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Lived experiences of diagnosis and treatment of tuberculosis patients receiving directly observed treatment short course at the University of Uyo Teaching Hospital, Akwa Ibom State, Nigeria

Oluwasayo Omolara Abudu[1], Jummai Sa'A Wennie[1], Chinomso Nwozichi[1], Rafiat Ajoke Anokwuru[2]

[1]Department of Adult Health/Medical Surgical Nursing, Babcock University, Ilishan - Remo, Ogun State, Nigeria;
[2]Department of Maternal and Child Health, Babcock University, Ilishan - Remo, Ogun State, Nigeria.

Abstract

Context: Tuberculosis remains a major public health concern in Nigeria, yet limited attention has been given to the lived experiences of patients undergoing the Directly Observed Treatment Short Course (DOTS), particularly in Akwa Ibom State.
Objectives: This study explored the lived experiences of diagnostic journeys and treatment challenges among TB patients receiving DOTS at the University of Uyo Teaching Hospital.
Materials and Methods: The study used a phenomenological design enabled in-depth interviews with 20 purposively selected participants who had been on treatment for three to six months. Rigour was ensured through credibility, dependability, transferability, and confirmability. Data were analysed using Tesch's open-coding method and results presented in tables.
Results: Themes that highlighted delayed diagnosis, misinterpreted symptoms, emotional distress, and systemic barriers to healthcare access were documented. Participants described shock, fear, stigma, and financial constraints that prolonged help-seeking. Treatment experiences were marked by severe medication side effects, high pill burden, and difficulties maintaining adherence, often leading to temporary discontinuation. Despite these challenges, support from family and healthcare workers played a crucial role in sustaining treatment.
Conclusion: The findings underscore the need for improved diagnostic access, enhanced patient support systems, and strengthened counselling to promote adherence and improve treatment outcomes.

Keywords: Tuberculosis, Lived Experience, DOTS, Diagnosis, Treatment Adherence

Introduction

Tuberculosis (TB) remains one of the most persistent infectious diseases affecting populations globally, despite centuries of medical advancement. TB has afflicted humanity since ancient times, shaping societies and challenging health systems across generations. In recent years, the disease continues to exert a substantial global burden, with approximately 10.6 million cases reported in 2021.[1] TB also remains one of the world's leading infectious causes of death, claiming an estimated 1.5 million lives annually.[1] The global distribution of TB is unequal, with countries such as India, Indonesia, China, the Philippines, Pakistan, Nigeria, Bangladesh, and South Africa together accounting for nearly two-thirds of worldwide cases.[1,2] The African region alone contributes significantly, with Nigeria, South Africa, and the Democratic Republic of the Congo representing a substantial proportion of the global TB burden.

In Nigeria, the rising prevalence of TB over the past two decades highlights the persistent challenges associated with diagnosis, access to care, and

Corresponding Author:

ABUDU Oluwasayo Omolara
Department of Adult Health/Medical Surgical Nursing, Babcock University, Ilishan - Remo, Ogun State, Nigeria

sayoabudu1972@yahoo.com

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treatment adherence. TB prevalence increased from 269,000 cases in 2000 to 467,000 in 2021.[3] Nigeria recorded an estimated 125,000 TB-related deaths in 2021, reflecting a death-to-infection ratio of 26.77%.[4] The geographical distribution of TB reveals distinct patterns, with the northern region showing high density around areas such as Kano, while cases in southern regions appear more widely dispersed.[5] Akwa Ibom State stands out as one of Nigeria's high-burden regions for TB, accounting for 12% of all reported TB cases in 2016 and maintaining a high prevalence of TB–HIV co-infection.

To address the ongoing burden of TB, the World Health Organization (WHO) recommends the Directly Observed Treatment Short Course (DOTS) as a cornerstone strategy for TB control.[2,6] DOTS requires that patients be observed while taking their medications to ensure adherence, minimize the risk of treatment failure, and reduce transmission. The strategy has proven effective; however, patient experiences under DOTS vary widely. Beyond its clinical function, DOTS influences multiple aspects of daily life, making the lived experiences of patients undergoing this regimen an essential area of inquiry.

