



Perceptions and experiences of drug-resistant tuberculosis, HIV, and AIDS patients who experience loss to follow-up based on life values and stigma: a phenomenological study



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ABSTRACT

Background: Human immunodeficiency virus (HIV), acquired immunodeficiency syndrome (AIDS), and tuberculosis are closely related and remain serious problems despite the implementation of various treatment strategies, but cases continue to increase. This research aimed to explore the perceptions and experiences of drug-resistant tuberculosis people with HIV/AIDS who experience loss of follow-up based on life values and stigma.

Methods: This qualitative study employed a phenomenological approach and (COREQ) guidelines. Researchers purposively sampled participants with HIV/AIDS and tuberculosis in Lampung Province, Indonesia. Data were collected through interviews and analyzed using Colaizzi's seven-step thematic analysis.

Results: The results of the study described 7 themes related to the perceptions and experiences of drug-resistant tuberculosis HIV/AIDS sufferers who experience loss to follow-up based on life values and stigma, including 1) understanding of HIV/AIDS and tuberculosis; 2) causes of TB and HIV/AIDS clients experiencing loss to follow-up; 3) what happens after experiencing loss to follow-up: economic problems and drug availability; 4) adaptation after experiencing loss to follow-up: comfort; 5) use of herbal medicine as therapy; 6) barriers and support when it comes to control and treatment; 7) hope to recover and regularly taking medication and environmental dilemmas.

Conclusion: HIV/AIDS and tuberculosis sufferers who experienced loss to follow-up provide an understanding of experience, including the process of disease transmission and spread as well as antiretroviral drug treatment, anti-tuberculosis drugs, and the side effects they experience. A further problem is the community's assessment of the condition of the disease. The support and facilities provided affected the issue of needs, both material and psychological.

Keywords: acquired immune deficiency syndrome, drug-resistant tuberculosis, human immunodeficiency virus, HIV/AIDS, life values and stigma.

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INTRODUCTION

Human Immunodeficiency Virus (HIV), acquired immunodeficiency syndrome (AIDS), and tuberculosis are closely related and are complex problems to solve. Various treatment strategies are carried out to perform end-TB programs and prevent HIV transmission.^{1,2} However, the proportion of tuberculosis (TB) cases will still be high in 2020, around 69,000 new cases of drug-resistant TB, including 37,000 cases of pulmonary TB. Additionally, HIV-TB co-infection is on the rise according to the WHO European Region, an estimated HIV infection rate of 12% among TB cases in 2020 (29,000 people with TB or HIV) compared with 9.7% in 2015.^{3,4} WHO

in 2020 shows that 44% of HIV sufferers experienced undetected TB infection in 2019, so increasing TB screening for HIV sufferers is very important. Meanwhile, HIV-TB treatment is still low at around 50% achieved in 2019, even though preventing TB in HIV patients has been proven to significantly reduce the risk of death from HIV-TB. Indonesia ranks second in the number of TB cases in the world, with 845,000 TB cases and 19,000 HIV-TB coinfecting patients in 2019. Of the 271 million population, an estimated 543,100 people live with HIV, and an estimated 4,700 HIV-TB patients died and around 96,000 died due to TB.^{3,5}

The incidence and prevalence of cases

of population living with HIV/AIDS (PLWHA) in Lampung Province in 2019 has found 5,643 people, and this was only around 50% of the cases seen. This condition is like an iceberg phenomenon, only the surface is visible, but there could be much more at the bottom. This situation is also comparable to the description of drug-resistant tuberculosis, which is an possible infection that is inherent in PLWHA.⁶ In addition, based on the target for suspected multidrug-resistant TB (MDR TB) condition in Lampung Province in 2015-2019 was estimated about 655 out of 935 (80%) cases. The cases included 25% MDR TB with loss to follow-up. The most significant number of cases was in

Bandar Lampung City, 144 cases in 2019. This condition was perpendicular to the national TB cases, which showed a figure of 15,127 cases, causing a high death rate due to TB. This problem arises because the treatment process was not optimal.^{5,7}

