EXPERIENCES OF PATIENTS LOST TO FOLLOW UP DURING TUBERCULOSIS TREATMENT IN OSHAKATI DISTRICT, NAMIBIA

PETRUS KAWIYU SHINGANDJI

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PETRUS KAWIYU SHINGANDJI

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MAIN SUPERVISOR: Dr Anna PK Shilunga (University of Namibia)

ABSTRACT

Tuberculosis (TB) remains a major public health concern affecting over 10.8 million people in 2024. Loss or lost to follow up (LTFU) during TB treatment is a pressing issue hindering the success of TB treatment worldwide. LTFU may lead to a prolonged TB infection, relapse, and multidrug resistance, and may contribute to treatment failure. Despite advancements in TB treatment, many patients still experience interruptions in their TB treatment, leading to higher rates of LTFU during TB treatment, which negatively impact both individual health outcomes and broader public health efforts. Oshakati District is a significant contributor to the national TB burden with a growing concern of patients LTFU during TB treatment.

The aim of the study was to explore and describe the experiences of patients LTFU during TB treatment in Oshakati District, Namibia. Ethical principles were applied throughout the conduct of the study. A qualitative design was adopted using a combination of exploratory, descriptive and phenomenological approaches. A non-probability, purposive sampling technique was used to select 11 participants who met the inclusion criteria of the study. A semi-structured interview was used to collect the data, and a tape recorder was utilized. Data were thematically analyzed and the findings were presented in themes and sub-themes.

The study identified two themes and eleven sub-themes. Findings revealed that TB patients lost to follow-up in Oshakati District faced intertwined social, economic, psychological, and systemic barriers. Financial hardship, stigma, weak support systems, pill burden, side effects, and limited health literacy significantly undermined treatment adherence. Disengagement from care was often a reflection of survival struggles and social exclusion rather than unwillingness. The Health Belief Model was utilized to interpret the findings. The study concluded that the experiences of patients LTFU during TB treatment were multifaceted.

The study recommends strengthening TB care through patient education, expanded and accessible services, financial support, and stigma-reduction campaigns. Nurses and Community Health Workers should provide culturally appropriate guidance, counselling, and peer support to enhance adherence. Future research should replicate similar studies in other districts to compare experiences of patients lost to follow-up during TB treatment. It also acknowledges limitations related to methodological constraints, participant-related challenges such as reluctance or bias, and difficulties in accessing certain individuals or settings.

Keywords: Experiences, patients, lost to follow up, tuberculosis, Oshakati District

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LIST OF ABBREVIATIONS AND ACRONYMS

CB DOT	Community Based Directly Observed Therapy
CHWs	Community Health Workers
CHW DOT	Community Health Workers Directly Observed Therapy
DEC	Decentralized Ethics Committee
DOT	Directly Observed Therapy
HB DOT	Hospital Based Directly Observed Therapy
HBM	Health Belief Model
HIV	Human Immuno-deficiency Virus
LMIC	Low- and Middle-income Countries
LTFU	Lost to follow up
MDR-TB	Multidrug-resistant TB
MoHSS	Ministry of Health and Social Services
SADC	Southern African Development Community
TB	Tuberculosis
UNAM	University of Namibia
WHO	World Health Organization

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Above all, I praise and thank Almighty God for His guidance, strength, and wisdom during this period. Without His grace and provision, I could not have completed this thesis. “I can do all things through Christ who strengthens me” Philippians 4: 13

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I am grateful to the University of Namibia and to the Ministry of Health and Social Services that granted me the opportunity to carry out this study.

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Thank you all for your contributions, support, and prayers.

DEDICATION

As I pause to reflect on the completion of this work, I dedicate this thesis to the cherished memory of my late supervisor, Dr Penehafo Angula, and my beloved late parents, Mr. Immanuel Muthingua Shingandje and Ms. Elise Shiweda. Though you are no longer with us, your spirits continue to guide and inspire me. May your souls rest in eternal peace, knowing that this achievement is a testament to your lasting influence on my life.

Dear Ndapewa, the torch is now passed to you!

DECLARATION

I, Petrus Kawiyu Shingandji, hereby declare that this thesis titled *"Experiences of patients lost to follow up during Tuberculosis treatment in Oshakati District, Namibia"* is a true reflection of my own work. This declaration confirms that this work or part of it has not been submitted for a degree at any other institution of high learning.

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October 2025

Petrus Kawiyu Shingandji

CHAPTER ONE

INTRODUCTION AND BACKGROUND TO THE STUDY

1.1 Introduction

Tuberculosis (TB) is a chronic infectious disease caused by Mycobacterium Tuberculosis. The disease mostly affects the lungs, and this is termed as Pulmonary TB, while in some instances it may affect other parts of the body (extra pulmonary TB) (1,2). TB remains a major public health concern affecting over 10.8 million people in 2024 (2). Over thirty (30) countries are reported to have the highest TB burden that has accounted for about 87% of all new cases of TB, with Bangladesh, China, the Democratic Republic of the Congo, India, Indonesia, Nigeria, Pakistan, and the Philippines leading the way and accounting for more than two thirds of the global total of TB cases (1,3). Like in many other countries, TB is a key health challenge in Namibia with its incidence reported to be 457 per 100 000 people (4). Loss or lost to follow up during TB treatment is a pressing issue hindering the success of TB treatment. The World Health Organization (WHO) defined lost to follow up (LTFU) during TB treatment as a patient who received treatment for at least four (4) weeks whose treatment has been discontinued for two consecutive months or more (5,6). LTFU may lead to a prolonged infection, relapse, multidrug resistance, and may contribute to treatment failure (7). According to a study by Kibuule et al., it is reported that 1 out of every 25 cases of TB is LTFU in Namibia (8). Despite advancements in TB treatment, many patients still experience interruptions in their TB treatment, leading to higher rates of LTFU during TB treatment, which negatively impact both individual health outcomes and broader public health efforts. Evaluating and determining the experience of the patient that is LTFU during the TB treatment is essential because each case of a patient lost to follow up has a story of the obstacles; this patient has experienced when trying to pursue her treatment process.

1.2 Background of the study

Tuberculosis (TB) is a leading cause of morbidity and mortality worldwide, and especially where Human Immuno-deficiency Virus (HIV) co infection rates are high. Although TB diagnostic and treatment benefits, particularly in low- and middle- income countries (LMICs), have greatly improved, TB is still a substantial public health challenge. The lost to follow up phenomenon in TB management is an important issue which not only affects individual patients but also threatens public health by promoting the spread of the disease and propagating drug resistant TB strains (9).

TB is a worldwide health issue; almost 10.8 million people are sick with the disease and approximately 1.4 million people die from it each year (1). Among issues related to TB treatment, patients LTFU (less than 90%) during TB treatment remain an unresolved challenge for TB control programs. In a study of 4,099 multi drug resistant (MDR) TB patients across 22 countries, 702 (17.13%) patients were LTFU; 75% of these cases are seen within first 11 months of treatment (10). Not only is that an alarming statistic, but it also highlights how serious a problem the issue is globally and that there is a need for targeted treatment adherence efforts.

Although the burden of TB is generally lower for the developed world compared to LMICs, numbers of patients LTFU during TB treatment are still quite high, especially for vulnerable populations. Common contributing factors to treatment interruption in these settings include homelessness, substance abuse, mental health issues and more. For high income countries, the challenge is the coining of the marginalised groups who are often in a risky instance of TB to gain consistent access to healthcare services and system support that encourage treatment completion (9, 10).

On the other hand, the situation in the developing world, and especially in Sub Saharan Africa, has been made worse by these social and health-related factors interacting with each other. For TB control programs in East and West Africa, these include very high HIV co-infection rates, limited healthcare infrastructure and socio-economic barriers that prevent patients completing their treatment regimens. This in turn promotes the spread of TB and drug-resistant TB and high rates of LTFU, and these are the reasons for the high rates of LTFU (9,11,12).

Among east African countries, Kenya and Tanzania physically suffer from high co-infection rates of TB and HIV which greatly complicates treatment adherence. Also, in West Africa, countries like Nigeria and Ghana also face issues including healthcare access, poverty and social stigma which are among the reasons why patients opt out of treatment (11,12,13,14). With weak healthcare systems, limited access to diagnostics and treatment, as well as political instability, central Africa also has large TB burdens. High rates of LTFU occur in people with active TB in countries that have ongoing conflicts and displacement such as the Democratic Republic of Congo and Chad (14,15).

South Africa and Namibia also have very worrying scenarios within the Southern African Development Community (SADC) region. In South Africa with a TB burden among the highest in the world, LTFU rates are reported to be 14.9 – 18.0% (16,17,18). In addition to a high prevalence of TB, there is a large burden of HIV in South Africa, putting further pressure on treatment adherence. In Namibia, LTFU is a major obstacle in TB control efforts, as is the case with the rest of the world. In Namibia, 1 in 25 TB cases is LTFU (8), and the problem is most serious in youth and in areas where migration is taking advantage of employment opportunities.

In addition, the National Tuberculosis and Leprosy Programme (NTLP) also indicates that 3.2% of new and relapse tuberculosis cases in Oshana Region was lost to follow up (LTFU) without completing the established treatment period by 2019 (4). Given that the country ranks among countries with a high level of burden of TB, as well as HIV-related burden of TB infections, this indicates the critical importance of combining social development efforts associated with the issue of TB and HIV related TB infections dilemma (1,19). In Namibia where TB is a problem, LTFU during TB treatment is not only one impediment to individual health outcomes, but also an extensive public health menace. Those patients who fail to complete the treatment of TB risk developing MDR-TB, a more difficult and costly to cure disease, but can pose a threat to others as well (8,20).

The phenomenon of LTFU during TB treatment is determined by a number of issues which do not differ very much even between countries and the conditions. Among some of the factors that have been cited to make it difficult to complete treatment of patients in Namibia include migration of the youth to the urban centres in the hope of finding a job, stigma attached to TB, and lack of access to adequate health care services in the rural areas, among others (4,6,8).

With the country listed among nations with a high burden of TB and HIV-related TB infections (1,2,5), it underscores the urgent need for comprehensive public health strategies to combat the disease. Effective TB control and management depend on ensuring that patients complete their treatment. If LTFU during TB treatment remains unaddressed, health challenges such as MDR-TB will continue tormenting nations.

1.3 Problem statement

Tuberculosis (TB) remains a significant public health concern in Namibia, which ranks among the high TB burden countries globally, with an incidence rate of 457 cases per 100,000 population (2,4,19). Within this context, Oshakati District contributes notably to the national TB caseload. Between 2019 and 2020, the district accounted for 405 of the 7,718 reported TB cases nationwide (5.2%) (4). A pressing concern in Oshakati is the persistent rate of patients lost to follow-up (LTFU) during treatment, with LTFU rates ranging from 2.9% to 6.2% between 2020 and 2022 (4).

LTFU undermines treatment success, elevates the risk of multidrug-resistant TB (MDR-TB), and sustains community transmission (4,8,19). Moreover, it imposes a substantial financial burden on the healthcare system, as managing treatment interruptions costs over four times more than uninterrupted care (9,21). Despite ongoing efforts by the National Tuberculosis and Leprosy Programme, the recurrence of LTFU cases indicates a gap in understanding the patient-level experiences and contextual factors contributing to treatment discontinuation in this district.

This study aims to explore the lived experiences of patients who were lost to follow-up during tuberculosis treatment in Oshakati District, Namibia. By identifying the underlying barriers that hinder treatment adherence, the study seeks to generate context-specific insights that can inform the development of more effective strategies to improve patient retention and support treatment completion.

1.4 Aim of the study

The aim of this study was to explore the lived experiences of patients who were lost to follow-up during tuberculosis treatment in Oshakati District, Namibia, and to identify the barriers that contributed to treatment interruption, with the goal of informing context-specific strategies for improving patient retention and treatment adherence.

1.5 Objective of the study

The objectives of the study were to:

- explore and describe the experiences of patients lost to follow up during TB treatment in Oshakati District, Namibia.
- establish the potential strategies to address patient loss to follow up during TB treatment in Oshakati District, Namibia.

1.6 Significance of the study

The results of the present study may be crucial to the Ministry of Health and Social Services (MoHSS), which is mandated with the development of policies and interventions to mitigate loss to follow-up (LTFU) during the treatment of tuberculosis. For these reasons then understanding the experiences of patients during LTFU in treating TB in Oshakati District is important. The study identified exactly what patients encountered which causes them to struggle with recurring TB disease. This study also identified factors that are critical for the development of targeted interventions to improve treatment adherence. Such interventions may have the potential to greatly lower the rates of LTFU and thus improve the overall impact of TB control programs in the district.

In addition, this study helps advance the development of more patient-centred health care practices through the demonstration of the need for patient perspectives to be drawn into TB management. By gaining a deeper understanding of these perspectives, interaction between healthcare givers and patients will become better communicated and will allow for more tailored and efficient care. In turn, this will enhance patient satisfaction and outcomes and will also increase the probability of completion of the treatment.

The results of this study are also likely to assist health education programs in emphasizing the need for adherence to TB regimen. Health education and information about better care and completion can reduce these alternatives by decreasing knowledge of risks and real-life consequences of incomplete treatment (e.g. drug-resistant TB, continued community wide disease transmission).