Studies across Africa and Nigeria have highlighted a range of lived experiences among TB patients undergoing DOTS. These experiences include emotional reactions to diagnosis, social stigma, financial strain, transportation barriers, co-existing illnesses, and the psychological burden of prolonged treatment.[7,8] Stigma and discrimination remain pervasive, while geographical barriers and transportation challenges further complicate treatment adherence, especially for individuals living in remote or rural communities. In Enugu, South-East Nigeria, patients reported difficulties related to distance, transportation costs, and poor road networks.[9] Conversely, some patients in South-West Nigeria described positive experiences, citing supportive and skillful healthcare providers.[10]

Lived experiences are also shaped by coping strategies. Guimond and Nugier observed that TB patients often rely on physical, emotional, social, and spiritual mechanisms to navigate the burdens of illness and treatment.[11] These experiences occur within broader social contexts influenced by stigma, socioeconomic status, support systems, and environmental conditions. Such factors affect how patients interpret their illness, their willingness to seek care, and their adherence to treatment.

Despite numerous studies on TB in Nigeria, there remains a gap concerning the exploration of lived experiences of TB patients undergoing Directly Observed Treatment Short Course (DOTS), especially within Akwa Ibom State. As the University of Uyo Teaching Hospital serves as a major referral center for respiratory diseases, understanding the lived experiences of patients receiving DOTS in this setting is crucial. Insights from such exploration can inform patient-centered approaches, strengthen DOTS implementation, and improve overall treatment outcomes. This study therefore seeks to explore the lived experience of diagnostic journeys and treatment challenges among TB patients on DOTS at the University of Uyo Teaching Hospital, Akwa Ibom State, Nigeria.

Materials and Methods

Study design: A descriptive phenomenological design was adopted to explore in depth the lived experiences of tuberculosis (TB) patients undergoing the Directly Observed Treatment Short Course (DOTS) programme at the University of Uyo Teaching Hospital in Akwa Ibom State. The study was conducted in a small but busy clinic that offers outpatient care and operates eight hours daily, staffed by professional nurses and community extension workers who attend to TB patients enrolled into the programme.

Research Setting: The University of Uyo Teaching Hospital (UUTH) is a tertiary medical facility located on Abak Road in Uyo, Akwa Ibom State. The Hospital has 600 beds and a total of 25 Departments, comprising 21 Clinical and 4 Non-Clinical departments as well as several Support Units serving a population of approximately 6.9 million people in Akwa Ibom State. The hospital staff strives hard to deliver their core competences in Research, clinical training and quality tertiary healthcare service delivery. Services provided are regular daily services obtained in General Out Patients Department (GOPD) 8am-4.00pm, emergency cases on twenty-four hour basis through Accident and Emergency(A&E),Children Emergency Unit (CHEU) for Paediatrics cases. Directly Observed Treatment Short Course (DOTS) clinic treats cohorts of averagely 700 active

tuberculosis cases annually.

Study Area: The study area entailed Tuberculosis Directly Observed Treatment Short Course (DOTS) clinic at the University of Uyo Teaching Hospital, Akwa Ibom State, Nigeria.

Study population: They were 46 TB patients on DOTS, from which participants were selected until data saturation was achieved. Data collection was terminated when saturation was reached, as no new information emerged from subsequent interviews.

Inclusion Criteria: The inclusion criteria allowed participation of the study population consisting of adults above 18 years who had been on DOTS for at least three months, as this ensured they possessed adequate lived experience.

Exclusion Criteria: Patients who had been on the programme for less than three months or were too ill to participate were excluded.

Sample size Determination and Sampling Technique: Purposive sampling was employed to recruit participants most experience or knowledgeable about the phenomenon under study, resulting in a final sample of 20 participants. These individuals were considered capable of offering rich, relevant, and detailed accounts of their experiences within the DOTS programme. A total of 37 participants were approached, 2 participants opted out of the study due to emotional breakdown related to their past experiences and the remaining 15 patients out-rightly declined due to fear of stigmatization and reluctance in sharing their experiences.