Loss of follow-up occurs because the client feels sad, bored, refused to exist, was helpless, complained a lot about the improvement in health conditions, and often thought that life is over. Nurses sometimes call to remind clients to visit the Health center. Previous study stated that the quality of life of TB and HIV/AIDS patients undergoing treatment depends on the physical condition experienced, emotional stress, individual and family coping, social support experienced by the family and surrounding people, as well as the surrounding environment of TB patients in living their lives.⁸ The problem of loss to follow-up will become serious if not immediately addressed. TB disease is very infectious and carries the risk of causing transmission to many people. The problem of loss of follow-up and reliability of treatment is a significant health problem and poses a risk to the process of controlling TB HIV/AIDS cases. This condition is partly caused by the patient's unique behavior.⁹

To address the significant challenge of treatment disengagement among individuals co-infected with MDR TB and HIV/AIDS, this research endeavored to yield original insights by investigating the underexplored influence of deeply ingrained life values and the pervasive experience of stigma. In contrast to extant literature that might predominantly emphasize clinical or logistical impediments to treatment adherence, this investigation distinguished itself by examined the subjective experiences of individuals with MDR TB and HIV/AIDS, specifically analyzing the frequently overlooked impact of their fundamental life values and the profound stigma they encounter factors deemed critical for comprehending and resolving the persistent issue of loss to follow-up.^{10,11} This research aimed to explore the perceptions and experiences of MDR TB people with HIV/AIDS who experience loss to follow-up based on life values and stigma.

METHODS

Research design and setting

This research used a qualitative research methodology with a phenomenological approach, which describes the exploration of the experiences of HIV/AIDS sufferers with TB who experience loss to follow-up in Lampung Province Indonesia. This approach emphasizes the experiences of participants who experience loss to follow-up based on situations experienced consciously and naturally without being directed by the researcher. This research used qualitative research reporting standards (COREQ).

Participants and sampling

Participants in this study were HIV/AIDS sufferers with TB infection in Lampung Province. The selection of participants was carried out using a purposive sampling technique, and they were actively involved in the research process and were able to understand and explain the problem being studied during the interview process.¹² The number of participants in this research was 15, who were selected through an identification process, then explained the research objectives and willingness to become participants until data saturation.¹³ Participants to ensure that those included met the following inclusion criteria: namely, HIV/AIDS sufferers with TB who underwent treatment and experienced dropout; the Sufferer are participants who underwent post-treatment, understood Indonesian, and was able to report the experience of loss to follow-up while undergoing antiretroviral treatment: drugs and anti-TB drugs. All participants were involved in this research, and a code was given to each participant (P1, P2, P3, ...) to comply with the research code of ethics.

In total, 15 participants participated in this study (Table 1). The participants consisted of 15 sufferers of HIV AIDS with TB infection with an age range of 30 to 50 years, including 11 females and 4 males, their level of education starting from junior high school to academy. The participants had diverse marital statuses among them married, not married, and divorced. Their employment roles varied: not employed, seller, and self-employed. While the religious characteristic participants were

mostly Islam 11 participants, Hindu 1, Buddhist 1, and Cristiani 2. This diversity provided a broad range of perspectives on the perceptions and experiences of MDR TB HIV/AIDS patients who experience loss to follow-up based on life values and stigma.

Data Collection

The data collection was conducted from August 1, 2024 to September 30, 2024 in Lampung Province. The choice of research location was adjusted to the research objectives and the high prevalence of loss to follow-up cases. The study used in-depth interviews to fully explore the participants' experiences with the phenomenon under study. Direct observations were conducted to validate participant responses by comparing their descriptions with actual practices and behaviors in their work environment. The guidelines were prepared before the research was conducted, and the test was performed on one participant for validity and reliability testing. After consulting with the supervisor and reviewing the pertinent literature, an interview guide was created. The interview was structured with the aid of the guide's general and specific questions, which also gave participants the freedom to freely discuss their experiences. By approaching the guide as a framework rather than a set script, flexibility was operationalized. Field notes were also maintained to document non-verbal cues, environmental factors, and informal interactions, providing additional context and capturing nuances that may not have emerged during the interviews.