This study, in the end, informs policies as well as practices that seek to reduce cases of LTFU during TB treatment with this leading to TB control strategies that are sensitive to the needs of the patient. By addressing the issue of lost to follow up the study may help to reduce the burden of TB in Namibia, protect public health and contribute to the global fight against the surge of TB and the peril of community infection.

1.7 Limitation of the study

Creswell (23,24) defined limitations as the possible weaknesses of the study that can affect the results, interpretations, and conclusion of the research. Therefore, it is worth noting these caveats to conduct a fair and critical evaluation of the study results, so that readers are informed about the issues which could have interfered with the research activities and its results. Such limitations are normally aspects that the researcher is unable to do like sample size, methodological restraints or forced interferences that might have relations to the study findings.

Notwithstanding the fact that there were only 11 people in the sample, it was still sufficient to perform the qualitative study because the focus is on achieving data saturation and not a statistical representation. Similar to qualitative inquiry, the study was not intended to make inferences on the overall population; instead, it aimed at providing a deep insight into the lived experiences of the persons who were lost to follow-up during TB treatment. Researchers depended on self-reports of the participants that were potentially subjected to social desirability or selective disclosure effects.

However, due to their close exposure to the topic, a set of participants was selected whose experience of this subject was vital in examining the subtle issues that hinder treatment compliance. In order to maximize the validity and reliability of the research, the researcher has used the well-known purports of qualitative validation, such as member checking and the presence of detailed audit trail. All these were done in order to make the study findings rooted and credible and able to represent the real-life situation being experienced by study participants.

1.8 Delimitation of the study

Delimitation of the study can be explained as boundaries or parameters within which a researcher establishes the scope of the research. These are the decisions related to what the study is going to focus on, the size of the sample, the geographical location, the time frame, and the study method. Delimitations are selective and they are made by the researcher to narrow down the study to a certain field of interest at the expense of other related topics that lies outside of the research. They help to clarify what the study will and will not cover, guiding the research process and ensuring that it remains manageable and relevant to the research questions (23,24).

The study included participants who had been diagnosed with tuberculosis, were registered for treatment within Oshakati District, and had been lost to follow-up for a period of two consecutive months or more during the course of their treatment. Individuals who did not meet these criteria such as those who completed treatment, were transferred out, or defaulted for less than two months were excluded from the study.

1.9 Definition of concepts

Patient: refers to a person receiving medical care (25) for treatment of a health condition. It is provided under supervision of a healthcare professional. In the context of this study, a patient refers to an individual who have been diagnosed with TB and was initiated on treatment for at least four (4) weeks, nonetheless, they could not complete their treatment, hence, they are classified as lost to follow up.

Lost (or loss) to follow up: Lost to follow up refers to the situation in which a patient who is enrolled in a healthcare program or study discontinue with their treatment or does not attend scheduled appointments, thereby losing contact with healthcare providers. This can lead to incomplete data and outcomes in clinical studies or treatment programs. Moreover, lost to follow up during TB treatment is defined as a patient who received treatment for at least four (4) weeks whose treatment has been discontinued for two consecutive months or more (5,26). In the context of this study, "lost to follow up" refers to TB patients in Oshakati District who were initiated on TB treatment for at least four (4) weeks but fail to complete their TB treatment regimen for two consecutive months or more, leading to interruptions in their treatment.

Tuberculosis (TB): Tuberculosis (TB) is a communicable infectious illness caused by a bacterium named *Mycobacterium tuberculosis* which usually affects the lungs and it may extend to other organs like, kidneys, spine and the brain. It spread through airborne particles when a person with active TB disease of the lungs or throat coughs, sneezes, or talks (1,2,4,25). In this study, Tuberculosis (TB) refers to the cases of *Mycobacterium tuberculosis* infection specifically within the Oshakati District of Namibia. The study included patients classified as lost to follow up during TB treatment as per WHO definition of lost to follow up.

1.10 Outline of chapters

The thesis is structured into five chapters, each contributing to a comprehensive understanding of the study's focus on the experiences of patients lost to follow up during tuberculosis (TB) treatment in Oshakati District, Namibia.

Chapter one: Introduction and background of study

This chapter establishes the study's tone. The study starts with an overview of Namibia's TB history, concentrating on the problems in the Oshakati District, which serves as its foundation. Further, this chapter provides the aim of the study, and study objectives. The chapter also highlights the scope and limitations of the study, offering readers a clear understanding of what to expect in the subsequent chapters.

Chapter two: Literature review

Chapter two looks at the literature regarding TB, treatment adherence and lost to follow up cases. The first part of the chapter is devoted to a global view on TB, and the second part is dedicated to the difficulties associated with TB in the developing world, with emphasis on the situation in sub-Saharan Africa. Various factors that contribute to treatment non-compliance and lost to follow up from East, West and Central Africa, are explored, as well as from the SADC region, through various studies. (The next part is supposed to be highlighting TB issues in Namibia). The chapter ends with analyzing gaps in existing literature and the current study aims to fill them.

Chapter three: Research methodology

Chapter three explains the research methodology by which the study was carried out. The aim is to provide a picture of the research design with respect to the study population and sample selection. The chapter then explains the data collection instruments such as interviews and questionnaires that were applied to interview and to get data from the interviewees. In addition, the chapter discusses the measures taken to ensure the trustworthiness of the data and the ethical considerations taken in the course of the research. The chapter ends with data analysis techniques that were used to analyse the collected data.

Chapter four: Data analysis, presentations and discussions of findings

The data collected from participants is presented in Chapter Four. The chapter unfolds through an analysis of the demographic characteristics of the study population while it details the factors that lead to loss to follow up amongst TB patients in Oshakati District. The conclusions are presented informally according to the perspectives described in the introduction. Finally, implications of these findings in the context of the existing literature are also discussed chapter which points out any new inputs by the study to the body of knowledge.

Chapter five: Discussion of findings, summary, conclusion, recommendations, and limitations

This is the chapter that synapses the main findings from the study and discuss their wider implications for TB control and public health strategy in Namibia. It recaptures the objectives and questions of research, then gives the conclusions derived with the results of the study. At the chapter level, the issue of lost to follow up in TB treatment is addressed with practical recommendations for addressing this issue and suggesting possible interventions and policy changes that could be put in place. Finally, this chapter suggests avenue for future research and it recognizes the study's limitations and provides areas through which the work demonstrated in that thesis can be built on.

1.11 Chapter summary

Chapter one gives a comprehensive introduction to the study, establishing the context for the research by providing a background and relating it to the experiences of the TB patients who are lost to follow up during the treatment process in Namibia, focusing on the patient's situation in Oshakati District. Finally, it points out the problem of losing patients to follow up during TB treatment and the consequences of this to patient health and to public health. The chapter also articulates the problem statement of lost to follow up in Oshakati District, Namibia during TB treatment to alleviate the impact of TB.

Chapter one also describes the research objectives to conduct the study and to investigate the patients lost to follows up experiences and factors associated with this phenomenon. The study is discussed in terms of its potential to inform interventions that target TB treatment adherence in the district. Another section to the chapter offers the scope and limit of the research so that the study boundaries are identified.

The chapter ends by showing that chapter two will make an in-depth review of the existing literature about TB treatment adherence, lost to follow up and other public health challenges as a sound theoretical basis for the study.

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

The second chapter is the establishing of the theoretical framework on which the study seeks to explore the experiences of patients lost to follow up of TB patient's treatment at Oshakati District, Namibia. The importance of this chapter lies in its ability to provide the conceptual foundation for comprehension of the intricate variables that contribute to patients' adherence to TB treatment and the implication of loss to follow up.

The chapter then reviews relevant theories and models of patient adherence, healthcare behaviour and challenges to TB treatment. The theoretical perspectives presented here will provide a framing to which the patients' experiences may be placed within a broader context in order to better interrogate the reasons behind treatment interruptions.

By introducing this theoretical lens, Chapter two lays the foundation for the empirical exploration of following chapters, in order to link the research with what we have known and to identify the limitations followed by the study. This chapter concludes by connecting the theoretical arguments with the objectives of the research and providing a justified explanation for the approach and methodology that the researcher has taken, to be elaborated on in the subsequent chapters.

2.2 Theoretical framework

A research study's framework holds significant importance, as it serves as the foundational structure within which the researcher examines a phenomenon, and also collects and analyzes the data. Brink et al. (28) emphasize that the chosen theory should apply to every step of the research process. For this study, the Health Belief Model (HBM) was employed as the guiding theoretical framework due to its relevance in understanding health behaviours. The HBM is an existing model relating to how individuals perceive and respond to health-related challenges. In particular, it is very useful to understand why patients may or may not engage in or abstain from certain health behaviours (e.g., the compliance or the cessation of treatment in the case of TB) (29). This is also supported by Tarkang and Zotor who described the HBM as a theory of how the psychological and social elements of knowledge, attitude, personality and beliefs influence the way in which people behave (30).

The HBM makes the suggestion that an individual's health related behaviours are prompted by the perception of the health issue, the probability of being impacted by such a health issue, the benefits or lack thereof of taking a certain action with regards to the health issue, and finally, obstacles that would prevent a person from taking certain actions with regards to the health issue. Furthermore, the model points out the significance of cues to action, or triggers that provoke people to modify behavior, and self-efficacy, which denotes the level of confidence that one has in his or her ability to do what's needed (29,30,31).

The HBM also provides a relevant focus in such a way that the experiences of patients lost to follow up during TB treatment in Oshakati District, Namibia, can be examined. The study is aimed at understanding what the patients in Oshakati District perceive (how severe it is), how susceptible they are to its consequences, how much they benefit from completing self-treatment, and how difficult it is to complete their treatment. Essentially, this encourages a deeper study of the kinds of psychological and social factors that affect patient behaviour.

It is also described by Tarkang and Zotor (30) that the HBM considers psychological and social aspects, including knowledge, attitude, personality and beliefs that are important determinants of health behaviour. This is particularly relevant in Oshakati District, where socio-economic challenges, cultural beliefs and limiting health system could all be determinants for patients to discontinue TB treatment.

Abraham and Sheeran (29) described the components of HBM as illustrated below:

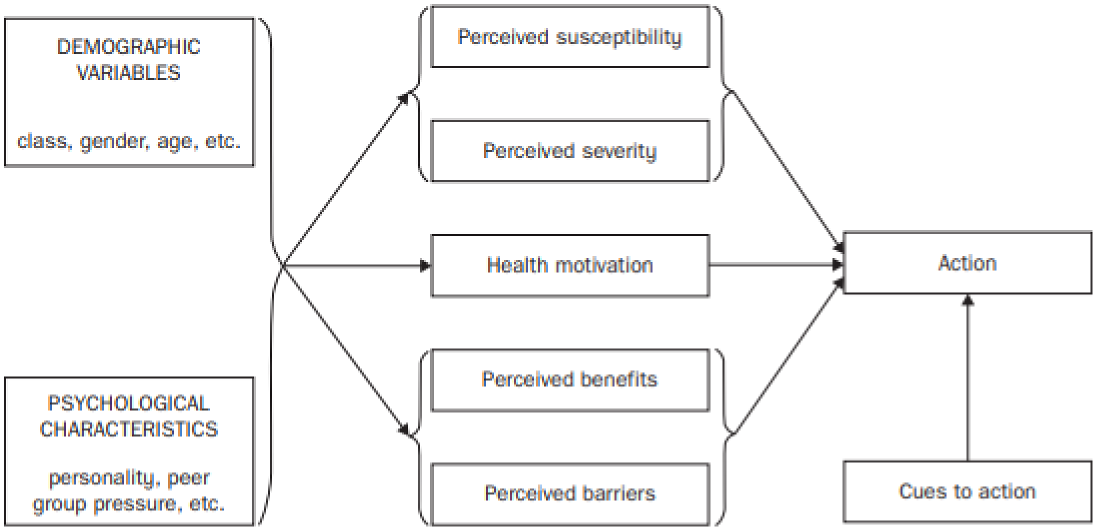

Figure 1: The Health Belief Mode

This study applied the HBM to learn the reasons for patients to be lost to follow up in TB treatment courses and to identify barriers that can be overcome. The results could guide the designing of interventions to improve TB treatment adherence in Oshakati District upon roll out, therefore contributing to better health outcomes in the district.

2.2.1 Constructs of the HBM

2.2.1.1. Perceived susceptibility

After taking anti-TB medications, patients may feel better. This may contribute to patients opting to discontinue their treatment. Patients lost to follow up during TB treatment may not perceive themselves as highly susceptible to severe TB as they may not fully understand the risks associated with incomplete treatment such as drug-resistant TB, prolonged hospitalization and disease recurrence.

2.2.1.2. Perceived severity

It is hoped that during the initial treatment of TB, the signs and symptoms of the disease may subside. This may contribute to premature discontinuation of treatment as the patient may think that they are recovering from the disease. Patients lost to follow up during TB treatment may underestimate the severity of the disease.