Study instrument: An in-depth interview was employed with the help of interview guide, digital recorder, and field notes as the study instrument.

Study procedure: This qualitative approach enabled the researcher to engage participants through rich, in-depth interviews that captured their personal narratives, perceptions, and the meanings they attach to their treatment experiences. Participants narrated their journeys in their own words, providing authentic insight into life on the DOTS programme.

Data collection: Data collection was carried out using in-depth phenomenological interviews supported by field notes. One pilot interview was conducted before the commencement of the main study and was utilized to evaluate interview techniques and the researcher's proficiency in conducting interviews as well as helped in identifying any flaws or limitations within the interview process. The results from the pilot interview were not incorporated into the main study findings since the participant did not offer reliable data.

An interview guide which consisted of two sessions (Section A & B) was developed to explore the lived experiences of participants on DOTS regimen. Section A derived information on the socio-demographic characteristics of the participants while section B consisted of interview questions in line with the study objective. The interview was conducted mainly in English language.

Interviews were recorded and later transcribed alongside detailed observational notes that documented non-verbal cues and contextual details. The field notes served to enrich the data and provide a 'thick description' that facilitated deeper interpretation of participants' experiences. Interviews were conducted in a private, comfortable environment with adequate ventilation and proper seating arrangements to ensure participants' comfort, privacy, and confidentiality. The researcher, who was skilled in interviewing techniques and effective use of open-ended questions, conducted all interviews herself. She employed probing, clarification, and other communication strategies to elicit comprehensive and meaningful responses while maintaining the conversational style characteristic of phenomenological inquiry. All transcriptions, translations, and coding procedures were carefully documented.

Statistical analysis: The transcribed data were analysed using Richard Tesch's open-coding qualitative content analysis method that organizes data into topic and catagories; commonly in qualitative research including some phemenological studies related to nursing and health sciences research. The researcher repeatedly listened to recordings and read transcripts to gain familiarity with the data. Initial ideas were noted, and one interview was analysed in depth to identify core meanings. Similar topics across interviews were grouped together and coded. These codes were then refined into descriptive categories and finally merged into broader themes that captured recurring patterns in the data. An independent coder analysed

the same transcripts following the same steps, and both parties later compared their analyses and reached consensus to enhance rigour. Demographic data were presented in tables while the responses were organised into sub-categories, categories, and overarching themes.

Ethical consideration: Ethical standards were strictly upheld to protect participants' rights throughout the study. Ethical clearance was obtained from Babcock University Health Research Ethics Committee (BUHREC 051/24) and from the University of Uyo Teaching Hospital (UUTH/AD/S/96/VOL.XXI/893).

Informed Consent: Written informed consent was secured, and participants were assured of voluntariness, confidentiality, and their right to withdraw without consequences. Confidentiality agreements were signed to protect participants' information. No identifying information was included in transcripts, and audio recordings were securely stored for two years with restricted access. Participants were protected from all forms of harm, treated fairly, and selected based on their experience with the TB DOTS programme. A pilot interview was conducted to test comprehension, interview duration, and technique, though its results were excluded from the final analysis.

Research rigour: Research rigour was ensured through credibility, transferability, dependability, and confirmability as outlined by Lincoln and Guba. Credibility was strengthened through prolonged engagement, member checking, repeated listening to recordings, and consensus discussions with an independent coder and supervisors. Transferability was enhanced by providing detailed descriptions of the study setting, methods, participant experiences, and supporting quotes. Dependability was ensured through transparent documentation of data collection and analysis procedures, dual coding, and systematic theme development. Confirmability was upheld through meticulous record-keeping and secure storage of all research documents and audio recordings for two years after publication, ensuring that the findings reflected participants' perspectives rather than researcher bias.

Results

A total of twenty (20) respondents participated in the study. The findings were presented and discussed according to the objective set for the study.