These complementary methods enriched the data collection process and ensured a holistic understanding of the challenges faced by sufferers. During the interview, the researcher used field note aids, an interview recording device (Sony IC brand), and an iPhone 13 Pro camera. Each participant's interview lasted 60-90 minutes. Next, the interview results were transcribed and analyzed to revalidate the meaning of the words spoken by the participants. Data saturation was met, as indicated by the central themes, and no other themes appeared.

The first author conducted the interviews during the study and received

interviewing skills training from the supervisor. With the help of this training, the interviewer was guaranteed to have the abilities needed to steer discussions, pose insightful queries, and extract thorough, in-depth answers. To maintain uniformity, the first author followed the interview outline and refrained from using leading questions when conducting the interviews. Peer debriefing meetings were held with the supervisor and research team during the analysis phase to minimize the impact of researcher assumptions and cross-check interpretations. This ensured that findings were based on participant replies.

Data Analysis

The data obtained in this research used thematic analysis. They were analyzed using Colaizzi's original seven-step method Colaizzi which was refined and simplified by Wu, Chen and Xu into five steps while still being guided by the method Colaizzi's steps include explaining the phenomenon word for word in the transcript, citing statements, describing them in the form of keywords, organizing keywords into categories, subthemes and themes and writing comprehensive report on the results.¹³

Trustworthiness

Researchers ensure the credibility of this research comprehensively and according to the parameters described by Lincoln and Guba.¹³ Data was validated by confirming it with all participants and then combining it into the analysis findings. After the data was transcribed, participants could read the transcript results to maintain credibility and ensure the data transcript was correct and accurate. There were no re-interviews, only clarification of the data obtained.

RESULTS

The study identified seven themes about perspectives on the perceptions and experiences of MDR TB HIV/AIDS patients who experience loss to follow-up based on life values and stigma. These themes outline the main issues obtained from the data, thus providing information on the experiences and perceptions of the problems of loss to follow-up that are being experienced. The themes and subthemes

of this study are explained in Table 2.

Based on the verbatim results compiled through data organization, 7 themes were obtained, which will be described as follows: The first theme is supported by three subthemes: understanding HIV/AIDS and TB, immunological complications, and disease transmission. The sub-theme Understanding HIV/AIDS and TB describes the sufferer's understanding of the HIV/AIDS and TB they suffer from. Participant 5 stated, "Yes, HIV makes us sick easily, bro, because the immune system is attacked, as far as I know, HIV is a disease for which there is no cure, bro (P5). Meanwhile, participant 2 said "sorry, but it's foreign to me. "It's like FLEXES, like spots, if you have TB, as far as I know the cough is caused by bacteria. it doesn't get better, instead you cough up blood" (P2).

In addition, immunological complications are also understood to be problems that arise in HIV/AIDS sufferers with TB infection. This is expressed by Participant 3 who stated, "a disease caused by a virus that damages our immune system..." (P3). Participant 1 also said, "I know, HIV is a disease that has no cure, while if you have TB, as far as I know, you cough because of bacteria. it doesn't get better, you even cough up blood due to HIV complications." (P1).

Transmission of HIV/AIDS sufferers with TB is felt as an understanding of the disease they suffer from. This condition was conveyed by Participant 15 who stated, "...I contracted HIV 10 years ago because I used to snack on chili girls and for the past year I have been experiencing complications from tuberculosis infection because while I was infected with HIV I often got sick and the peak this year felt like my body was no longer normal." (P15).

Theme 2 explores the reasons why TB and HIV/AIDS patients experience loss to follow-up. This issue was supported by four sub-themes that highlight the problems contributing to patients discontinuing their treatment. The majority of participants stated that socio-economic factors were a problem for them not undergoing treatment. Participant 11 said, "so far I don't have money to go to the health center, especially since the health center is quite far from home, the distance is

more than 40 km and I don't have a vehicle, buses don't pass through here and there is no availability of medicines other than that at the health center" (P11).