2.2.1.3. Perceived barriers

Patients lost to follow up may face several factors that may hinder their motivation to complete their treatment. These factors may include financial constraints, stigma associated with TB, and the side effects of medications. Moreover, the length of treatment may seem not to be encouraging for patients to complete their treatment.

2.2.1.4. Perceived benefits

Perceived benefits depend on a person's opinion about the value of a new behaviour in reducing the risk of developing a disease (29). Thus, the side effects of anti-TB medications may discourage patients from continuing with their treatment. Hence, they may choose to discontinue treatment with the hope to prevent side effects.

2.3 Loss to follow up during TB treatment as a public health concern

Loss to follow-up (LTFU) during tuberculosis (TB) treatment presents a critical public health challenge, particularly in high-burden and resource-limited settings. Patients who disengage from treatment continue to harbour and transmit *Mycobacterium tuberculosis*, thereby increasing the risk of ongoing community-level transmission among family members, colleagues, and the broader population (7, 9). Beyond transmission, LTFU is strongly associated with adverse clinical outcomes, including prolonged illness, relapse, and the development of multidrug-resistant TB (MDR-TB), which is significantly more difficult, costly, and less effective to treat than drug-susceptible TB (11,32). As shown by (11) patients who interrupt their treatment are at a considerably higher risk of acquiring MDR-TB, which exacerbates the complexity of treatment and undermines TB control strategies (11). Similarly, Opperman and Du Preez underscore that LTFU accelerates the spread of resistant strains, placing greater pressure on already overburdened health systems (32). The economic implications are also severe; (33) report that managing cases of LTFU incurs costs up to four times greater than those associated with patients who complete treatment, reflecting a significant financial strain on national health services (33). In many low- and middle-income countries, where healthcare systems are fragile and TB prevalence is high, the recurrence and escalation of LTFU threaten to derail progress toward TB elimination targets (9,33). Addressing LTFU, therefore, is not only essential for individual patient outcomes but also for ensuring the sustainability and efficacy of public health interventions aimed at controlling TB on both national and global levels.

Moreover, patients who are lost to follow up continue to be infectious, spreading TB within their communities. This ongoing transmission not only perpetuates the TB epidemic but also undermines the efforts of public health programs aimed at controlling the disease (9,11). Reducing the rates of loss to follow up is, therefore, critical for both individual patient outcomes and the overall effectiveness of TB control programs (33). Public health strategies must focus on improving adherence to treatment to prevent the development and spread of MDR-TB and to ensure that TB can be effectively managed at the community level (9,11,12). Efforts to address LTFU include strengthening patient retention strategies, addressing socioeconomic barriers, and enhancing healthcare support systems. Behavioral and qualitative research is also essential for identifying context-specific factors that influence treatment adherence (7,33,34).

2.4 Experiences of patients lost to follow up during TB treatment

This literature review examined personal experiences of patients lost to follow up on TB treatment for two or more months. Among critical domains, it discusses socio-economic experiences, psychological determinants, challenges in the healthcare system, stigma and discrimination, cultural views, public health significance, communication between patient and provider, support systems, treatment side effects, and health education. The information in these domains significantly enhances the knowledge of patients lost to follow up in TB treatment and offer ideas for solving this problem.

2.4.1. Socio-economic status

A study done in Iran (9) found that the socio-economic status is a good determinant of health outcomes, including treatment adherence in patients suffering from TB. Many barriers stand in the way of completing treatment for the patients from lower socio-economic backgrounds. Amongst other things, financial constraints are a massive barrier. Many TB patients cannot afford transportation to health care facilities, which results in missed appointments and ultimately, loss to follow up (9). Fees for consultations and medications in some settings also contribute to the financial burden of TB treatment, it is further reported. Further exacerbating the economic strain on the patients and their families are indirect costs like lost income due to time off from work (20).

Additionally, patients of low income might choose work over health to meet present financial requirements. This situation is especially common in areas where there is no social network or financial support for patients while they remain in treatment for multiple months (11). Thus, some patients may choose to discontinue tuberculosis (TB) treatment to avoid losing their source of income, especially when the demands of treatment such as frequent clinic visits, side effects, and long recovery periods conflict with their ability to maintain employment. In such contexts, poverty, unemployment, and limited access to healthcare services interact to produce poor health outcomes. These factors are mutually reinforcing, creating a vicious cycle in which economic hardship leads to treatment non-adherence, further illness, and deepening social vulnerability, particularly among already disadvantaged populations (16).

2.4.2. Psychological effects

The psychological burden of TB is great and has a potentially significant impact on treatment adherence. When diagnosed, fear and anxiety ensue because of the stigma attached to TB and the long lengthy, uphill treatment. Despite the fact that the mental health impact of TB is frequently underrated, it is considered to be critical in patients' compliance with their treatment. In addition, depression, which is the commonest comorbidity in TB patients, leads to hopelessness and apathy, which may erode treatment adherence (35).

The psychological landscape of TB patients is complicated further by anxiety and fear of the disease itself and of the side effects of medication (20,36). TB also causes stress to patients, who are often socially isolated through processes often associated with stigmatization of the disease in heavily affected societies. These psychological factors, when combined, create a high rate of treatment default as patients are already overwhelmed by physical demands of treatment and may not be able to cope with the emotional aspect of their condition (20,35).

2.4.3. Healthcare system challenges

The role of the structure and functionality of the healthcare system in patient adherence to TB treatment is important. Many healthcare systems are underfunded and understaffed, which results in several problems that affect patient care directly. For example, long waiting times can make patients less likely to attend follow up appointments if, for example, they have to take time off work or travel a long way to get to the healthcare facility. Furthermore, in health care systems with heavy burdens on healthcare providers, patients may not receive the individualized attention and counselling they require to stay committed to their regimen of care (21,33).

Lack of continuity in care is another important challenge in the healthcare system. If the patients are with different healthcare providers at each visit, it makes them feel disconnected and therefore less motivated to follow through the treatment plan. Such inconsistencies can also cause patient-provider communication confusion around treatment importance and result in loss to follow up. Additionally, resources such as medications, diagnostic tools, and support services are available in different healthcare settings to varying degrees, affecting the quality of care that TB patients receive (37,38).

2.4.4. Stigmatization and discrimination

Stigma remains a major barrier to tuberculosis (TB) treatment adherence and care-seeking. TB is often associated with negative stereotypes, including perceptions of poor hygiene, poverty, and links to HIV, which contribute to its stigmatization in many communities (9,35). This stigma can manifest in various forms of discrimination, such as social exclusion, loss of employment, and rejection by family members (35). As a result, individuals may hide their diagnosis or delay seeking care to avoid being labelled, thereby endangering their own health and increasing the risk of transmission within their communities (1,9). The World Health Organization underscores that stigma and discrimination significantly hinder efforts to control TB by discouraging timely diagnosis and consistent treatment adherence (1,2). In the Namibian context, the Ministry of Health and Social Services has also acknowledged stigma as a persistent challenge to effective TB programme implementation and patient retention (4). Addressing stigma is therefore essential to improving health outcomes, ensuring continuity of care, and reducing the public health burden of TB.

More specifically, the problem lies in the stigma of TB and HIV intersecting. Patients with TB are assumed to be HIV positive since TB is closely linked to HIV, thereby adding to the stigma. The combined stigma of being homeless and mentally ill can be disheartening, apart from having TB, can be devastating with profound social isolation and mental distress that in turn drives up the risk of defaulting on treatment (35,36). Thus, it is crucial to address stigma in order to improve treatment adherence and empower patients during their treatment TB (33,38).

2.4.5. Cultural beliefs

Beliefs and practices among the culturally diverse populations are vital to determine and they are critical to change health behaviors, evidenced by the impact on TB treatment adherence. Some cultures prefer traditional healing than biomedical practices, and patients from such cultures prefer to abandon their TB treatment and resort to traditional remedies. These traditional practices may involve the use of herbal medicines, spiritual rituals or any other method that is not known as scientific methods of curing or managing TB (36,39). However, while these practices are critical components of cultural identification, regarding TB treatment, they may indeed conflict with the biomedical model of TB treatment and thus result in non-adherence (39).

There are also many cultures where misconceptions exist about TB, mainly its causes and how it is treated. Misguided beliefs of witchcraft or supernatural causes of TB in some communities has the potential to discourage patients from seeking medical treatment; instead, they may be referred to traditional healers. Because cultural beliefs are deeply embedded and often resistant to change, TB treatment strategies must be adapted to align with local cultural contexts in order to ensure that patients are supported in completing their treatment. Thus, public health interventions on TB must be culturally sensitive, involve collaboration with community leaders and traditional healers and promote adherence to TB treatment (34,39).

2.4.6. Healthcare worker communication

It is essential for patients' TB treatment adherence that communication between patients and healthcare providers be effective. Empathetic clear communication between patient and providers builds a strong trust which is an essential factor in ensuring adherence to the treatment regimen of patients. The better the patient feels listened to and supported by their healthcare provider, the more the patient will follow through with their treatment plan and attend follow up appointments (16,34). However, effective communication between healthcare providers and TB patients is often hindered by multiple barriers, including language differences, limited health literacy, and cultural misunderstandings. These barriers can contribute to poor comprehension of treatment instructions, reduced trust in medical advice, and ultimately, treatment default. According to the World Health Organization, communication challenges, especially in linguistically diverse settings, significantly affect patients' ability to follow through with TB care (5). Low health literacy has also been identified as a critical factor influencing adherence in various low- and middle-income countries (34). Furthermore, studies have shown that cultural misalignment between patients and healthcare providers can lead to misconceptions about TB and mistrust in treatment processes, thereby increasing the likelihood of loss to follow-up (40,41).

Healthcare providers must be trained in culturally sensitive communication techniques to effectively address and overcome language barriers, health literacy challenges, and cultural misunderstandings that hinder TB treatment adherence. To make that possible, providers should be able to explain treatment in a way that is easy to understand and relate to patients given their cultural beliefs and personal background. In addition, engaging patients in the decision-making process and providing them with clear, actionable information regarding their treatment can be empowering to patients to be active participants in their care, and thus reduce the risk of patients being lost to follow up (34,40,41).

2.4.7. Support systems

Successful tuberculosis (TB) treatment often depends on strong social support systems that assist patients in adhering to lengthy and demanding treatment regimens. Family members, friends, and community networks play a critical role in providing both emotional reassurance and practical assistance, such as accompanying patients to clinic visits, reminding them to take their medication, and offering encouragement during periods of distress (40,41). The World Health Organization emphasizes that community and household support significantly improves treatment adherence and reduces the risk of loss to follow-up (1,2). Conversely, the absence of such support can leave patients feeling isolated, emotionally burdened, and overwhelmed by the demands of treatment, ultimately increasing the likelihood of non-adherence or default (40,41).

Effective community-based support programmes such as peer support groups and Community Health Workers (CHWs) initiatives play a crucial role in enhancing adherence to tuberculosis (TB) treatment. These interventions not only encourage patients to complete their treatment but also promote consistent adherence to the correct dosage and timing of medication, which is critical to achieving cure and preventing drug resistance. By fostering shared experiences through group or peer support, such programmes help patients feel less isolated and more motivated throughout the treatment journey. Furthermore, the active involvement of communities in TB control efforts contributes to reducing stigma, building trust in health services, and creating a socially supportive environment that encourages sustained adherence. Strengthening these community-based support systems is therefore essential for improving overall treatment outcomes, minimizing the risk of treatment default, and ultimately reducing the incidence of loss to follow-up. (40,42,43).

2.4.8. Treatment side effects

Often, TB treatment requires several months of taking a variety of drugs, and they can have many side effects such as nausea, vomiting, fatigue and liver toxicity, apart from the transportation costs and sick days they require. Thus, these side effects can be severe and debilitating, preventing patients from continuing their treatment (1,9,16). Some patients who are not sufficiently informed about how to deal with these side effects tend to stop taking their medication when they develop these (2,4,16).

Management of treatment side effects is key to ensuring the patient upholds his/her treatment regime. Before patients start the treatment, healthcare providers should constantly engage them on the potential side effects and offer ways to manage them. This includes prescribing appropriate medications to manage side effects, adjusting the treatment regimen when necessary, and conducting regular follow-ups to monitor the patient's condition. By responding promptly and effectively to side effects, healthcare providers can significantly reduce the risk of treatment default and improve overall treatment outcomes (35,43).

2.4.9. Role of health education

TB treatment adherence requires a good deal of health education. Giving patients information on the nature of their TB, why they must complete the treatment, and how to best cope with side effects can help patients to become more pro-active in their own care (1,2,9,16). There are studies that indicate advocating that health education integrated into every stage in TB care, from diagnosis to completion of treatment, helps educate patients along this journey (16,35,38,43,47). However, health education is effective only if delivered properly. Education that is more likely to improve adherence and reduce loss to follow up is culture-appropriate education, education that is culturally appropriate for the patient population's educational needs and level as well. In addition, for better adherence of patients to their treatment plan, it is important to cultivate a sense of responsibility by including patients in their treatment plan (32,35,43).