Table 1: Characteristics of Participants

Partici-Pants	Age in Years	Gender	Level of Education	Occupation	Religion	Ethnicity	Marital Status
1	36	Male	Secondary	Driving	Christianity	Anang	Married
2	28	Female	Secondary	Civil Servant	Christianity	Ibibio	Married
3	50	Female	Secondary	Civil Servant	Christianity	Oron	Married
4	41	Male	Tertiary	Teaching	Christianity	Yoruba	Married
5	25	Male	Tertiary	NYSC	Christianity	Igbo	Single
6	19	Male	Secondary	Schooling	Christianity	Ibibio	Single
7	19	Male	Secondary	Computer Operator	Christianity	Ibibio	Single
8	29	Female	Tertiary	Teaching	Christianity	Yoruba	Single
9	35	Male	Secondary	Motor Mechanic	Christianity	Ibibio	Single
10	48	Female	Primary	Trading	Christianity	Ibibio	Married
11	36	Male	Tertiary	Trading	Christianity	Oron	Single
12	65	Female	Primary	Farming	Christianity	Ibibio	Married
13	27	Male	Primary	Welding	Christianity	Ibibio	Single
14	25	Male	Secondary	Pos Operator	Christianity	Ibibio	Single
15	62	Male	Primary	Farming	Christianity	Ibibio	Married
16	47	Male	Tertiary	Driving	Christianity	Ibibio	Married
17	50	Male	Secondary	Farming	Christianity	Anang	Married
18	40	Male	Tertiary	Driving	Christianity	Anang	Married
19	36	Male	Tertiary	Banking	Islam	Hausa	Single
20	32	Male	Secondary	Estate Management	Christianity	Oron	Married

The participants in the study represented a diverse group in terms of age, education, occupation, and ethnic backgrounds, providing a broad view of the lived experience of individuals undergoing TB treatment. Ages ranged from 19 to 65 years, showing that tuberculosis affects both young adults and older individuals. Most participants had primary or secondary education, and their occupations varied widely, including farming, driving, trading, civil service, teaching, and skilled manual work, reflecting different socioeconomic backgrounds. The sample was predominantly male and overwhelmingly Christian, with only one Muslim participant, and included major ethnic groups such as Ibibio, Anang, Oron, Yoruba, Igbo, and Hausa. Marital status also varied, with a mix of married and single participants. Overall, the characteristics highlight a heterogeneous group, indicating that TB impacts individuals across different demographic categories within the community.

Themes and sub-themes

Theme 1: Experiences Before and During Diagnosis

Participants shared their prolonged journeys of misinterpreted symptoms like persistent coughing, fatigue, and weight loss, delaying medical attention. Financial constraints, lack of awareness, and

misdiagnosis compounded these delays. Emotional reactions to diagnosis ranged from disbelief and fear to feelings of shame and stigma, highlighting the heavy psychosocial burden carried by individuals as they navigated the healthcare system.

Table 2: Themes and subthemes of the lived experience of persons living with Tuberculosis

Theme	Subtheme
Experiences Before and During Diagnosis	Initial Symptoms and Delayed Medical Attention
	Barriers to Early Diagnosis
	Emotional Reactions to Diagnosis
Treatment Adherence and Challenges	Side Effects of Medication
	Struggles with Adherence

Sub-theme 1.1: Initial Symptoms and Delayed Medical Attention: Many participants experienced prolonged periods of symptoms, including persistent coughing, weight loss, and fatigue, before seeking medical attention. Delays were often attributed to misinterpreting symptoms as minor illnesses or a lack of awareness about tuberculosis (TB).