In addition, participants expressed complaints that they still face high levels of stigma. This section describes the conditions experienced by HIV/AIDS sufferers in everyday life. Participant 9 said, "sometimes I'm also lazy and choose to just stay at home, people always look at me when I want to go to the health center to get medicine, people often even talk about me as being a former prostitute" (P9).

Apart from that, there was also a sub-theme of very low social support received by HIV/AIDS sufferers with TB infection. Participant 7 conveyed this situation during the treatment process. "when I was infected with HIV, at first I was still in ..., bro, it was still easy for me to get medicine because it was in the city, because I had been sick for a long time and often went back and forth to the community health center, many people knew about my illness but they seemed so indifferent, bro, because there I didn't have any work, I went home." Here, it was even more difficult to get medicine, even the neighbors and the environment didn't care about my condition, including my own family, they also seemed hands-off" (P7).

The distance of access, difficulty in transportation, and health services create a picture of geographic mobility that causes loss to follow-up. This is reflected in Participant 13's statement: "the availability of drugs is only at the health center, whereas to get there it's far away and I don't have a vehicle, bro, there's no public transportation here either, so now I never take medicine anymore and if there are complaints I take regular medicine, buy it at the shop, sometimes I make herbal medicine, in fact here health services are still very lacking, it's sad" (P13).

Theme 3 focuses on the consequences of experiencing loss to follow-up, particularly issues related to economic problems and drug availability. This theme is supported by three sub-themes that further explain the challenges faced by patients after discontinuing treatment. Economic constraints due to the inability of HIV/AIDS sufferers with TB infection to meet their living needs, especially

Table 1. Characteristics of 15 participants who were patients with loss to follow-up human immunodeficiency virus (HIV), acquired immunodeficiency syndrome (AIDS), and tuberculosis (TB)

No	Participant (Code)	Age (Years)	Gender	Level of Education	Religion	Employment	Marital Status
1	P1	38	Female	Senior High School	Islam	Not Employed	Not Married
2	P2	40	Female	Junior High School	Islam	Not Employed	Divorced
3	P3	37	Female	Senior High School	Islam	Seller	Married
4	P4	30	Female	Junior High School	Islam	Not Employed	Not Married
5	P5	33	Male	College	Hindu	Self-employed	Married
6	P6	38	Female	Senior High School	Islam	Not Employed	Not Married
7	P7	50	Female	Junior High School	Buddhis	Not Employed	Divorced
8	P8	37	Female	College	Islam	Seller	Not Married
9	P9	39	Female	Senior High School	Islam	Not Employed	Not Married
10	P10	39	Male	Junior High School	Christian	Self-employed	Not Married
11	P11	48	Male	College	Islam	Not Employed	Not Married
12	P12	40	Female	Junior High School	Islam	Not Employed	Married
13	P13	50	Female	Senior High School	Islam	Seller	Not Married
14	P14	48	Male	Junior High School	Islam	Not Employed	Not Married
15	P15	50	Female	College	Christian	Self-employed	Not Married

Table 2. Themes and subthemes

Sub themes	Theme
1. Definition of HIV/AIDS and tuberculosis	1. Understanding of HIV/AIDS and tuberculosis
2. Immunological complications	
3. Disease transmission	
1. Social Economics factor	2. The reason TB and HIV AIDS patients experience loss to follow-up
2. Stigma	
3. Social Support	
4. Geography mobility	
1. Economics Barrier	3. Things that happen after experiencing loss to follow-up: economic problems and drug availability
2. ART clinic support and drugs	4. Adaptation after experiencing loss to follow-up: comfort
1. Anxiety and afraid	
2. Spiritual comfort	
3. Increased awareness about compliance	
1. Symptom management	5. Use of herbal medicine as therapy
2. Motivation for using herbal medicine	
3. A holistic view of culture and beliefs	
1. Treatment-related barriers and discrimination	6. Barriers and support regarding control and treatment
2. Social support (family, friends, health workers)	
1. Hope of recovery	7. Hope to recover regularly consume medication and be accepted by the environment
2. Adherence	
3. Social acceptance	
4. Elimination of stigma	

AIDS, acquired immunodeficiency syndrome; ART, antiretroviral treatment; HIV, human immunodeficiency virus

medication, as expressed by Participant 6: “I don’t want to go anywhere because I don’t have money, so that’s fine, whatever, go to the shop, go to the pharmacy to buy at least drink. Even if you have a headache, Sanmol, cough medicine, at least buy cough

medicine" (P6).