2.5 Potential strategies to improve patient adherence to the TB treatment

LTFU during TB treatment is a barrier to the positive outcome in individual TB cases and, at the same time, is an important public health problem in several countries. Patients who do not complete their TB treatment have a greater likelihood of developing multidrug resistant TB (MDR-TB) – the strain of TB that is more difficult and more expensive to treat and has a higher risk of transmission to others (8,20). Several strategies have been proposed to strengthen patient adherence to tuberculosis (TB) treatment and reduce the risk of non-adherence. These strategies form part of a broader set of patient-focused interventions designed to address the multifaceted barriers to adherence.

Key among them is patient-centred health education, which aims to improve patients' understanding of TB, its treatment process, and the consequences of non-compliance (9). Additionally, adopting a supportive and responsive approach to patient care one that prioritizes respect, empathy, and ongoing communication has been shown to foster greater trust and adherence among patients (32). Community support groups also play a vital role by offering emotional encouragement and practical assistance throughout the treatment journey, thereby reducing the sense of isolation that patients may experience (11).

2.5.1. Patient-centred care approaches

Increasingly, patient-centred care is recognized as a critical way of reducing treatment loss to follow up in TB management. Patient-centred care aims to deliver healthcare that is tailored to individual patient needs, preferences, and circumstances. It seeks to overcome barriers to treatment adherence through a combination of personalized care plans, psychosocial support, and active community engagement.

Tola et al. (9) reviewed existing literature and found that loss to follow-up in tuberculosis treatment is particularly prevalent in resource-constrained settings, where it is strongly associated with inadequate patient education, insufficient counselling, and weak systems for monitoring and follow-up. Similarly, the WHO advises for patient-centeredness inclusion of socio-economic support, stigma reduction, decentralized care models and others in order to sustain patients on treatment (1,2).

Patient-centred care such as peer support groups and home-based care can greatly improve patient adherence to the treatment. For example, loss to follow up rates among patients with drug resistant TB were reduced when community-based treatment was provided for patients and supervised through the observation of healthcare professionals (11). In addition, in a ten-year retrospective review, it was found that interventions tailored to environmental and individual barriers improved treatment outcomes in Ethiopia (44).

Socio-economic interventions, particularly cash transfers and nutritional support, have proven effective in improving tuberculosis (TB) treatment adherence in resource-limited settings. Ukwaja et al. (14) demonstrated that in rural Nigeria, conditional cash transfers provided when patients attended clinic appointments or adhered to medication schedules significantly reduced treatment default rates. These transfers helped alleviate the indirect costs of TB treatment, such as transportation expenses, income loss due to clinic visits, and food insecurity, all of which are common barriers in impoverished communities. By addressing these economic challenges, cash transfers enabled patients to prioritize their health without compromising their basic survival needs. Nutritional support, often provided in tandem, further contributed to patient well-being and encouraged ongoing engagement with treatment services. In parallel, stigma-reducing interventions have also played a critical role in enhancing adherence. In Nepal, for example, community-based programmes aimed at reducing TB-related stigma through peer education, public awareness campaigns, and family counselling helped create supportive environments where patients felt safer to seek and continue treatment (35). Together, these socio-economic and psychosocial strategies underscore the importance of comprehensive, patient-centred approaches that recognise the interplay between poverty, stigma, and health behaviour in shaping TB treatment outcomes.

To ensure the sustainability of patient-centred care, supportive policies must be accompanied by robust health system reforms and active community involvement. Patient-centred care, which addresses the structural and emotional factors leading to loss to follow up for TB treatment, provides a solid basis for improving global TB treatment outcomes.

2.5.2. Patient health education

Health Education is an important part of adherence to TB treatment. Patients must be educated on the significance of treatment completion, taking their treatment as prescribed, the side effects of medications, and the serious risks of discontinuing treatment, including the onset of multidrug-resistant TB (MDR-TB). Poorly educated patients are more likely to discontinue treatment, often with disastrous consequences, both to themselves and for society in the form of continuation of disease, often transmitted, and development of drug-resistant TB strains (1,9). Low levels of health literacy have been linked with lower uptake of health interventions (45).

Health education sessions that can be embedded in regular clinic visits may be a building block for improving adherence. Evidence has shown that printed educational material, when delivered during healthcare encounters offer an effective strategy for enhancing patient knowledge, positive attitudes and healthy practices towards TB treatment (11,37). Therefore, the use of a by health professionals of a language and terminologies well understood by patients is of vital importance. Utilization of visual aids, pamphlets and interactive discussions are especially useful due to their ability to break complex medical facts into simpler terms and encourage interaction (27). For instance, Tola and others' (9) advice that visual material in combination with verbal explanations is most likely to improve patient learning and retention of the important treatment principles

Working with local leaders and community leaders to spread educational messages is another effective approach (27,9). People who stopped treatment after being previously lost to follow up during TB treatment but who have managed to successfully complete treatment, may well be an important motivating factor for others who have stopped treatment. Through sharing their own rocky paths to treatment graduation, these individuals can serve as examples to follow, inspiring others who have difficulty finishing their treatment. In their arduous journey, they offer important lessons and can give patients who are not adhering powerful encouragement.

In Ethiopia, community-based programs with the involvement of local leaders reduced stigma and improved adherence rate by correcting myths and emphasizing a collective community responsibility towards TB (11,44). Involving religious leaders in TB education in Nigeria has also been found to have the potential of upscaling and credibility in health promotion initiatives (14).

Educational interventions serve two purposes by arming patients with the information required to actively monitor their treatment, namely, empowering patients and building stronger systems in the process. Personalized and culturally sensitive education interventions in collaboration with healthcare providers and communities are crucial to control default from treatment and end TB globally (32,35,43).

2.5.3. Community-based support programs

Community-based treatment support programmes enhance both TB treatment adherence and outcomes by harnessing the social capital and trust within local networks. By focusing on both the practical barriers to care and the psychological ones that can lead to non-adherence, these programs offer patients a supportive environment. For example, social support groups provide patients with an opportunity to share their experiences, to feel that they are not so unique, to benefit from each other by learning what works best for those in the group, and to support one another to stay disciplined with treatment regimens (1,2). These group-cohesion-building techniques, research suggests, help patients feel more motivated and connected, and can significantly boost rates of adhering to treatment (37,46,47).

Community Health Workers (CHWs) are essential in assisting people with TB. Their involvement is known to be a successful strategy to strengthen TB care, particularly in resource-limited settings (38,44). CHWs are central to engaging TB patients and default-tracing to monitor treatment progress, identify potential problems with adherence and intervene early as well as to ensure Directly Observed Treatment (DOT). By establishing an accountability framework and a relationship of trust between patients and healthcare workers, DOT enhances treatment adherence (49). One study in Uganda has shown that Community Based DOT (CB DOT) is effective and has better outcomes than Hospital Based DOT (HB DOT) (50). CHWs are also vital in issuing prescription reminders to drug recipients to ensure that they take their doses and also attend to side-effects at an early stage. In addition, CHWs can provide essential emotional support, ameliorating the stigma and isolation often associated with TB patients (14,49). CHW-led interventions ease the burden on the already overburdened health facilities (44). Regular counseling is important in reducing LTFU while on TB treatment (36). Policies and programs must be expanded to provide more opportunities of social support for TB patients and survivors, and this is crucial to all systems (48). According to the overwhelming majority of key informants and treatment completers, treatment LTFU can be avoided with regular counselling and prompt action if a patient misses one or two doses (14,49).

2.5.4. Incentive-based programs

Incentive-based programs provide tangible rewards to patients adhering to TB treatment regimens. These incentives, including food parcels, transportation vouchers, and small financial stipends, address the financial and logistical burdens associated with long-term treatment (33,51). For many patients, these burdens, such as transportation costs and income loss due to frequent clinic visits, serve as significant barriers to adherence (33). By alleviating these challenges, incentive-based programs effectively reduce the risk of patients discontinuing treatment prematurely.

The relevance of socioeconomic determinants of health to TB treatment adherence is refined by research. Moreira et al. emphasized that catastrophic costs of TB care lead to increased drop-out rates among patients (52). Targeting such financial stress with incentives has demonstrated to be an efficacious approach to mitigating these barriers and increasing adherence. Similarly, Wilder et al. (51) showed that if social determinants, including income and access, are addressed, adherence to medication is better; and this supports the use of incentive-based interventions in management of TB.

Tok et al. (33) identified that logistics and financial difficulties were the major factors associated with treatment cessation in Malaysia, therefore, supportive measures such as incentives would be helpful to address these problems. Incentive-based initiatives may also be effective in enhancing retention by targeting psychosocial determinants of care. As emphasized by Dixit et al. (35), stigma associated with TB and depression can impede patient adherence to treatment. Incentives are not simply a means of helping patients fulfill economic needs, but also a sign of societal backing which can alleviate the emotional burden of TB and increase the likelihood of adherence to treatment.

2.5.5. Addressing stigma

Stigma continues to be a major obstacle to TB treatment compliance that can isolate social support and alienate patients from health-seeking practices and treatment(ref?). Fear of judgment or discrimination often prevents individuals from beginning or completing treatment, which only amplifies the spread of TB and exacerbates individual health (9,11,20).

Public health programs that target stigma reduction have been successful in improving knowledge and changing negative attitudes toward TB. These campaigns commonly comprise community mobilization, social media and educational events to counteract widespread myths and achieve empathy for TB patients. For example, evidence suggests that including stigma-reduction messages within regular community-based health promotion activities is conducive to a more supportive health environment, thereby promoting patient adherence and linkages to healthcare services (14,44). Stigma reduction is thus important for enhancing adherence and general TB control (35).

2.5.6. Involvement of family and social networks

Family and social networks play a critical role in supporting TB patients throughout their treatment journey. Family members often provide emotional reassurance, help manage stress and anxiety associated with the illness and assist with practical needs such as transport to clinics or reminders to take medication (35). There is a social bond between individuals, especially in patients who encounter stigma or depression, therefore support can help adherence by decreasing the feeling of isolation and hopelessness (35). Families may also be involved actively, for example by advising patients to take their treatments on time, driving them to health clinics, and taking care of domestic chores. This multifaceted support may result in greater compliance and benefit in treatment (53).

Social support from friends and community members is one factor in treatment success. Social networks provide support and motivation that are crucial for successful completion of lengthy and difficult TB treatment courses (16,54). Community participation can also contribute to a culture of accountability and encouragement that can overcome obstacles such as stigma and treatment fatigue that often result in non-compliance or loss-to-follow-up (55,56). The availability of a supportive community can lessen feelings of shame and fear that represent common barriers to TB diagnosis and treatment initiation/adherence (20,36).

Enhancement of family and social support structures via focused community outreach and education is a priority intervention to enhance TB treatment compliance. Community outreach efforts can help families and peer groups understand TB, its treatment, and the need to support patients. They can also dispel myths and reduce stigma, which helps to make an environment more welcoming for patients (21,42). Further incorporating support networks into treatment regimens, for example by engaging family members in DOT sessions, can improve responsibility and minimize treatment discontinuity (14,34).

2.6 The research gap

Although there are substantial efforts in TB control, the problem of loss to follow-up for TB treatment remains a significant challenge, particularly in the Oshakati district, Namibia. There are numerous main factors for noncompliance with TB treatment identified in literature, including socioeconomic factors, psychosocial factors, and health-system barriers.

Most previous research has covered general adherence barriers and no in-depth localized research has been done on how these adherence barriers are experienced in the Oshakati District. Further, although different strategies have been recommended and tried elsewhere, their effectiveness in the unique cultural, economic and health system scenarios of Oshakati District is not well documented.

Poverty and transportation costs are, for example, well known socio-economic obstacles to treatment adherence that have been demonstrated with study results (9,32,35). Whether these factors influence patients in Oshakati District is not well established. Likewise, although the psychological challenges of TB such as stigma and mental health problems, have been described as obstacles to adherence, the nature of such problems for TB patients in Oshakati District has not been well characterized.

The current study attempts to address this gap by analyzing the personal experiences of TB patients who are lost to follow up while having TB treatment in Oshakati district. The study analyses how the system of socio-economic, cultural and health system related factors interact to result in discontinuation of treatment and develops contextualised knowledge that could be used to design more focused interventions to increase adherence to TB treatment in the district. The proposed study also aims to fill the knowledge gap by looking at the effectiveness of these potential interventions in the context of Oshakati District, culture and socio-economic settings.

2.7 Chapter Summary

Chapter two: the literature review of TB treatment adherence is presented in which the researcher specifically focuses on the challenges and barriers encountered by TB patients in Oshakati district in Namibia. It discusses important factors that contribute to LTFU such as socio-economic, psychological barriers, as well as health system inadequacies, stigma, and cultural issues. Lastly, it examines possible mechanisms for improving patient adherence, patient-centred care, health education, community-based support, and incentive programs.

The chapter raises the wedge in research and the urgency for studies to be conducted locally to deal with the unique experiences and contexts that have an impact on TB patients in Oshakati District. Chapter two, through a comprehensive review of relevant literature, lays the groundwork for the empirical examination of factors influencing loss to follow-up among TB patients in the Oshakati District. The methodology of the research will be explored in the following chapter.