"I started coughing and went to the chemist for drugs, but there was no improvement. It wasn't until I saw blood in my cough that my wife insisted, I go to the health center." **(Participant 1, 36 years/Male)**

"I thought it was just a mere cough. It lasted for four months before I finally went to the hospital because my condition was getting worse." **(Participant 6,19 years/Male)**

"I didn't take the symptoms seriously because I have had coughs before, and they always went away. But this one didn't, and it got to the point where I couldn't breathe well anymore." **(Participant 10, 48 years/F)**

"I thought it was a curse because I had never been this sick in my life. People in my village told me it was from witchcraft, and I wasted months trying herbal remedies before going to the hospital." **(Participant 17, 50 years/F)**

The statement from participant 19 highlights their initial experiences with tuberculosis (TB), starting with mild symptoms like cough and sleeplessness, which gradually progressed to more concerning signs such as night sweats. Despite self-medicating with over-the-counter drugs and antibiotics, their condition did not improve, leading them to seek medical care. This eventually resulted in a diagnosis of TB after undergoing various tests at the hospital.

"Okay. Um, I noticed I was having a little cough and a sleeplessness. I wasn't sleeping the way I should because of the cough, and then I was beginning to have some night sweats and then I gradually resorted to taking over the counter drugs, going from one drug store to the other pharmacies to get some antibiotics and some drugs to help with the cough. So, from one cough syrup to another… there was no improvement. That's how I got myself to the hospital. And I was subjected to various tests and all that, among which was a test for tuberculosis, which is normally done for people with symptoms that I was having. It was eventually turned out positive **(Participant 19, 36 years/Male)**

"I was coughing thinking that it is malaria. I was also taking other local drugs, buying drugs at the chemist. I was not getting better and I was loosing weight and the cough was also increasing . If you see me at that time you will pity me, I look like skeleton, like HIV person. **(Participant 20, 32 years/Male)**

Sub-theme 1.2: Emotional Reactions to Diagnosis: The diagnosis of TB often elicited feelings of shock, disbelief, and fear. Participants struggled with the stigma of the disease and its potential impact on their lives.

"When they told me I had TB, I was devastated. I couldn't believe it because my house is well ventilated, and I'm not around sick people. It took me months to accept it." **(Participant 2, 28 years/Female)**

"I was scared and wondered how I could have TB at such a young age. It felt like a death sentence." **(Participant 7, 19 years/Male)**

"The doctor told me TB was treatable, but all I could think about was how people would see me. I was more worried about the shame than the sickness itself." **(Participant 19, 36 years/Male)**

"I cried for days because I didn't know how I'd tell my family. I thought they'd see me differently or think I had done something wrong to deserve it." **(Participant 20, 32 years/Male)**

Sub-theme 1.3: Barriers to Early Diagnosis: Systemic barriers, including financial constraints

and inaccessible healthcare services, contributed to delays in receiving a diagnosis. Participants highlighted the challenges they faced in navigating these barriers while managing worsening symptoms.

"I didn't have money to go to the hospital, so I kept treating myself with herbal mixtures. It wasn't until I collapsed at work that someone took me to the clinic." **(Participant 12, 65 years/Female)**

"The clinic is far from my house, and I didn't have the transport money. I kept thinking the sickness would go away, but it only got worse." **(Participant 19, 36 years/Male)**

"I went to three different hospitals before I got the right diagnosis. They kept giving me cough syrups and telling me to rest, but nothing worked." **(Participant 8, 29 years/Female)**

"The waiting time at the government hospital was so long that I gave up and went back home the first time. By the time I went back weeks later, my symptoms had worsened." **(Participant 3, 50 years/Female)**

Theme 2: Treatment Adherence and Challenges

The rigorous TB treatment regimen presented significant hurdles. Participants battled with severe medication side effects like nausea, dizziness, and abdominal pain, which often led to temporary non-adherence. Emotional struggles and high pill burdens added to the difficulty of maintaining consistent treatment. However, participants acknowledged the importance of adherence, despite the physical and emotional challenges it posed.

Sub-theme 2.1: Side Effects of Medication: The treatment regimen for TB, while necessary, was often described as overwhelming and physically taxing. Participants faced side effects such as nausea, vomiting, abdominal pain, dizziness, and blurred vision. These adverse effects not only affected their physical well-being but also made adherence to treatment more challenging. Many participants questioned whether the medications were helping or worsening their condition.

The side effects of medication caused a loss of appetite, which further weakened participants and prolonged their recovery.