In addition, the need for the availability of antiretroviral treatment (ART) clinics and the availability of ARV and OAT drugs are also reasons why sufferers do not complete the treatment process. This is expressed by Participant 4 who stated: *"so far we have only consumed paracetamol and cough medicine from stalls, because the health centers and clinics that provide medicines for us are only there, sometimes even when we take medicine there the stock is empty and we have to take it at other clinics and health centers even further away"* (P4).

Theme 4 highlights the adaptation process after experiencing loss to follow-up, particularly the sense of comfort in not taking medication. This theme is supported by three sub-themes that illustrate how patients adjust to life without treatment. Fear and anxiety often arise in the minds of HIV/AIDS sufferers with TB infection, especially if the disease is chronic. Participant 14 said: *"sometimes I feel that I will die when I feel pain, difficulty breathing and coughing, with the condition that there is no medicine, I feel afraid and I often cry, I don't worry that tomorrow I won't wake up again"* (P14).

In addition, spiritual comfort as a sub-theme emerged due to self-acceptance efforts regarding the experiences learned and accepted. As stated by Participant 12: *"it's just that there's a fear that maybe when I meet a friend who knows what I used to do, then I'm like this, why do I change my language to be more diligent in going to the mosque or maybe I'm religious, I often wear the hijab, many people ask that now the change is drastic compared to yesterday"* (P12).

Increasing awareness of compliance with taking ARVs and OAT is an effort made by sufferers to continue to survive as people with HIV AIDS. As stated by Participant 8: *"I am more comfortable if I consume and it is better to take ARV and OAT, I feel that when I consume first my body is healthier and not burdened as much"* (P8).

Theme 5 reflects the use of herbal medicine as a form of therapy, supported by three sub-themes: symptom management, motivation for using herbal remedies, and a holistic view influenced by culture and

beliefs. Participant 10 said: *"so far I only drink herbal medicine, even medicine that I buy at the shop to relieve headaches, coughs, aches and pains, fever and vomiting."* (P10). and as stated by Participant 7: *"almost every morning I drink herbal medicine made from boiled herbal plants to improve my health, even as long as I drink herbal medicine I feel better than not taking medicine at all, so now I regularly drink herbal medicine every morning."* (P7).

In addition, the existence of a holistic view of culture and beliefs toward herbal medicine efforts increases confidence in the efficacy of this treatment technique. As stated by Participant 9: *"...ever since my grandmother told me that if someone was sick, they would always give me herbal medicine made by my grandmother, bro.. it contained a mixture of ginger, turmeric, galangal, ginger, and red lemongrass which was boiled and then added with honey and lime. At first, I didn't like this herbal medicine, bro, but it was a suggestion from my parents and this has also been passed down from generation to generation so I believe it can be used as medicine..."* (P9).

Theme 6 describes the barriers and support experienced by HIV/AIDS patients with TB in managing their treatment. This theme is supported by two sub-themes that explore the challenges and assistance encountered during the treatment process. In the first subtheme, treatment-related barriers and Discrimination were obtained. Participant 1 said: *"I find it difficult to take medicine every day because every time I take it I feel nauseous, and dizzy, especially if I have to get my own medicine to the health center, I feel afraid and worried about other people's ridicule as if I am someone who does not deserve the same service"* (P1).

In addition, sub-theme two about social support became part of what was conveyed by Participant 11 such as the statement: *"even though there are many difficulties in undergoing treatment, I feel grateful that there are still family and friends who always give me advice and often give me encouragement to stay healthy, in fact health workers also always remind me via WhatsApp to regularly remind me to take medicine"* (P11).