CHAPTER THREE

RESEARCH METHODOLOGY

3.1 Introduction

Chapter three describes the research methodology of the study. The chapter presents the study design and approaches, as well as methods used in data gathering and analysis. Descriptions regarding participant selection, data collection instruments and procedures are also made, together with rationales for the qualitative methods chosen as most appropriate for the study. It also covers some ethical considerations adopted in the study to ensure the integrity of the results.

3.2 Study design

Grove et al. (57) described the research design as a general scheme for carrying out a study. It describes how data are to be collected, analysed, and interpreted. The approach followed in this study is qualitative, utilizing exploratory, descriptive and phenomenological designs, with the aim of exploring the experiences of those TB patients who are lost to follow-up whilst on treatment in Oshakati district.

3.2.1 Qualitative approach

The research is designed to be qualitative in order to probe and understand the experiences of TB patients lost to follow up while on TB treatment in Oshakati District, Namibia. The nature of the research questions makes it relevant to use qualitative approach as a conceptual framework to explore the personal, social and context factors, which determine the patient's behaviour. While quantitative methodologies aim to judge variables, qualitative methodologies such as in- depth interviews and focus groups can result in rich, data that explain the detail of these experiences. That level of understanding is needed to provide insights into what is affecting patient behaviour, insights that are not always as easy to quantify (24,58,59).

Table 1: Characteristics of qualitative research

CHARACTERISTICS	DESCRIPTION
Natural setting	Qualitative researchers often collect data in the field at the site where participants experience the issue or problem under study. The study was conducted in Oshakati District, where people with TB live and experience the challenges of TB treatment in their real-life environment.
Researcher as key instrument	Qualitative researchers collect data themselves by examining documents, observing behaviour, or interviewing participants. Data were collected using individual in-depth interviews.
Multiple sources of data	Data in qualitative form are gathered using multiple forms, such as interviews, observations, documents, and audio-visual information, rather than relying on a single data source. After data collection, the researcher review all data, make sense, and draw conclusions and establish themes and subthemes.
Inductive and deductive data analysis	Because they work from the bottom up, collecting data and grouping it into increasingly abstract categories, and from there seeking out patterns, qualitative researchers work inductively. This inductive approach represents a cyclical, iterative movement from themes to re-engagement with the database, and back to the refined set of themes until the researcher becomes satisfied with this process. Researchers, in a deductive approach, work backwards from the

	themes and see whether more data can be found to support each theme or if they need to seek out more information.
Participants' multiple perspectives and meanings	In qualitative research, the investigator focuses on understanding the meanings that participants attribute to the problem under study, rather than imposing their own interpretations or relying on existing literature.
Context-dependent	The study is conducted within the specific context or setting of the participants or sites. This approach is crucial as it helps researchers understand how events, actions, and meanings are influenced by the unique circumstances of their environment.
Emergent design	The study design might evolve based on preliminary findings once the researcher has entered the field of study. For instance, it might be necessary to adjust the interview questions as new insight emerges from initial data collection.
Reflexivity	Researchers position themselves in a qualitative research study. This means that researchers convey their background, how it informs their interpretation of the information in a study and what they have to gain from the study.
Holistic account	In qualitative study, the researchers tries to develop a complex picture of the problem or issue under study.

Adopted from Creswell and Creswell (58).

The qualitative design was selected for its ability to generate an in-depth understanding of the context of behaviour.

3.2.2 Exploratory design

Exploratory design is a research approach used to investigate a phenomenon when there is limited prior knowledge. This approach is particularly appropriate when the research topic is relatively new or underexplored, allowing for in-depth understanding and the identification of key patterns and themes (58). The exploratory nature of the design is very appropriate because the study seeks to expose what happened to the patients who were lost to follow-up while on TB treatment in Oshakati District, Namibia. In this instance, the exploratory approach allowed the required flexibility to explore the complex relationships between the socio-economic, cultural and health system factors influencing patient behaviour without predetermining a theoretical framework or assumptions (24).

3.2.3 Descriptive design

The study also used a descriptive design which is suitable for providing in-depth explanation to the experience of TB clients for stopping treatment. Descriptive studies concentrate on truthfully identifying and depicting the features of some set of persons or happenings and in providing a comprehensive view of what is happening (24). The descriptive nature of this study provided a detailed reporting of the patient experiences, including insights such as the perceived nature of the illness, the obstacles they encountered in adhering to treatment, and the particular contributing factors associated with LTFU. This level of detail is necessary in order to comprehend the magnitude of the problem, and to inform interventions.

3.2.4 Phenomenological design

Phenomenology aims to describe how individuals make sense of their experiences and the meanings that they give to it (58). Using a phenomenological methodology, the research revealed momentous levels of insight into the individual, subjective experiences of TB patients that could not be achieved by any other means, including the personal meaning of their illness, treatment explanation and reasons for default. It facilitated a more subtle range of the emotional, psychological, and social dimensions of their experiences, the identification of which is necessary for the development of clinically relevant, patient-centred interventions.

3.3 Population of the study

The population of a study is a group of those the study focuses on, and among whom the sample is drawn according to set criteria (23,24). In this study, the population is defined as all persons who were diagnosed with TB of any form, lost to follow up under TB treatment for two months or more and are 18 years of age and older, in the Oshakati district of Namibia. Purposive sampling of individuals who were lost to follow-up during TB treatment is crucial in this study, as it allows for the selection of participants who have directly experienced the phenomenon under investigation and can provide valuable insights into the factors that influenced their treatment interruption. This could imply better data quality and better results.

3.4 Study setting

The study was carried out in the Oshakati District in the Oshana Region, which has three hospitals, namely; Intermediate Hospital Oshakati (a public hospital), Ongwediva Medipark Private Hospital and Ondangwa Private Hospital. The town also has five health centers and twelve clinics. One such centre is the Intermediate Hospital Oshakati TB Clinic, which is a key facility in offering tuberculosis (TB) services and is the central reporting point for all TB cases in the district. Thus, this study was conducted at the

Intermediate Hospital Oshakati TB Clinic as well as in the homes of patients who defaulted TB treatment and whose contact details were retrieved from the reporting center.

3.5 Sample and sampling method

A sample is a fraction of a whole or a subset of a larger population that the investigator selects to represent the broader population being studied (59). Sampling refers to the systematic process of selecting a subset of individuals or cases from a larger population to participate in a research study (60). In this study, a non-probability, purposive sampling technique was employed to identify and recruit participants who had been lost to follow-up during tuberculosis (TB) treatment within the Oshakati District (59). A total of 11 participants were selected, which is appropriate for a qualitative, exploratory design where the aim is not statistical generalization but rather in-depth understanding of a specific phenomenon. The sample size was guided by the principle of data saturation, the point at which no new themes or insights emerge from additional data collection (59).

Participants were recruited with the assistance of local TB clinic staff, who identified individuals from clinic records who met the inclusion criteria: having been diagnosed with TB, registered in Oshakati District, and lost to follow-up for a period of two consecutive months or more during treatment. Eligible individuals were contacted via phone or in person and were provided with detailed information about the purpose, procedures, and voluntary nature of the study. After individuals expressed interest in participating, appointments were scheduled at mutually convenient locations. Prior to data collection, participants were taken through a written informed consent process, during which the study was explained in their preferred language. They were assured of confidentiality, their right to withdraw at any point, and how the information would be used. Only after obtaining signed informed consent were participants included in the study.

3.5.1 Inclusion criteria

The study included participants who met specific inclusion criteria. These were the set criteria:

- These were patients who had been diagnosed with TB, all forms, and had been lost to follow up for two consecutive months or more during their TB treatment.
- Additionally, only those patients who were 18-years of age or older and received care in Oshakati District during the data collection period were included.

3.5.2 Exclusion criteria

In contrast to inclusion criteria, participants were excluded from the study based on several criteria as follows:

- Patients who had been diagnosed with TB but were not lost to follow up, or who had been lost to follow up for less than two consecutive months.
- Furthermore, individuals who were younger than 18-years of age were not included in the study.
- The study also excluded patients who had been formally transferred out to other districts, even if they had been classified as lost to follow up prior to their transfer.

3.6 Data collection instrument

Data collection instruments are tests, questionnaires, inventories, interview guides or any other form which is used to collect data from the participants (59). In this study, a semi-structured interview guide was used to gather data. The interview guide was translated from English into Oshiwambo (Oshindonga), which is the most widely spoken language in Oshakati District. This process helped to maintain the semantic and conceptual equivalence of the questions across both languages. To address the objectives of the study, participants were asked to share their personal experiences of being lost to follow-up during TB treatment in Oshakati District, as well as their views on what could have supported them to remain in care. This approach not only allowed for an in-depth exploration of the circumstances and challenges surrounding treatment interruption but also facilitated the identification of potential strategies rooted in patient perspectives to improve retention and adherence in similar settings. A tape recorder was also used during the interview sessions after obtaining consent from the participants. Field notes were taken.

3.7 Data collection procedure

Ethical approval to conduct the study was first obtained from the University of Namibia Decentralized Ethics Committee (UNAM DEC), followed by formal authorization from the Ministry of Health and Social Services. Once these approvals were granted, the researcher liaised with healthcare staff in Oshakati District to identify potential participants who met the inclusion criteria. Each potential participant was approached individually and provided with a detailed explanation of the study's purpose, procedures, and their rights, including the voluntary nature of participation, the assurance of confidentiality, and the right to withdraw at any time without consequence. Those who expressed willingness to participate were then taken through a formal informed consent process, during which written consent was obtained. Only after consent was secured were in-depth, face-to-face interviews conducted with participants in a private and comfortable setting, ensuring respect for their dignity and autonomy throughout the research process.

This approach was selected considering the qualitative design and the purpose of this study, which was to obtain in-depth patient perceptions (59).

One of the primary reasons for using a face-to-face interview was its ability to facilitate an in-depth understanding of participants' experiences. This method allowed the researcher to engage directly with the participants, providing the opportunity to probe further into their responses, clarify ambiguities, and gather rich data.

Data were collected by the researcher using a semi-structured interview approach, beginning with a central open-ended question and followed by probing questions that were guided by participants' responses. Some interviews were conducted at the TB Clinic in the Oshakati District, in a private consultation room allocated by the Clinic's Unit Manager. This setting ensured a quiet and confidential environment, allowing participants to speak freely and without fear of being overheard. Additionally, some data were collected at the participants' homes after obtaining their contact details from the Oshakati District TB register. With participants' permission, each interview was audio-recorded using a digital voice recorder to ensure accurate capture of the conversation. The recordings were later transcribed verbatim to preserve the authenticity and detail of participants' responses. In addition to the audio recordings, the researcher also took field notes during the interviews to document non-verbal cues, emotional expressions, and contextual observations that could enrich the interpretation of the data. These three components the verbal interview, audio recording, and field notes were used collectively to enhance the depth, accuracy, and trustworthiness of the data collected. All interviews took 20 – 30 minutes. Data collection process continued until saturation of the data. That is, only 11 participants were included in the study.

3.8 Data Analysis

During the data analysis, a thematic analysis approach was utilized to systematically examine the experiences of patients lost to follow up during TB treatment. Recorded data were analyzed manually. Here is a full text description of how the analysis was performed according to the Tesch's data analysis technique (28):

- Step 1: following data collection, the audio recordings of the interviews were transcribed verbatim as the first stage of analysis. Once transcription was completed, the researcher carefully reviewed each transcript multiple times to familiarize herself with the content and begin identifying patterns and key expressions. During this process, initial ideas, reflections, and emerging concepts were documented in the form of analytic memos. This iterative reading enabled the researcher to draw preliminary meanings from the data and to highlight important terms and recurring themes for deeper analysis.

  During the data analysis phase, the researcher reads the transcripts multiple times to fully internalize and understand the content. To ensure the application of bracketing a key aspect of phenomenological research researcher consciously reflected on her own field notes and prior assumptions that may have arisen from existing literature, professional experience, or personal beliefs. These preconceived ideas were set aside to minimize bias and allow the analysis to remain grounded in the participants' own words and lived experiences, as expressed during the interviews.
- Step 2: during this step, the researcher selects one of shortest yet interesting interview to listen to and establish the core meaning.

The recordings were played repeatedly to gain insight on what the respondents had to say regarding their experiences of loss to follow up during TB treatment. The researcher, also, wrote down the emerging thoughts.

- Step 3: arrange topics into columns headed as major, unique topics and or leftovers. The study included eleven (11) participants from which topics were clustered in a table headed as themes and sub-themes.
- Step 4: to allow categories and codes to emerge, code each topic and write codes alongside relevant text segments.

  Following the placement of topics as themes or sub-themes, the researcher returned to the data by condensing the topics into codes. It was aimed at ensuring credibility and trustworthiness of the study. Statements or excerpts within the transcripts that conveyed similar meanings were grouped under the same sentence units and assigned a common code.
- Step 5: the researcher then chooses the most descriptive words for the study and turns them into categories by arranging topics that are related into one category.

  All topics which were grouped together were checked for coherency. Grouping themes that are alike reduced the total list of categories.
- Step 6: a final abbreviation was assigned to each category, and the codes were then arranged in alphabetical order.

  After careful assessment of the notes, themes and sub-themes were generated.
- Step 7: data that are related, were arranged and preliminary analysis was performed.
- Step 8: where necessary, available data were recoded.