"Every time I took the medicine, I felt like throwing up. My stomach was always upset, and I couldn't eat anything without feeling sick." **(Participant 5, 25 years/Male)**

"The drugs made me feel like I was burning inside. My stomach hurt so much that I couldn't eat, and I felt weaker with each passing day." **(Participant 5)**

"The dizziness was so bad that I fell twice while trying to walk to the bathroom. It scared me because I live alone." **(Participant 9, 35 years/Male)**

"I had rashes all over my skin because of the medication, and it made me .. not comfortable that I wanted to stop taking it." **(Participant 12, 65 years/Female)**

The combination of physical discomfort and impaired vision made even basic tasks unmanageable for participants.

"The medications made me dizzy, and I couldn't see properly for hours after taking them. It was hard to function normally, even at home." **(Participant 2, 28 years/Female)**

Despite the debilitating side effects, participants were often aware of the necessity of the medications, creating an internal conflict.

"I was afraid of using the medicines because they made my body feel worse than the TB itself. But I knew I had to keep going if I wanted to live." **(Participant 6, 19 years/Female)**

The prolonged nature of the treatment regimen exacerbated the emotional toll of the illness, leading to moments of despair.

"The side effects were unbearable. It was bad. In fact… it was bad. Sometimes I would sit in bed and cry because I didn't know how much longer I could take it." **(Participant 8, 29 years/Female)**

The statement from participant 7 highlights the role of external motivations, such as family, in helping participants endure the challenges of treatment.

"The pills were so many, and they made me feel so weak that I started wondering if they were worth it. But then I thought of my children and forced myself to continue." **(Participant 7, 19 years/Male)**

Sub-theme 2.2: Struggles with Adherence: Adhering to the strict treatment schedule was a significant challenge for participants. The high pill burden, coupled with the side effects and emotional

distress, often led to non-adherence. Some participants stopped their medications temporarily, while others tried to hide their non-compliance. This lapse in adherence sometimes resulted in worsened symptoms and further hospitalizations. The cyclical nature of non-adherence and symptom worsening underscores the difficulty of maintaining long-term treatment.

"I stopped taking the drugs because they were too many, and I couldn't handle the side effects. But stopping made me sicker, and I ended up in the hospital again." **(Participant 6, 19 years/Male)**

"I would forget to take my pills on some days, and the nurse would scold me. But she also reminded me why it was important, which helped me try again." **(Participant 13, 27 years/Male)**

Shame and guilt often accompanied participants' struggles with adherence, leading them to hide their behavior.

"I used to hide because I didn't want my family to know I wasn't going to the clinic. I just couldn't face another day of feeling like vomiting and I am weak." **(Participant 7, 19 years/Male)**

Support from healthcare workers played a crucial role in motivating participants to adhere to their treatment despite the challenges.

"The nurse told me to keep taking the pills no matter what, but it was so hard to continue when I felt worse after every dose. She encouraged me, though, and that kept me going." **(Participant 2, 28 years/Female)**

The burden of treatment was mitigated by participants' sense of responsibility toward their families, which provided a strong incentive to persevere.

"The pills were so many, and I had to take them every day at the same time. It was exhausting, but I had to do it for my children." **(Participant 4, 41 years/Male)**

This acknowledgment of the consequences of non-adherence reflects the difficult choices participants faced in balancing their immediate discomfort with long-term recovery.

"When I stopped the treatment, my symptoms got worse, and I realized I had no choice but to continue, no matter how hard it was." **(Participant 3, 50 years/Female)**.