This seventh theme was obtained based on subthemes that emerged from the

patient's experience including Hope for recovery and Compliance in HIV/AIDS patients with TB infection emerged from the statement of Participant 4: *"I have been feeling this incurable pain for a long time, but I still have the desire to recover even though the possibility is small, so far I have not been compliant in taking medication, but I have the desire to comply and hope to be given the ease of getting treatment so that I can take medication without any obstacles and worries"* (P4).

Two important components in the lives of HIV/AIDS sufferers with TB are social acceptance and eliminating stigma. It is greatly influenced by support from the surrounding environment on the patient's desire to undergo treatment and improve their quality of life. As stated by Participant 1: *"...I want the people around me to accept me regardless of my status as a person with HIV infection, even now I have a tuberculosis infection, sometimes this makes me afraid to go to the clinic." But I hope that one day no one will be embarrassed or perhaps afraid of people with HIV infection like me and they will accept people like me..."* (P1).

DISCUSSION

Theme 1 understanding of HIV/AIDS and TB highlights that HIV/AIDS is a disease that attacks the immune system and has no cure. These sentences support this theme category. This is in line with Adnan, Adam and Razak who said that patients have basic knowledge about HIV/AIDS, but there is a lack of knowledge in several areas, such as modes of transmission and clinical signs of this disease⁸. In addition, there are positive attitudes towards people living with HIV/AIDS, but consistent prevention practices are still lacking. In fact, understanding about HIV/AIDS in rural areas tends to be lower than in urban areas, and there are still misunderstandings about HIV/AIDS.¹⁴ Understanding HIV/AIDS is important in efforts to prevent, treat and control the disease globally. This literature provides comprehensive insight into various aspects of HIV/AIDS, including epidemiology, pathogenesis, social determinants, community interventions, and vaccine development. HIV is a virus that attacks the human immune system, especially CD4+ T cells which are an

important part of the immune system to fight infection. HIV reduces the number of CD4+ T cells, weakening the immune system and making the body susceptible to infections and other diseases. Without treatment, HIV progresses to AIDS.

AIDS is an opportunistic infection that weakens the immune system, making it susceptible to several types of cancer. An AIDS diagnosis is made when a person living with HIV experiences one of the medical conditions associated with AIDS or has a low CD4+ T cell count.¹⁵ TB is understood as coughing, coughing up blood, and can be transmitted through the air. Patients feel they have recovered when there is no cough, even side effects can also cause loss to follow-up. Annisa, Ramadani, Yusmaini, Atari also said the same thing, who stated that TB is an infectious disease that can be transmitted through the air and is caused by *Mycobacterium TB*. TB infects the lungs, but can also infect other parts of the body, such as the bones, kidneys or brain. This disease spreads through the air when sufferers cough or sneeze, expel droplets containing TB bacteria, and are inhaled by other people. TB has two main forms, namely active TB and latent TB. Active TB can be transmitted to other people, while latent TB is not contagious but can develop into active TB.

Theme 2 reasons for loss to follow-up among TB-HIV patients includes the patient's belief that they will eventually die, as well as experiencing severe side effects or feeling healthy, which leads them to stop taking their medication. This is also supported by three categories, namely about to die, unable to overcome side effects, and feeling cured or healthy.¹⁶ Participants stopped treatment (lost follow-up) because they felt they had recovered, the side effects of treatment were severe, and they were pessimistic about their future. Some participants felt hopeless and thought it was not worthwhile to continue treatment because they believed death was imminent. Patients with chronic diseases such as HIV-TB often face significant psychological challenges.¹⁷ Various factors can influence this perception, including knowledge about the disease, social stigma, treatment experience, and social support. This condition is also influenced by limited knowledge about medical

advances in HIV-TB treatment. Sufferers are not aware that with proper treatment, HIV sufferers can live healthily for years, and TB can be cured with treatment compliance.¹⁸