By following these steps, the researcher ensured a thorough and systematic approach to thematic analysis, providing valuable insights into the experiences of patients lost to follow up during TB treatment in Oshakati District.

3.9 Measures to ensure trustworthiness

Trustworthiness sometimes referred to as qualitative validity, denotes the application of procedures to ensure accuracy of the findings. In this study, five key data trustworthiness domains; credibility, dependability, confirmability, and transferability were ensured to maintain the integrity and reliability of the findings, following established qualitative research guidelines (28,58,59).

3.9.1 Credibility

Credibility refers to how the study findings represent reality, and it demonstrates a true reflection of the participants' experiences regarding the phenomenon under study (58). Credibility was enhanced by playing back portions of the recordings to participants for verification of their responses. Although informed consent obtained after participants agreed to take part reflected ethical compliance, it also contributed to building trust. Moreover, credibility was attained through prolonged engagement with participants and the use of individual, in-depth, face-to-face interviews. The researcher spent a significant time building rapport with participants and ensured that they felt comfortable and open during the interviews, leading to more honest and detailed responses.

The use of probing questions allowed for a deeper exploration of participants' experiences, ensuring that the data collected accurately reflected their realities. Additionally, member checking was employed, where participants were asked to confirm the accuracy of the information gathered during the interviews, further enhancing the credibility of the findings.

3.9.2 Dependability

Dependability alternatively referred to as reliability, denotes the provision of data to remain stable over time. It refers to the provision of evidence if the study was to be repeated with the same participant using the same methods, and applied to a matching context, the findings would be similar (28,58,59). This was ensured by using an audio recorder to capture all interviews and data were thematically analyzed according to Tesch's approach. Themes and sub-themes were generated. The researcher maintained an audit trail that recorded all steps taken during the study. This audit trail allows for the study's processes to be reviewed and evaluated, ensuring that the findings are consistent and could be replicated in similar studies.

3.9.3 Confirmability

Confirmability is defined as the degree to which study findings are a true representation of participants' experience and that the interpretation is not fuelled by the researcher's perspectives (28,58,59). In the context of the study, confirmability was ensured by maintaining objectivity in the study. The usage of a tape recorder also supported the efforts of ensuring confirmability as it allows the researcher to replay the records, reducing the risk of misinterpretation during the data analysis phase. Moreso, a thorough audit trail that documents decisions and steps taken throughout the research process. A reflection to field notes where non-verbal reactions were recorded also assisted with strengthening confirmability.

3.9.4 Transferability

Transferability refers to ability to apply the study findings to a different setting with similar situations (28). The study included participants who were knowledgeable about the topic under study, patient lost to follow up during TB treatment in Oshakati District. Participants’ responses and verbatim transcription were used. Further, transferability was maintained by the provision of the number of participants who were engaged in the study, methods utilized to collect data and the selection criteria of participants, also clarifying the scope and limits of the study’s applicability.

3.9.5 Authenticity

Authenticity refers to the extent to which the researcher indicates a range of realities in a fair and true manner (28). This was ensured by presenting the participants’ perspectives in a balanced and fair manner, ensuring that their voices were accurately represented without any distortion. This involved careful consideration of the diversity of experiences shared by the participants and the context in which their stories were situated, allowing for a more comprehensive and truthful representation of their experiences.

3.10 Ethical Considerations

The ethical clearance was obtained from the University of Namibia Decentralized Ethics Committee (UNAM DEC – DEC OSH 0077; Appendix A), also a permission to conduct the study was granted by the Ministry of Health and Social Services (Ref 22/4/2/3; Appendix B). The following ethical considerations were adhered to: principle of respect, principle of beneficence, and the principle of justice.

3.10.1 The principle of respect

Respondents' autonomy was respected throughout the study (28). Consequently, prior to data collection, the researcher made the participants aware of the purpose of the study, and he gave an additional explanation that participation in the study is voluntary, and they have the right to withdraw from the study without any consequence. Written informed consent was obtained from participants. Participants aged 18 years or older, who were able to understand the study information and voluntarily provide informed consent, were included in the study.

3.10.2 The principle of beneficence

It is important that the researcher secure the participants well-being by protecting them from potential harmful environment and discomfort whether physical, psychological, emotional, social and or legal (28). To ensure beneficence of the study, participants were informed of the benefit associated with the study which is aimed at exploring their experiences regarding their loss to follow up during TB treatment. No harm predicted in the study, however, it was anticipated that there was a likelihood for participants to feel guilt and self-blame. Fortunately, this did not happen, otherwise, those needing counselling would have been counselled by the researcher or referred for necessary care either to the Ministry of Health and Social Services or their chosen facilities. On the contrary, some participants expressed willingness to restart their TB treatment, hence, they were referred to nearby healthcare facilities for possible resumption of the treatment.

3.10.3 The principle of justice

The principle of justice refers to a participant’s right to fair selection, treatment and without prejudice (28). This was observed by ensuring that participant who meet the inclusion criteria were not discriminated based on their gender, ethnicity, or socioeconomic status. All respondents were given equal opportunities to participate in the study without any judgments. The researcher ensured that discussions during the interviews were conducted in a private and comfortable setting to protect participants' dignity and minimize any distress. Moreover, personal identifiers were kept confidential by anonymizing all data and using codes rather than names to prevent the likelihood of linking participants with data. Additionally, data was securely stored, and only the researcher had access to the raw data, ensuring that participants' privacy was protected throughout the study.

3.11 Chapter Summary

Chapter Three provided a detailed overview of the research methodology employed in this study, which aimed to explore the experiences of patients lost to follow up during TB treatment in Oshakati District, Namibia. The chapter outlined the research design, including the use of exploratory, descriptive, and phenomenological approaches, and justified the suitability of these methods for the study's objectives.

The chapter described the selection of participants using a non-probability, purposive sampling technique, focusing on individuals who were knowledgeable about the subject matter and met specific inclusion criteria. The data collection process involved conducting in-depth, face-to-face interviews and data analysis process were also highlighted. Issues of trustworthiness were also discussed. The chapter also detailed the ethical considerations that were carefully addressed, including obtaining the principle of respect, principles of beneficence and principle of justice. The next chapter, chapter four, presents the data analysis, presentations and discussions of findings.

CHAPTER FOUR

DATA ANALYSIS, PRESENTATION AND DISCUSSION OF FINDINGS

4.1 Introduction

Data analysis in this study followed a thematic approach, guided by the objectives of exploring the lived experiences of patients lost to follow-up during TB treatment and identifying strategies to improve adherence. The recorded interviews of all eleven (11) participants were transcribed verbatim to ensure accuracy and to preserve the authenticity of the participants' original expressions. Each transcript was then read multiple times to facilitate familiarization with the content. Significant statements were identified, and meanings were formulated from these statements, which were subsequently organized into emerging themes and sub-themes. The data were manually coded and categorized using a colour-coded system to enhance organization and clarity. Field notes taken during the interviews were reviewed alongside the transcripts to provide additional context and enrich interpretation. The process was inductive, allowing themes to emerge directly from the participants' narratives rather than being pre-determined. Bracketing was applied throughout the analysis to minimize researcher bias and ensure that interpretations remained grounded in the participants' perspectives.

4.2 Demographic information of participants

Table 2 below illustrates that the study included 11 participants, from diverse backgrounds and unique circumstances influencing their experiences with TB treatment. Data were collected through in-depth, individual interviews, with participants sharing their personal experiences related to loss to follow up during TB treatment. The data were collected at numerous sites in Oshakati District, depending on participants' preferences between February and August 2024.

Table 2: Demographic information of participants

Participant Number	**Gender**	**Age**	**Marital status**	**Educational level**	**Employment status**	**Lost to follow up after how many months?**	**Drug susceptible TB or Multi-drug resistant**
P1	Male	29	Married	Grade 8	Employed	3 months	Drug susceptible TB
P2	Female	33	Cohabiting	Grade 9	Unemployed	12 months	Drug-resistant TB
P3	Female	28	Cohabiting	Grade 12	Employed	11 months	Drug-resistant TB
P4	Male	43	Unmarried	Grade 10	Unemployed	10 months	Drug-resistant TB
P5	Male	27	Unmarried	Grade 6	Unemployed	14 months	Drug-resistant TB
P6	Male	19	Unmarried	Grade 7	Unemployed	12 months	Drug-resistant TB
P7	Female	26	Unmarried	Grade 8	Unemployed	3 months	Drug susceptible TB
P8	Male	29	Co-habiting	Grade 10	Employed	13 months	Drug-resistant TB
P9	Male	39	Unmarried	Grade 9	Unemployed	11 months	Drug-resistant TB
P10	Female	41	Unmarried	Grade 8	Unemployed	10 months	Drug-resistant TB
P11	Male	23	Unmarried	No formal education	Unemployed	12 months	Drug-resistant TB

Participant 1 was a 29-year-old male who was employed and married. Was lost to follow up after taking anti-TB medications for 3 months. His highest educational background was Grade 8. He was diagnosed with a drug susceptible TB.

Participant 2 was a 33-year-old female who was cohabiting and unemployed. With an educational background up to Grade 9 and lost to follow up after completing more than 12 months of TB treatment. She had drug-resistant TB.

Participant 3, a 28-year-old female, was cohabiting and employed. She had completed Grade 12 and had been lost to follow up after completing 11 months of treatment. She had drug-resistant TB.

Participant 4 was a 43-year-old male who was unmarried and unemployed, with a Grade 10 education. This participant discontinued their treatment after completing 10 months of treatment. He was classified as having drug-resistant TB.

Participant 5, a 27-year-old male, was unmarried and unemployed, with only a Grade 6 education. He had completed 14 months of TB treatment before getting lost to follow up. Like for participants 2, 3, and 4, participant 5 had drug-resistant TB.

Participant 6 was a 19-year-old unmarried and unemployed male who had completed Grade 7. He was classified as lost to follow up after defaulting on his TB medication following 12 consecutive months of treatment. Initially diagnosed with drug-susceptible TB, he later developed resistance to key anti-TB medications.

Participant 7, a 26-year-old female, was unmarried and unemployed, with a Grade 8 educational background. Was lost to follow up after taking medication for TB for 3 months. Had a drug susceptible TB.

Participant 8 was a 29-year-old male who was cohabiting and employed, with a Grade 10 education. He had defaulted on his treatment after taking the medication for 13 months. He was classified as having drug-resistant TB.

Participant 9, a 39-year-old male, was unmarried and unemployed, with a Grade 9 education. He missed his scheduled appointments since taking medication for 11 consecutive months. He was classified as having drug-resistant TB.

Participant 10 was a 41-year-old female who was unmarried and unemployed, who managed to complete Grade 8 education. Was on treatment for 10 months, thereafter, was lost to follow up. She had drug-resistant TB.

Participant 11 was a 23-year-old male who was unmarried and employed, with no formal education. He had missed his TB treatment since taking medication for 12 consecutive months. Like many others, he was diagnosed with drug-resistant TB.

Each participant's background and circumstances have played a significant role in their experience with TB treatment, highlighting the complexity of factors influencing treatment adherence.

4.3 Experiences of patients lost to follow up during TB treatment

Thematic analysis of the interview data, following repeated and thorough readings of the transcripts, led to the identification of two main themes aligned with the study objectives: (1) Experiences of patients lost to follow-up during TB treatment, and (2) Potential strategies to improve patient adherence. These two overarching themes were further broken down into a total of eleven sub-themes, as presented in Table 4.2. Under the first theme experiences six sub-themes emerged: financial constraints, stigma and social isolation, lack of support systems, pill burden and side effects, poor health education, and challenges with healthcare provider attitudes. These sub-themes reflect the complex personal, social, and systemic factors that contributed to treatment interruption.

The second theme, potential strategies to improve adherence comprised five sub-themes: financial support programmes, stigma reduction initiatives, enhanced patient education, improved healthcare access and patient-provider communication, and the involvement of Community Health Workers (CHWs) for ongoing support and follow-up. These strategies, derived from the participants' own perspectives, provide insight into feasible, context-specific interventions aimed at improving retention in TB care. The following sections present a detailed discussion of each theme and its associated sub-themes, organized according to the two main study objectives.

