia ranks second globally in the number of tuberculosis cases, following India, accounting for 10% of all new cases worldwide and West Java Province ranked second for the highest TB case detection coverage in Indonesia in 2024 (8). Bandung Regency ranked fourth for the highest number of tuberculosis cases in West Java in 2024 (9). Data from the Penabulu organization in Bandung Regency indicates that there are tuberculosis patients in the regency who have discontinued treatment or been lost to follow-up. These patients are distributed across several districts: Banjaran (3 people), Arjasari (3 people), Rancaekek (1 people), Cimaung (6 people), Baleendah (1 people), and Margahayu (4 people) (10). The presence of TB patients who have

discontinued treatment in Bandung Regency indicates that challenges remain in keeping patients engaged in the continuum of care and treatment until completion.

A phenomenological approach is relevant to this study because it aims to understand the meaning of lived experiences for individuals encountering a specific phenomenon. In this context, the phenomenon is the experience of TB patients undergoing treatment and subsequently discontinuing it. This approach enables the researcher to explore the patients' journeys in depth ranging from the initial diagnosis and treatment process to facing various obstacles, the decision to stop, the consequences of discontinuation, and the potential emergence of motivation to resume treatment.

Based on the preceding discussion, a research gap can be identified. Various studies employing both quantitative and qualitative methods have identified factors associated with non-compliance and treatment discontinuation among tuberculosis (TB) patients. However, there remains a need for research that specifically explores the lived experiences of TB patients who have discontinued treatment within the local context of Bandung Regency, utilizing a phenomenological approach. This study aims not only to address the question of what factors cause patients to discontinue treatment but also to gain a deeper understanding of how patients experience

the process of discontinuation and how they derive meaning from that experience.

Qualitative evidence from other settings, such as a study of patients lost to follow-up in Malaysia (11), has mostly described the barriers and reasons for leaving TB care at the personal, interpersonal, and health-system levels. The novelty of the present study is that it follows the experience of patients in an Indonesian district as a whole, from the initial treatment period, through the decision to stop and its consequences, to the motivation that brought patients back to care, and that it translates these experiences into recommendations for local TB control, particularly the role of TB volunteers and family support in Bandung Regency.

2. METHOD

The research method employed in this study is a qualitative method using a phenomenological approach to explore the experiences of the individuals participating in the research. Data collection for this study was conducted from May to July 2023. The participants in this study were five tuberculosis (TB) patients in Bandung Regency, located within the TB control service area of the Penabulu organization in Bandung Regency.

A phenomenological approach was chosen, rather than grounded theory, ethnography, or a case study, because the research question concerns the meaning that patients give to a lived experience (stopping

TB treatment) and not the development of a theory, the description of a cultural group, or the examination of a single bounded case. Colaizzi's descriptive method was used because it keeps the analysis close to participants' own statements and includes a step of returning the findings to participants for validation.

In this study, lost to follow-up was defined as a TB patient whose treatment was interrupted for two consecutive months or more after treatment had started, which is consistent with the definition used by WHO (1) and by the national TB control program in Indonesia (8). Patients classified as treatment failure, or who had a recurrence after being declared cured, were not included, so that the experiences explored were those of treatment discontinuation.

Participants were selected by purposive sampling from the list of patients lost to follow-up held by the Penabulu organization in Bandung Regency. The inclusion criteria for this study were TB patients aged at least 18 years who resided in the Penabulu TB service area in Bandung Regency, had a history of treatment interruption for a minimum of two consecutive months, had resumed TB treatment at the time of the interview, and were able to communicate verbally and willing to have their voices recorded. Exclusion criteria included patients with treatment failure or relapse after being declared cured, patients with drug-resistant

TB, and patients who were critically ill and unable to be interviewed.

The researcher coordinated with the Penabulu team in Bandung Regency regarding data on TB patients who had discontinued treatment. The Penabulu team provided a list of patients residing in the sub-districts, and participants were selected using purposive sampling specifically by choosing patients who had direct experience with the phenomenon and were able to articulate it. Prospective participants were contacted by the research team. Of the 18 patients on the list, five did not meet the inclusion criteria, five could not be contacted, three declined to be interviewed, and five agreed to participate. Interviews were conducted with the five individuals who consented and signed informed consent forms, and the interviewing process concluded once data saturation was reached.