The perception that HIV-TB inevitably causes death often stems from complex psychological and social factors. Ignorance of the effectiveness of modern medicine, inherent social stigma, negative experiences with treatment side effects, and lack of social support all contribute to pessimism. Understanding HIV-TB related deaths is an important step in improving treatment outcomes and quality of life. Good education, reduced social stigma, effective management of side effects, and increased social support help clients develop a positive outlook about their future.¹⁹

Theme 3 challenges post lost to follow-up financial difficulties and limited medication availability highlights that participants were unable to afford their medication and resorted to purchasing only paracetamol or cough medicine from local stalls. This category is supported by 3 categories: no money, buying medicine in a shop, and taking medicine (Paracetamol). This condition indicates a disruption in the routine of taking medication that should be taken regularly and causes problems with medication adherence. So, efforts are needed to reduce the risks and burdens experienced by HIV-TB sufferers through optimizing treatment.^{20,21} This condition highlights the need for more significant intervention in providing affordable health access.²²

Access to treatment is every individual's right. However, for HIV-TB sufferers, economic problems are the main obstacle to obtaining adequate treatment. In this research, some participants felt they did not have the money to buy the necessary medicines so they relied on essential medicines available in stalls or first aid medicine stocks. Economic problems are a significant obstacle for participants getting optimal treatment. The solution requires the role of government and health organizations to provide affordable medicines and support patients to overcome financial obstacles. Providing better access to health services will improve the quality of life.²³

Theme 4 on adaptation post loss to follow-up perceived comfort indicates that HIV sufferers experience less physical fatigue when not using antiretroviral (arv) drugs and anti-tb drugs due to fewer side effects. The feeling of comfort that arises when not taking ARVs and OAT reinforces this theme. The complex interaction between physical and psychological variables is seen in the comfort patients feel when stopping treatment. Although patients may achieve temporary relief, stopping treatment will pose serious dangers, such as serious complications and possible death over time.²⁴ Understanding these patient experiences is important, as is offering appropriate assistance to improve treatment adherence. Patients with chronic diseases, such as those with HIV-TB, often experience drug side effects that interfere with their quality of life and ability to follow their treatment plan.²⁵ Although this decision puts their health at risk, some patients report feeling better physically and psychologically when they stop treatment. Factors influencing the decision to stop taking medication and the perceived comfort in doing so are reviewed in this article.²⁶ This condition directly affects treatment compliance, so it is important to understand it. Healthcare professionals can help patients stick to treatment plans and improve long-term health outcomes by recognizing and resolving underlying problems, such as adverse drug reactions and lack of social support.

Theme 5 on actions taken post loss to follow-up use of herbal medicine as a treatment alternative reveals that participants used herbal medicine as an alternative therapy to maintain their stamina and health. This is supported by new behavioral patterns that use herbs as therapeutic treatment.²⁷ HIV-TB is a chronic disease that requires long-term treatment. The side effects of conventional treatment and the need to improve quality of life encourage patients to seek alternative treatments, including herbal therapy.²⁷ Herbal treatment for HIV-TB is very popular as a means of supporting health and stamina. several factors for the use of herbs as HIV-TB therapy. First, more natural and effective methods of dealing with chronic diseases are now increasingly

popular. Second, herbal remedies reduce the adverse effects often associated with traditional therapies. Third, herbal medicine increases public awareness of the importance of endurance and health management.²⁸ According to research, certain herbal plants can help treat HIV-TB due to their immunomodulatory and antibacterial qualities. For example, turmeric has anti-inflammatory and antioxidant properties, while garlic has antibacterial properties that help fight infections. Herbal treatment can help HIV-TB patients feel better and have more energy. However, combining conventional and herbal medicine is better. Proper knowledge and interaction with medical professionals is essential to ensure the safe and efficient use of herbal medicines.²⁹