Table 3: Themes and sub-themes

Themes	Sub-themes
4.3.1. The personal experiences of TB patients in Oshakati District	4.3.1.1. Financial constraints
	4.3.1.2. Stigma and social isolation
	4.3.1.3. Lack of support systems
	4.3.1.4. Pill burden and side effects
	4.3.1.5. Poor health education
4.3.2. The potential strategies to improve patient adherence	4.3.2.1. Financial support programs
	4.3.2.2. Reducing stigma
	4.3.2.3. Enhanced patient education
	4.3.2.4. Improved healthcare access
	4.3.2.5. Patient counselling and support
	4.3.2.6. Community Health Worker involvement

Table 4: Theme and sub-themes for objective 1 – Experiences of TB patients lost to follow-up in Oshakati District

Main theme	**Sub-themes**
4.3.1. The personal experiences of TB patients in Oshakati District	4.3.1.1. Financial constraints
	4.3.1.2. Stigma and social isolation
	4.3.1.3. Lack of support systems
	4.3.1.4. Pill burden and side effects
	4.3.1.5. Poor health education

Table 5: Theme and sub-themes for objective 2 – Potential strategies to improve TB treatment adherence

Main Theme	**Sub-themes**
4.3.2. The potential strategies to improve patient adherence	4.3.2.1. Financial support programmes
	4.3.2.2. Reducing stigma
	4.3.2.3. Enhanced patient education
	4.3.2.4. Improved healthcare access
	4.3.2.5. Patient counselling and support
	4.3.2.6. Community Health Worker involvement

4.4 Findings

4.4.1 Theme 1: The personal experiences of TB patients in Oshakati District

Theme 1 focuses on the lived experiences of TB patients in Oshakati District who were lost to follow up in the course of their treatment. This sub-section aims to reveal and describe the peculiar difficulties and obstacles that the patients experienced, and which drove them to interrupt their treatment. The proposed studies will aim to explore these experiences in depth to better understand the factors influencing adherence to TB treatment, particularly within the context of Oshakati District. Insights gained will help guide the development of future intervention strategies aimed at enhancing treatment adherence in similar settings.

4.4.1.1 Sub-theme 1: Financial constraints

Economic challenges were a major issue to treatment adherence of TB patients in Oshakati District. Participant 5 recounted their battle, "*When I started with TB treatment in the beginning days… I was living near the clinic. But later I had to go and live in the village. Transporting myself to the clinic was a challenge and this led me to miss appointments at times,*" he says. This was also explained by Participant 9 who added that "*Visiting the clinic every time was weighty; I could not keep up with my small income.*" Participant 2 voiced this sentiment, "*I know how important my treatment is but I could not afford to go to the clinic that often, I even had to miss my appointments so I could have money for other important stuff*".

Although anti-TB medication and investigation are provided free of charge in Oshakati District, the study found that patients and their families incurred direct and indirect costs including costs of transportation, dietary supplements, loss of income and expenditure on hospital admission. TB patients' experiences in Oshakati District provide insight into the broader issue of how economic barriers impact on health behaviour. Lack of money was commonly mentioned as a key reason that prevented patients from staying on treatment.

The experiences reported by the participants in this study are reflective of these broader research findings. For example, participants frequently mentioned that the high costs associated with TB treatment, including medication and transportation, were significant barriers to their adherence. These personal accounts illustrate how financial challenges can directly impact patients' ability to consistently follow their treatment plans.

The financial burden of TB patients in Oshakati District is not an isolated finding in health-related research. The convergence of this personal experience with what the research literature has demonstrated more widely is the lamentable societal obstacle posed by economic barriers to health care compliance and outcomes.

4.4.1.2 Sub-theme 2: Stigma and social isolation

Stigmatization and social isolation were reported as common and affected the adherence of TB patients. Participant 3 explained, "*It made me feel embarrassed to go to the clinic, things were said about me behind my back which made me stop going, you know, to come in for regular check-ups.*" Participant 10 supported this when he stated, "*The fear of being criticized and ostracized by my community played a role in seeking healthcare. ...I didn't deserve to be saved.*" Participant 6 also added "*One felt very lonely and avoided people because of the stigma of TB; and would make it even more difficult to adhere on taking your medication*".

The testimony of the study subjects underscores the devastating effects of stigma on their ability to access and use TB care.

Participants often spoke of stigma around TB influencing their willingness to seek treatment and adhere to it. For example, Participant 2 explained, “*I felt embarrassed and did not want to tell anyone that I became unwell, so I just avoided the clinic.*” Participant 5 also described this feeling, “*I was afraid of other people’s judgment, which motivated me to quit my treatment.*” Likewise, Participant 8 added, “*I was scared of what the neighbours will say so I stopped walking to the clinic.*

These personal narratives are consistent with the literature's findings that the social stigma of TB may produce profound psychological suffering. Stigma often includes shame and social isolation, which inhibit patients from seeking healthcare, as well as isolating from communities. The stigma takes a toll not only in terms of its effect on the patient’s mental health, but it also helps to maintain the cycle of non-adherence by further erecting barriers to care.

In addition, stigma can influence a broad set of negative consequences, such as decreased health-care utilization, lower willingness to adhere to prescribed courses of treatment and schedules. The experiences of the respondents demonstrate how stigma can undermine successful management of the disease by discouraging people from attending health appointments and following through on treatment plans.

The resonance between the participant narratives and literature overall underscores the entrenchment of stigma and impact on adherence to TB treatment. Reducing the stigma and its effect on patients' health behaviours are key to enhancing treatment results and enabling patients to gain access to and adhere to their requisite care.

4.4.1.3 Sub-theme 3: Lack of support systems

The absence of support networks was found to be a key factor in treatment compliance. Participant 7 explained: "*I didn't have anybody to tell me to take my medicine or to take me to the clinic and that would make me forget and missing appointments.*" Participant 2 expressed similarly: "*Lacking family or friends to guide me through treatment I sometimes felt lost and abandoned.*" Participant 11 further added "*I was fighting on my own and it made it harder because I did not have a support network to rely on*".

These voices are echoed by the evidence base which support that social support can influence treatment adherence. It is well documented that patients who receive emotional and practical support, are more likely to maintain adherence to treatment. Encouragement, reminders and assistance in accessing health care resources, are all extremely important for encouragement and support, and family, friends and community are all support systems for these survivors.

Conversely, participant 5 stated "*I, well I had family support. My mum and sister were there for me. They did everything they could to make me keep up with my treatment, but I was very much involved in my social life as a musician, so I also did not have so much time or cared enough.*" This guidance assists patients with the hurdles associated with adherence to treatment and barrier management.

This lack of strong support networks among the participants highlights an important deficiency in healthcare plans. The experiences of the study participants are in line with a general trend reported in the literature, which suggests that individuals with less social support are less likely to adhere and exhibit poorer health outcomes. The inclusion of social support into medical regimens is necessary for better compliance and response to treatment.

The absence of robust support systems among the participants underscores a crucial gap in healthcare strategies. Integrating social support into healthcare strategies is essential for improving adherence and overall treatment success. This could include the development of community-based services offering patients emotional and practical support (e.g., peer support groups, home visiting, and support with transport and medication management). Providers can improve patient adherence and treatment outcomes by addressing the need for support systems.

4.4.1.4 Sub-theme 4: Pill burden and side effects

Pill burden of TB regimens and TB treatment side-effects were mentioned as main reasons for loss to follow up during TB treatment. Participant 1 "*They were like massive pills. I used to struggle sometimes to get them down." I used to take a handful of medicine. I only hope someday in future they release a tablet.*" Participant 6 also explained, "*at the beginning of the treatment, the side effects were horrible. Nearly always I was nauseous, and had a general sense of body weakness, while some days I was dizzy. It really made me ask myself if the treatment was worth it.*"

Furthermore, Participant 4 noted "*well, I used to hide my medicine under the pillow because I could not swallow them, they made it too big*". Participant 9 also said: "*it was hard to move the joints," and "I could not stand my joint. They were sore. When I was on those tablets, I was insanely tired and had the added bonus of breathing issues so that really did not help things that I was not sure what was going on and why. So, I decided not to take medicine, and stopped going to the hospital.*"

Patients in the study expressed challenges juggling their pill burden and side effects. These findings are in line with studies indicating that pill burden, side effects and complexity of TB treatment regimens can act as a major hindrance towards adherence. It is well documented from studies that, drug side effects are significantly associated with loss to follow up as side effects increase the chance of stopping TB therapy.

TB patients, and especially patients with drug-resistant TB, have to endure a long and complicated treatment regimen with several drugs, leading to physical and psychological struggles. High pill load has been identified as a main reason to be associated with non-adherence to treatment among TB patients. On the other hand, the high pill burden and associated side effects of tuberculosis medication have been identified as significant contributors to treatment non-adherence. TB medication is commonly associated with side effects such as stomach pain, joint discomfort, nausea, and fatigue. These adverse effects can discourage patients from continuing treatment, especially when they interfere with daily functioning or when patients perceive the medication as causing more harm than benefit, ultimately leading to non-adherence or premature discontinuation of therapy. In addition to physical side effects, patients often develop psychological barriers to adherence, such as fear of continued discomfort, anxiety about taking medication, or loss of motivation due to prolonged illness. These psychological responses can significantly contribute to initial LTFU, particularly when patients associate treatment with worsening symptoms or emotional distress. In addition to experiencing symptoms such as skin rashes, many participants reported physical discomfort and a lack of confidence in managing everyday responsibilities, including work and family duties. These challenges were significant enough to lead some to miss doses or even consider discontinuing treatment altogether.

The challenges cited by patients demonstrate the need for interventions to streamline treatment regimens. Simpler regimens, approaches that may result in fewer drugs provided to the patient that would reduce the cognitive burden on the part of the patient, are likely to promote drug adherence. Moreover, if patients received better support arrangements such as clear instructions, reminders and aids, it could contribute to increasing their capability to self-manage their treatment.

4.4.1.5 Sub-theme 6: Poor health education

Poor health education was identified as a barrier to adherence. Participant 8 noted, *"I did not fully understand why I needed to complete the full course of treatment, which made me question the importance of following through."* Participant 11 supported this, saying, "*The lack of clear information about TB and its treatment made it hard for me to stay committed."* Participant 3 also shared, *"Without proper education, I was not aware of the consequences of stopping treatment early, which led me to miss doses."* Participant 10 hinted that *"I felt better after taking my medication for three months. Thus, I felt it was pointless to continue with treatment."*

Participant 2 echoed that *“I received health education on importance of taking medication when I was first diagnosed with TB. They even told me that I will take my medication for six months. But then when I came back just to be told I have resistant TB, they did not tell me how long I will take my medicine.”* This was disputed by Participant 4 who said “*nurses are good. They told me everything about TB and the duration of taking medicines.”*

The narratives of the participants serve to emphasize the importance of health education in patient adherence to treatment. The lack of health literacy results in a wide discrepancy in the patients' knowledge levels regarding their disease and treatment. Patients may find it difficult to adhere to self-management plans when they do not have sound and complete information about their illness and its management.

The experiences of the study participants in the light of these findings deftly illustrate how suboptimal health education can minimise barriers to follow through their treatment. For example, some participants reported confusion about when to take their medications, and what would happen if they missed doses. This knowledge gap in patients can contribute to non-adherence if they do not understand the risk thereof and how to manage their treatment effectively. Hence, the experiences shared by these participants reflect the realities encountered in everyday practice, highlighting the need for comprehensive health education initiatives that promote treatment adherence. Such education could serve as a key strategy in improving patient understanding, engagement, and sustained commitment to completing TB treatment.

4.4.2 Theme 2: The potential strategies to improve patient adherence

Theme 2 seeks to describe and suggest options to improve adherence of patients with TB to treatment in Oshakati District. The importance of this theme is that it seeks to fill gaps which were identified in the TB patients' personal experiences, as noted in Theme 1, as well as finding how possible this can be, to practically achieve improving treatment adherence rates.

4.4.2.1 Sub-theme 1 Financial support programs

Economic challenges were suggested to be countered with financial support schemes. Participant 2 proposed, "*Making financial support available for transportation can reduce some of the pressures.*" Interviewee 4 reflected this sentiment, "*Offering subsidies or monetary help could change the way patients adhere to their treatment.*" Participant 9 also stated, "*Financial support for those experiencing cost-related difficulties may help in ensuring good treatment adherence.*"

These results were supported by the participants' ideas for how to operationalise financial support programs. They suggested that targeted financial aid can lower the patient's out-of-pocket treatment costs by addressing financial barriers. This assistance can help to alleviate the financial burden on patients and serve as an incentive to continue their treatment.

The association of monetary support with better adherence is also reinforced by participant experiences and perceptions about how financial constraints can compromise health care decisions. The study indicates that financial assistance is not only beneficial in helping to manage treatment expenses but can also lead to improved adherence as the main obstacle preventing patients from receiving continuous care is taken away. This alignment with the literature emphasizes the need for financial incentives to be included in health care plans to optimize patient outcomes.

4.4.2.2 Sub-theme 2: Reducing stigma

Stigma reduction was highlighted as a key approach. Participant 9 recommended, "*Re-education efforts within the community can help diminish stigma and encourage more people to seek and continue treatment.*" Participant 7 also stated "*There could potentially be a big difference in adherence rates by addressing stigma through education and community engagement.*" Participant 3 also mentioned, "*Reducing stigma is key for patients to feel free to say they need help and not feel ashamed of being supported on their care path".*

Incorporating messages to reduce stigma in typical community health education initiatives establishes a more supportive context for patients, thereby also promoting adherence and use of health services. This way, the negative attitude that the community holds against TB can be tackled and peace of mind can be restored to the patient regarding his or her condition and the treatment. This realization is reflected in the suggestions from participants to work towards meeting the specific challenges relating to stigma and providing appropriate support to patients. This is important in order to create an atmosphere in which patients are more inclined to follow their treatment plan and attain better health.