The research activities consist of data collection, data processing, and data analysis stages. Data collection is conducted through semi-structured, in-depth interviews lasting approximately 30 to 60 minutes. Tools used to facilitate the indepth interviews include a voice recorder, writing instruments, and a notebook. The interview guide was developed by the researchers from the study objectives and the literature, and covered four areas: the experience of the initial treatment, the reasons for stopping, what happened after stopping, and what motivated the return to treatment.

Data analysis in this study employed Colaizzi's method, which encompasses transcription, identification of statements, interpretation of meaning, and formulation of themes. In-depth interviews were conducted with participants until data saturation was reached, indicated by the recurrence of the same statements from the participants. Saturation is considered reached when interviews no longer yield significant new statements or sub-themes compared to previous interviews. This number of participants also aligns with phenomenological studies, which typically employ small and relatively homogeneous samples.

Data validity in this research employs the criteria of credibility, dependability, confirmability, and transferability. Credibility was established through member checking with participants to verify the results of indepth interviews. Member checking was conducted by presenting the interview transcripts and draft themes directly to each participant, who were then asked whether the themes reflected their experiences. Dependability and confirmability were addressed through verification by qualitative research experts. Transferability was achieved by presenting a comprehensive description of the research findings, aligned with the research objectives.

3. RESULTS AND DISCUSSION

Results

This study involved five participants

two men and three women aged between 21 and 67. All participants were Muslim, worked as private-sector employees, retirees, or homemakers, and resided in the Bandung Regency area. All participants had a documented interruption of treatment of at least two consecutive months and none had been classified as treatment failure or recurrence.

Research Theme

The researchers identified four themes in the study:

1. Duration of the initial treatment

Indepth interviews with the participants revealed varying experiences regarding the duration of their initial tuberculosis treatment. Participants reported discontinuing treatment at different stages some after two months, others after three or four months. This is illustrated by the following statements from the participants:

....."I underwent treatment for about a year; I started in 2022, then stopped it's been a long time, about three months since I stopped...."
(P1)

....."The first course of treatment was in November 2022 about a year ago but it wasn't completed because I only took the medication for two months".....(P3)

....."The previous treatment lasted about four months, but I just stopped" ...(P4)

2. Reasons for discontinuing treatment

Based on the results of indepth interviews with the participants, the majority stated that they discontinued their initial

course of treatment because they no longer experienced TB symptoms such as a reduction in coughing and felt healthy again. This is reflected in the following statement by a participant:

...."After three months of treatment, I felt my cough was gone"...(P1)

....."Felt the medication wasn't right for me, even though symptoms persisted"....(P2)

....."It seems I didn't take it seriously enough; once I felt fit, I became irregular with taking the medication and stopped treatment after three months"...(P3)

Another factor contributing to the discontinuation of treatment among TB patients is cost. Participants stated that they lacked the funds for transportation and other expenses such as food associated with visiting the Community Health Center (Puskesmas), even though the medication itself was provided free of charge. This is reflected in the following statement from a participant:

...."There is no cost to go to the Community Health Center"...(P4)

...."I have a problem with the cost; I don't have the money to seek treatment at the Community Health Center"...(P5)

3. Consequences of discontinuing treatment

The participants stated that after discontinuing their TB treatment, they experienced a recurrence of symptoms similar to those present when they first contracted the disease such as a persistent cough, fatigue, shortness of breath, and dizziness with some even falling into depression due to

a loss of hope. This is illustrated by the following participant:

..."Symptoms returned, such as coughing and fatigue...(P2)

..."After stopping treatment around the fourth month, I felt aching and soreness in my legs; the coughing returned frequently....I even lost hope and felt utterly despondent, Sir... I went so far as to tell my wife that if I were to pass away, she should forgive my wrongdoings"...(P3)

....."When stopped treatment, experienced shortness of breath again, along with frequent coughing and dizziness"...(P5)

4. Motivation to seek treatment again

The participants stated that they sought treatment for TB again due to a desire to regain a healthy life. This was driven by the TB patients' internal motivation to quickly return to normal activities, free from the disease. This is illustrated by the following participant's statement:

...."Once I started feeling those same symptoms again the coughing, the pain, the aches I felt I had to go back to the Community Health Center for treatment, even though it meant the risk of having to start all over again from scratch... (P3)