Theme 6 on barriers and obstacles bio-psycho-socio-spiritual-cultural during typical treatment or examinations highlights that stigma, self-stigma, and barriers to support are the main problems faced by hiv-tb sufferers. As stated by clients who only go to health workers because they are afraid of being known and shunned by other people. Even though there is high stigma among clients, the support system for HIV/AIDS sufferers is still low. This statement is supported by categories of support received from family, foundations, social services, friends and abroad. This condition shows that the support system that has been built is still limited and not optimal. HIV-TB sufferers often face obstacles in the form of social stigma and self-stigma.³⁰ This stigma can affect patients' quality of life, adherence to treatment, and mental health. Adequate social support plays an important role in reducing the negative impact of stigma and self-stigma.³¹ This stigma can affect quality of life, adherence to treatment, and mental health. Adequate social support plays an important role in reducing the negative impact of stigma and self-stigma.³² Therefore, interventions to reduce stigma and increase social support are essential to improve client well-being.³³

Theme 7 on expectations for recovery, finishing medication, and community post lost to follow-up reveals that participants hope to recover, complete their treatment, and be accepted by their community. This is supported by the hope of recovering,

mingling with family, and being accepted to improve oneself to return the favor.³⁴ HIV-TB sufferers often face major challenges, including social stigma and treatment side effects. Hope is important in motivating clients to survive and fight against their illness.^{35,36} Apart from the hope of recovering and continuing treatment, some participants also hope to be accepted by their environment and be able to serve their families, especially their parents. These results explore how clients can realize these hopes through medical and social support.³⁷

HIV-TB patients have the hope of recovery and continuing treatment, this is driven by knowledge about treatment. Even being accepted in the environment also improves the sufferer's psychological condition.³⁸ Clients who are accepted by their environment have better mental well-being and are more compliant with treatment. Clients are encouraged to return the favor to their parents by being filial; they use this as a strong motivation to recover and continue treatment.^{31,39} Hope to recover, continue treatment, be accepted by the environment, and return the favor to parents are important aspects in the lives of HIV-TB clients. Social and medical support is essential to help patients achieve hope and effective treatment, and social acceptance significantly improves patients' quality of life and well-being.^{10,40,41}

This study has several limitations that should be acknowledged. Firstly, the research was conducted solely in Lampung Province, which may limit the transferability of the findings to other geographic or sociocultural contexts. Secondly, the relatively small sample size of fifteen participants may not fully capture the diversity of experiences among individuals co-infected with MDR TB and HIV/AIDS. Thirdly, the data were collected through self-reported interviews, which are inherently subject to recall bias and social desirability bias. Despite these constraints, the study contributes meaningful insights into the influence of life values and stigma on loss to follow-up among this population. Future research should consider multi-site studies across varied regions to enhance generalizability, employ larger and more heterogeneous samples, and incorporate longitudinal or

mixed-method designs. Such approaches may offer a deeper understanding of the complex psychosocial dynamics involved and inform the development of more effective, culturally responsive interventions to support treatment adherence. Implications for nursing practices include the need for nurses to play an active role in increasing screening and early detection by implementing government policies, raising awareness and education for HIV-TB patients, improving treatment compliance, and developing community-based education programs. Nurses should also provide psychosocial support through a holistic approach, involving the family, and work towards improving monitoring and evaluation systems while fostering multidisciplinary collaboration in healthcare services.

CONCLUSION

HIV/AIDS and TB sufferers who experience loss of follow-up provide an experience of understanding, including the process of transmission and spread of disease. Administration of antiretroviral drugs, anti-TB drugs, and the side effects they experience. A further problem is the community's assessment of the condition of the disease, the support and facilities provided, and the impact on the issue of material and psychological needs. This situation will increase hopes for recovery, compliance with medication consumption, and acceptance by society.

ETHICAL CONSIDERATION

This research has been tested by the research ethics commission of the FoN, Universitas Indonesia, and approved through an ethical permit with number KET 175/UN2.F12.D1.2.1/PPM.00.02/2024.

CONFLICT OF INTEREST

All author no conflicts of interest to declare.

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AUTHOR CONTRIBUTIONS

The authors IA and AW contributed to the conceptualization, methodology, and investigation of the study. IA and AW were responsible for data curation, formal analysis, and software development. AW handled funding acquisition, project administration, resources, and supervision, while IA and AW collaborated on the validation and visualization of the results. Additionally, IA and AW wrote the original draft of the manuscript.

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