Discussion of Findings

The findings reveal that delays in seeking medical attention were a major factor shaping participants' experiences with tuberculosis (TB). Many endured prolonged symptoms such as persistent cough, weight loss, and fatigue before seeking professional care, often misinterpreting these symptoms as minor illnesses. This aligns with a similar report of delays influenced by low TB awareness and limited access to quality healthcare.[3] Participants frequently relied on self-medication or traditional remedies, consistent with findings of similar study which found that home remedies and over-the-counter drugs often delay formal care.[12] Makgoba & Madiba reinforced the need for heightened public TB awareness to promote early detection.[13] Stigma also played a critical role in delaying care, as shown by Chaychoowong, et al. and Jang, & Chung, who highlighted the fear of discrimination and fragmented healthcare access as contributors to delayed diagnosis.[14,15] Cultural beliefs, including attributing illness to spiritual causes, further hindered timely health-seeking, consistent with a study conducted by Teo, et al.[16] These findings underscore the importance of community engagement and tailored health education, as supported by Cheong, et al., who suggested a need to dispel myths and encourage earlier diagnosis.[17]

Participants' emotional reactions to diagnosis were marked by shock, fear, and disbelief, revealing widespread misconceptions about TB transmission is similar to findings by Makgoba & Madiba and Mohan, et al.[13,18] Some perceived TB as a "death sentence," reflecting entrenched stigma, as observed by Nascimento, et al.[19] Stigma profoundly shaped emotional responses, with many fearing judgment, isolation, and discrimination. Thomas & Stephen, similarly reported that stigma is a major driver of social losses among TB patients.[20] Shame, guilt, and fear of disclosure further compounded emotional distress, consistent with a report by Sabin, et al, who found that most patients conceal their diagnosis.[21] Stigma also adversely affected quality of life, contributing to depression and social withdrawal, as highlighted by Adekola, et al.[22] These emotional burdens extended into family relationships, where

participants struggled with disclosure due to fear of rejection. Redwood et al. found similar self-isolation driven by fear of infecting loved ones.[23] Women appeared especially vulnerable, facing heightened economic hardship and marginalization, consistent with findings of Sazali, et al.[24] These findings reinforce the need for psychosocial support and community-level stigma reduction initiatives.

Barriers to early diagnosis were strongly linked to financial hardship. Participants described significant economic strain due to consultation fees, diagnostic tests, and transportation costs, echoing by Teo, et al and Portnoy, et al, who noted that economic burdens impede timely diagnosis and treatment completion.[16,25] Poverty, stigma, and treatment-related income loss further delayed care, as similarly observed by Dixit et al.[26] Low monthly income among participants mirrors findings by Iweama, et al, where financial insecurity shaped patients' DOTS experiences.[27] These constraints often forced individuals to delay formal healthcare and rely instead on ineffective alternatives. Socioeconomic vulnerabilities were worsened by health system barriers, including limited access to diagnostic facilities and weak referral systems, as reported by Der, et al.[28] Geographic distance, poor transportation, and long waiting times further discouraged early care-seeking consistent with observations by Pradipta, et al. and Oga-Omenka, et al.[29,30] These obstacles enabled disease progression and heightened transmission risk.

Addressing these multifaceted barriers requires comprehensive interventions targeting financial, geographic, systemic, and social factors. Olatunji et al emphasized the critical need for improved access to rapid diagnostic technologies in low-resource settings to accelerate diagnosis and treatment initiation.[31] Gill et al. likewise highlight cost and resource limitations that hinder widespread diagnostic implementation.[32] Strengthening social protection programs and reducing economic barriers would mitigate delays and improve access to care. Engel et al. support the use of rapid molecular testing to overcome laboratory access challenges and bring diagnostics closer to affected communities.[33] Collectively, these findings demonstrate that tackling delays in diagnosis and addressing stigma, financial hardship, cultural beliefs, and systemic barriers are essential for improving TB outcomes.

The findings highlight the significant physical, psychological, and social burden imposed by anti-tuberculosis medications, particularly the severe side effects that shaped participants' lived experiences and influenced their treatment behaviors. Participants consistently reported nausea, vomiting, dizziness, abdominal discomfort, blurred vision, and loss of appetite, all of which weakened them and interfered with adherence. These experiences align with report of Prasad, et al, who note that anti-TB drugs can cause a range of adverse drug reactions (ADRs) from gastrointestinal disturbances to hepatotoxicity and neurotoxicity.[34] The study further supports Ausi, et al, whose findings show that ADRs substantially affect patients' quality of life and shape beliefs regarding treatment.[35] Psychological consequences were equally profound, as participants questioned the usefulness of medications while dreading their side effects. This mirrors findings of Atif, et al, who identified depression as a frequent adverse event among TB patients.[36] Daily functioning was heavily affected, consistent with findings of Khan, et al, who report that MDR-TB regimens place significant strain on patients due to more frequent and severe side effects.[37]