...."It really came from within myself; I had to get healthy again and seek treatment I felt sorry for my children, too....(P4)

In addition to the internal motivation of TB patients, there is also motivation from external sources, such as family members and

health volunteers. This is reflected in the following statement by a participant:

...."My mother often advised me; she would tell me I had to keep going until the illness was cured.... She said I shouldn't end up like my older sibling, who passed away from TB too"....(P3)

...."As for me, my husband often motivates me, saying, 'You have to get well—think of me and the family'.... (P5)

Another factor aiding TB patients in resuming their treatment is the presence of TB volunteers from the Penabulu organization in Bandung Regency. These volunteers regularly visit and monitor the patients' treatment, as reflected in the following statement by a participant:

...."The community health volunteer who often visits and advises me to seek treatment again"....(P1)

...."I feel supported by the community health volunteer.... She regularly visits my home, offering advice and motivation, and she is patient"....(P4).

Discussion

The four themes identified in this study duration of initial treatment, reasons for discontinuing treatment, consequences of discontinuation, and motivation to resume treatment illustrate the sequence of experiences undergone by participants from the start of treatment through to their decision to return to care. These four themes are discussed below in relation to the study's

objectives and relevant findings from previous research.

1. Duration of the initial treatment

The study results indicate that all participants discontinued treatment between two and four months after the initial treatment began specifically, while still in the intensive phase of Category 1 TB treatment, which is supposed to last for two months and be followed by a continuation phase for the subsequent four months. These findings reinforce the fact that the initial two-month treatment period is critical for TB patient adherence (12), as clinical symptoms such as coughing begin to subside during this time, leading to the mistaken belief that the patient has recovered (11). The age range of participants in this study spanning from 21 to 67 years is consistent with a scoping review by Agus et al. (2024), which identified older age, male sex, lower education, lack of family support, and drug side effects as factors associated with non-adherence to anti-TB treatment (13); in this study, discontinuation occurred across a wide age range.

The perception that symptom improvement means recovery appears to have formed from participants' own bodily experience. Participants described that their cough eased or disappeared after two to three months of treatment and that they felt fit again (P1, P3), and they used the disappearance of symptoms, rather than completion of the full regimen, as the sign of cure. When the reason for continuing

treatment after symptoms subside is not well understood, feeling healthy gives little reason to keep taking the drugs, and P3 described how this led to irregular intake and then stopping. This is in line with the explanation that clinical improvement in the intensive phase leads patients to believe that they have recovered. Not all participants followed this pattern, however: P2 stopped because the medication felt unsuitable even though symptoms persisted, which suggests that perceived drug intolerance and perceived recovery are two different routes to discontinuation.

2. Reasons for discontinuing treatment

Regarding the patient-related aspect, the dominant causes identified by participants were the subjective perception that symptoms had disappeared, the feeling that the medication was unsuitable, and a tendency to downplay the importance of treatment once their physical condition seemed to improve. Qualitative research by Khaitan et al. (2022) in Faridabad, India, illustrates a similar phenomenon: some patients even stated they preferred to discontinue treatment due to severe side effects, indicating that the issue of TB treatment adherence is not merely a matter of knowledge but also involves patients' subjective experiences regarding the effects of the therapy (14).

In addition to factors related to the patients themselves, this study identified other factors specifically cost constraints,

such as transportation expenses to health facilities and the cost of food during treatment even though TB medication is available free of charge at Community Health Centers (Puskesmas). These findings reinforce the results of the study by Soedarsono et al. (2021), which emphasize the importance of psychosocial and economic aspects as determinants of loss to follow-up among patients with drug-resistant TB (15). Research by Mishra et al. (2021) among vulnerable populations in India also revealed a similar pattern: cost barriers and transportation access issues were among the primary reasons for loss to follow-up, even though TB treatment is essentially provided free of charge (16). Thus, discontinuation of TB treatment in Bandung Regency is not solely attributable to factors related to the individual patient but is also influenced by socioeconomic conditions that limit patients' access to healthcare services.