Despite these challenges, participants recognized the importance of completing treatment, echoing on the necessity of monitoring adverse events to support adherence. However, the prolonged treatment duration, physical discomfort, and fear of failure generated emotional distress, reinforcing findings by Noor, et al on the prevalence of hepatotoxicity and the need for better medication management.[38] Understanding drug pharmacokinetics, as emphasized by Sturkenboom, et al remains critical for minimizing ADRs.[39] Social support emerged as a major facilitator of adherence, consistent with observation by Gao, et al, who highlighted the need for strong pharmacovigilance systems to ensure safer DR-TB treatment regimens.[40]

Adherence difficulties were significant, driven by high pill burden, severe side effects, and psychological strain. Participants sometimes interrupted medication temporarily or hid non-adherence, resulting in worsening symptoms and repeated hospitalization. This reflects findings from Khan, et al on the consequences of non-adherence

and Noor, et al on its link to treatment failure and drug resistance.[37,38] Although DOT is designed to strengthen adherence, participants experienced it as inconvenient and stigmatizing.[41] Nonetheless, external support particularly from family and healthcare providers remained crucial. This corresponds with findings of similar study by Ohamaeme, et al who show that better understanding of side effects improves adherence.[5] Shame and guilt further complicated adherence, aligning with Khan, et al who emphasizes the role of patient-provider relationships.[37] Participants' sense of responsibility to family also motivated adherence, consistent with the report by Osunmakinde, et al on the role of social support and education.[42] Addressing these complex barriers requires multifaceted interventions, supported by Gao, et al who recommend community-based and digital adherence tools to improve MDR-TB treatment outcomes.[40]

Limitations of the Study

While this study provides valuable insights into the experiences of TB patients, it has certain limitations:

Small Sample Size: The study was limited to a specific number of participants, which may not fully represent the broader TB population.

Geographical Constraints: The study was conducted in a specific region, and findings may not be generalizable to other populations with different healthcare systems and cultural perspectives.

Self-Reported Data: Participants' experiences were self-reported, which may introduce recall bias or social desirability bias.

Lack of Longitudinal Data: The study captured a snapshot of patients' experiences rather than long-term changes in their perceptions and treatment adherence.

Conclusion

The findings reveal that the lived experiences of individuals with tuberculosis are shaped by a complex interplay of diagnostic delays, emotional distress, and significant treatment challenges. Participants described prolonged periods of unrecognized symptoms, financial barriers, and systemic obstacles that hindered early diagnosis, often worsening their condition. The emotional burden of receiving a TB diagnosis marked by fear, stigma, disbelief, and shame further complicated their health-seeking behavior. Once treatment began, severe medication side effects, high pill burdens, and psychological strain made adherence difficult, leading some to temporarily discontinue therapy despite understanding the consequences. Support from family and healthcare providers emerged as a crucial motivator in sustaining treatment. Overall, these findings highlight the need for improved diagnostic access, enhanced patient support systems, and strengthened counseling to ease the treatment journey and promote better health outcomes for TB patients.

Recommendations

Based on the study findings, the following recommendations are proposed:

1. Health education and awareness should be enhanced through targeted public health campaigns aimed at reducing TB-related stigma and misconceptions. Communities should be educated on the early signs and symptoms of TB to encourage timely diagnosis and treatment.
2. Healthcare access should be strengthened by improving healthcare infrastructure, especially in rural areas, and providing financial assistance programs to support low-income individuals in accessing TB care and treatment.
3. Treatment adherence strategies should be enhanced by developing patient-centered approaches such as reminder systems and community-based treatment support. Patients should be educated about the importance of completing treatment and given strategies to manage side effects effectively.

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