Economic barriers, access barriers, and individual motivation were distinguished during analysis by coding each significant statement according to the reason the participant gave. Statements about symptoms, the suitability of the drugs, and attitude toward treatment (P1, P2, P3) were coded as patient-related factors, while statements about the money needed for transport and food (P4, P5) were coded as economic factors. No participant described problems with the availability of drugs or the attitude of health workers, and difficulty

reaching the Community Health Center was expressed only as the cost of travelling there, so access and economic barriers were grouped together. Participant characteristics were considered in the interpretation.

3. Consequences of discontinuing treatment

The third theme describes the consequences experienced by participants after discontinuing treatment namely, the recurrence of clinical symptoms such as persistent coughing, fatigue, shortness of breath, and pain with one participant even experiencing psychological distress in the form of feelings of hopelessness. These findings provide empirical insight into the impact of treatment discontinuation a phenomenon previously described largely in epidemiological terms specifically the increased risk of resistance to anti-tuberculosis drugs and the risk of developing multidrug-resistant tuberculosis (MDR-TB) (4).

The emergence of psychological impacts specifically feelings of hopelessness among the study participants aligns with the findings of Agbeko et al. (2022), whose scoping review identified anxiety and depression as the most common mental health problems among TB patients, with poor social support and stigma also affecting treatment; consequently, patients who experience a recurrence of symptoms after discontinuing treatment are at risk of facing an additional psychological burden alongside

the physical burden of the disease (17). These findings underscore the multidimensional impact of discontinuing TB treatment encompassing clinical aspects, the risk of transmission to others, and the patient's psychological well-being thereby necessitating a holistic approach to managing patients who drop out of treatment, rather than focusing solely on pharmacological aspects.

4. Motivation to seek treatment again

The participants' motivation to resume treatment comprised internal motivation specifically, the desire to regain their health and fulfill their roles within the family and external motivation derived from family support (from the participants' mothers and husbands) and support from TB health volunteers associated with the Penabulu organization in Bandung Regency. The role of family support in encouraging patients to resume and complete their treatment is consistent with the findings Zuhair and Ismah (2024), who reported a significant relationship between family support and treatment dropout (18). Findings regarding the role of TB cadres in supporting, counseling, and monitoring patients to ensure they resume treatment reinforce the importance of the Directly Observed Treatment Short-course (DOTS) strategy the national approach to TB control, are consistent with a scoping review showing that empowering health cadres improves patient adherence to treatment (19), and provide an

empirical basis for this study's recommendation that the Bandung Regency local government empower health cadres, particularly TB cadres at the village or urban-village level, to facilitate the continuous monitoring and reporting of TB patients' treatment progress.

Overall, the four themes identified in this study are interconnected and illustrate the treatment experience of TB patients in Bandung Regency as a continuum ranging from patient-related and economic factors that drive treatment discontinuation and the resulting physical and psychological impacts, to the role of family and health worker support in encouraging patients to resume treatment. These results align with findings indicating that the factors contributing to loss to follow-up in TB treatment are multifactorial encompassing individual, socioeconomic, and social support factors (20), consequently efforts to address treatment discontinuation in Bandung Regency must be comprehensive; they should not focus solely on the provision of free medication but also on strengthening family support, educating patients on the importance of treatment adherence until completion, and empowering health volunteers to monitor TB patients within their respective service areas.

Study Limitations

This study is limited by the small number of participants (five individuals) and a geographical scope confined to Bandung Regency; consequently, the findings cannot

be widely generalized, though they can serve as a basis for developing more context-specific interventions to reduce TB treatment discontinuation rates in the area.

4. CONCLUSIONS

The study identified four themes: the duration of the initial treatment, reasons for treatment discontinuation, the consequences of discontinuing treatment, and the motivation to resume treatment. A recommendation is made for the Bandung Regency local government to empower health volunteers specifically tuberculosis volunteers at the village or urban-village level to monitor and report on the treatment progress of tuberculosis patients.

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Conflict of Interest

The authors declare no conflict of interest.

Author Contributions

The First Author contributed to the conceptualization, research design, data collection, data analysis, and manuscript preparation. The second author contributed to data collection, data analysis, critical revision of the manuscript and validation.

Artificial Intelligence (AI) Use Disclosure

The authors used [Claude, 2026] solely to improve clarity and grammar during manuscript preparation. This tool was not used to generate research ideas, collect or analyze data, interpret findings, or draw conclusions. All results were critically reviewed and edited by the authors, who take full responsibility for the content, accuracy, and integrity of this publication.

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