4.4.2.3 Sub-theme 3: Enhanced patient education

Better patient education was reported as a means to increase adherence. Participant 3 suggested, "*More information would encourage patients to appreciate why adherence is important and persuades them to do so"*. Participant 7 concurred, "*Educational programs must be personalized so a patient understands the value of the treatment procedure"*. Participant 11 also stated, "*If we could do a better job educating patients about what they have and what is needed for treatment, then they can get more motivated to stay in treatment.*"

The recommendations to enhance patient education are consistent with the literature that underscores the importance of good health education in adherence to treatment. Formal health education programs can greatly improve patients' understanding of their disease and the tremendous importance of maintaining adherence to prescribed therapies. Educational interventions like these generally result in better-informed, more motivated and better-prepared patients to follow their treatments.

Educational interventions targeted at the varied needs of patients can help patients to increase their knowledge and therefore accept and manage their illness. The emphasis placed by participants on patient-centred education suggests that such interventions are not only beneficial but also essential for promoting consistent and effective treatment adherence. This approach outlines a method through which the patient is provided with sufficient information to successfully adhere to and complete treatment.

4.4.2.4 Sub-theme 4: Improved healthcare access

Improved healthcare access was identified as a key strategy. Participant 5 noted, *"Sometimes you may have a busy day on your follow up day and you might only get time after clinic operational hours. You may miss your appointment as the clinic closes at 5 O'clock PM. Therefore, ensuring that clinics are consistently open and accessible would help patients keep up with their treatment."* Participant 9 added, "*Expanding clinic hours and reducing waiting times could make a big difference in adherence rates."* Participant 1 also suggested, "*Making healthcare services more readily available and accessible would support better treatment adherence. Perhaps they can consider boxes that can be accessed by patients at their convenience just like other people who collect monthly medications."*

These findings corroborate with the participants recommendations on enhancing the accessibility of healthcare, such as extended clinic hours and reduced clinic wait times. The removal of such obstacles can help health care organizations enable improved care access and thereby increase patients' treatment compliance. This focus on quality of care, and specifically on enhancing the delivery of health services, is in accordance with literature calling for system changes to make health care more patient centred and responsive to the needs of the patient.

Enhanced access to health care contributes to patients' adherence to their prescribed treatment and increases the likelihood that patients will not miss appointments or discontinue treatment. The advice offered by those who participated highlights an important facet of healthcare service delivery, namely the direct connection between accessible healthcare and adherence to sustained treatment.

4.4.2.5 Sub-theme 5: Patient counselling and support

Patient counselling and support were realized as important measures. Participant 4 noted "*I believe that monthly counseling may be necessary for emotional support to continue to strive,*". Participant 6 added that "*support groups and counseling can assist the patients to cope with the psychological impact of their disease and treatment.*" Participant 2 also recommended, "*The availability of counselling services may be useful for patients to deal with the stress they might face in the course of the treatment.*"

Counselling may support patients to manage the psychological aspects of their condition, offering them space to be heard about fears, worries and any other emotional obstacles that could hamper adherence. Recommendations for incorporating holistic counselling and support services into activity programs are illustrated by these study findings. The recommendation to enhance counselling highlights the importance of addressing both the emotional and psychological dimensions of treatment adherence. This helps ensure that patients receive the conductive advice they need to commit to treatment, and improve overall health results.

4.4.2.6 Sub-theme 6: Community Health Workers involvement

The engagement of Community Health Workers (CHWs) was suggested as one of the strategies. Participant 1 commented, "*We recognize the role of community health workers in our society in terms of monitoring of patients, reminders and motivation but they need* *to be more visible*". Participant 11 agreed that, "*Involving a community health workers could help fill the gap between patients and health care.*" Participant 8 also noted, "*Community health workers can provide ongoing support and follow up which may contribute to treatment adherence.*"

The participant did mention the important role that Community Health Workers (CHWs) play in encouraging treatment adherence by providing education, motivation, and ongoing support to patients managing their tuberculosis (TB) regimens. Their close proximity to patients both geographically and socially allows them to better understand the personal and contextual challenges patients face. This positions CHWs to address specific barriers such as stigma, misinformation, or logistical difficulties that may hinder adherence.

The suggestions made by participants for engaging Community Health Workers (CHWs) illustrate the various ways in which CHWs can play a beneficial role in supporting treatment adherence. By maximising the capabilities of community health workers, health systems can enhance patient engagement and adherence, resulting in improved health outcomes.

4.5 Chapter Summary

Chapter Four discusses the experiences of TB patients lost to follow-up (LTFU) in Oshakati District, highlighting the challenges that contributed to their treatment default, as well as their suggestions for strengthening future approaches to treatment adherence. According to participants, financial difficulties, stigma, absence of support, the high pill burden and side effects of the TB treatment, as well as minimal health education, were among the major barriers to adhere to their treatment. Solutions for identified challenges are also covered in this chapter. It details the importance of financial support, strategies to lower societal stigma, bolstering patient health literacy, better access to health care, patient counseling, and the involvement of Community Health Workers., These tactics are designed to create a more conducive atmosphere and foster greater treatment adherence.

CHAPTER FIVE

DISCUSSION OF FINDINGS, SUMMARY, CONCLUSION RECOMMENDATIONS AND LIMITATIONS

5.1 Introduction

Chapter Five presents a synthesis of the study's key findings and their implications. It brings together the individual experiences of patients lost to follow-up during TB treatment in Oshakati District and outlines the participant-proposed interventions to improve adherence. The chapter also addresses the limitations of the study, offers recommendations for practice and policy, and suggests areas for future research. Through a critical reflection on the data and its broader significance, Chapter Five provides an integrated discussion of the study's contribution to the understanding and improvement of TB treatment adherence within the Oshakati District context.

5.2 Discussion of findings

5.2.1 Theme 1: The personal experiences of TB patients in Oshakati District

5.2.1.1 Sub-theme 1: Financial Constraints

The data reveals that economic hardship significantly contributed to LTFU among TB patients in Oshakati District. These findings are in line with those by Ukwaja et al. (14), who demonstrated that providing economic support improved TB treatment outcomes in rural Nigeria. Similarly, Moreira et al. (52) confirmed that catastrophic costs are a major deterrent to adherence, especially in low-resource settings. Opperman and Du Preez (32) further found that indirect costs such as transport and nutrition were critical barriers to sustained treatment.

Tola et al. (9), in a systematic review, observed that financial hardship was a key cause of non-adherence across developing countries. Fuady et al. (42) argue that achieving universal social protection is crucial to preventing treatment abandonment. In Namibia, Amkongo et al. (68) also noted that financial limitations contributed to unsuccessful TB outcomes in northern regions. Biermann et al. (74) pointed out that transport costs and income insecurity discouraged case follow-up in community TB programmes. Lastly, McNabb et al. (72) demonstrated that long travel distances and associated costs in South Africa strongly correlated with LTFU among drug-resistant TB patients.

5.2.1.2 Sub-theme 2: Stigma and Social Isolation

The data reveals that stigma and fear of social rejection discouraged patients from continuing their TB treatment. These findings are in line with those by Dixit et al. (35), who linked stigma with depression and reduced treatment completion in Nepal. Tola et al. (9) also found stigma to be a recurrent cause of LTFU in TB patients. Akeju et al. (40) documented similar experiences in Gauteng, South Africa, where stigma resulted in isolation and poor outcomes.

In Tanzania, Kapyolo et al. (64) highlighted the profound impact of TB-related stigma on health-seeking behaviour. Hayward et al. (56) emphasised the need for multi-level stigma interventions co-designed with patients. Nabisere-Arinaitwe et al. (36) noted how stigma among co-infected TB-HIV patients reduced willingness to continue care. Anindhita et al. (55) found that community-based psychosocial support was effective in mitigating stigma and improving adherence. Appiah et al. (69), in Ghana, concluded that stigma remained a persistent barrier even in well-resourced treatment programmes.

5.2.1.3 Sub-theme 3: Lack of Support Systems

The data reveals that poor or absent support systems hindered treatment adherence. These findings are in line with those by Lutfian et al. (53), who showed that family support improved both adherence and quality of life. Makabayi-Mugabe et al. (50) found that community-based DOTS improved treatment outcomes through direct social support. Kilima et al. (48) highlighted how peer and family support structures helped patients during and after TB treatment in Tanzania.

Wilder et al. (51) showed that social determinants such as support networks influenced medication adherence. Tok et al. (33) reported that patients with strong familial bonds were less likely to default. Dilas et al. (47) found that health education mediated through nurses improved adherence when coupled with family support. Mishra et al. (37) noted that in tribal communities of India, absence of family support contributed to LTFU. Anthoney et al. (34) similarly emphasised that support from family and health workers was a key facilitator of adherence in Peru.

5.2.1.4 Sub-theme 4: Pill Burden and Side Effects

The data reveals that high pill burden and side effects caused physical discomfort and psychological distress, leading to treatment discontinuation. These findings are in line with those by Kim et al. (62), who found that financial hardship compounded by side effects led to poor adherence. Tola et al. (9) identified pill burden and adverse effects as significant drivers of LTFU. Opperman and Du Preez (32) noted that medication side effects made patients question the value of continuing treatment. Tok et al. (33) also found that fear of side effects prompted patients to abandon treatment early. Soedarsono et al. (65) confirmed that drug-resistant TB patients faced psychosocial and economic side effects that influenced LTFU.

Chaidir et al. (27) highlighted the role of visual education in improving comprehension of side effects, thereby promoting adherence. Khaitan et al. (20) reported that patients often stated they preferred to die than continue with pills that induced intense suffering. Pradipta et al. (67) found that simplifying treatment and managing side effects were critical strategies for improving adherence in Indonesia.

5.2.1.5 Sub-theme 5: Poor Health Education

The data reveals that insufficient or inconsistent health education undermined patients' understanding of the importance of completing treatment. These findings are in line with those by Shahid et al. (45), who found that low health literacy correlated with poor health outcomes. Tola et al. (9) identified inadequate education as a key factor in non-adherence. Dilas et al. (47) showed that when nurse-led education was combined with psychosocial support, adherence rates improved significantly. Watumo et al. (26) observed that poorly explained treatment instructions led to confusion and LTFU.

Venokulavo (41) in northern Namibia documented that many patients defaulted because of limited health information. Chaidir et al. (27) found that culturally tailored visual media improved knowledge among MDR-TB patients. Mishra et al. (37) identified a widespread misunderstanding of TB progression due to poor communication. Nezenega et al. (66) concluded that structured and comprehensive education is critical in TB adherence interventions in Ethiopia.

5.2.2 Theme 2: The Potential Strategies to Improve Patient Adherence

5.2.2.1 Sub-theme 1: Financial Support Programs

Participants strongly recommended financial support mechanisms such as transport subsidies, food parcels, and conditional cash transfers to improve adherence. For example, Participant 2 highlighted the importance of support for transport costs, while Participant 9 emphasised financial help for those facing economic hardship. The data reveals that the alleviation of financial burdens is central to improving patient adherence. These findings align with those by Ukwaja et al. (14), who found that economic support interventions in rural Nigeria significantly enhanced TB treatment outcomes.

Similarly, Fuady et al. (42) underscore the role of social protection in reducing catastrophic costs for TB patients. Mburu et al. (54) also caution against punitive approaches to LTFU and instead advocate for rights-based financial interventions. Consistently, Wilder et al. (51) and Moreira et al. (52) demonstrate that financial constraints are powerful determinants of non-adherence, and their mitigation leads to more consistent engagement with care. These studies affirm the participant view that financial assistance is not merely supportive but foundational to sustained TB care.

5.2.2.2 Sub-theme 2: Reducing Stigma

Participants recognised that stigma limits help-seeking and adherence, advocating for re-education and community engagement. Participant 3 highlighted that stigma suppresses disclosure and leads to avoidance of care. The data reveals that stigma has both social and psychological implications that limit adherence, and these findings are in line with those by Dixit et al. (35), who reported that stigma and depression were linked to reduced quality of life and poor adherence among TB patients. Anindhita et al. (55) also highlight the importance of psychosocial interventions in reducing stigma and improving mental health.

Similarly, Hayward et al. (56) documented that co-designed stigma interventions contributed to patient empowerment in South Africa. In a Namibian context, Amkongo et al. (68) confirmed that perceived stigma was a barrier to treatment adherence. Therefore, reducing stigma through education and cultural sensitivity remains an essential part of improving adherence outcomes.

5.2.2.3 Sub-theme 3: Enhanced Patient Education

Participants suggested that improved, patient-centred education could foster understanding and commitment. Participant 11 remarked that education clarifies the nature of the illness and the purpose of treatment, enhancing motivation. The data reveals that inadequate health literacy impairs patients' ability to comply with their treatment, and these findings are in line with those by Shahid et al. (45), who observed that low health literacy significantly affects patient outcomes. Educational interventions, as highlighted by Chaidir et al. (27), also enhance understanding of TB among patients and caregivers.

Similarly, Dilas et al. (47) demonstrate that nurse-led education improves adherence through its mediating effect on quality of care. Law et al. (46) further advocate for educational strategies to ensure retention and engagement in TB treatment, especially among drug-resistant patients. Thus, tailored education is indispensable for empowering patients to follow through with their treatment plans.

5.2.2.4 Sub-theme 4: Improved Healthcare Access

Participants recommended expanded clinic hours, reduced wait times, and decentralised access points. Participant 5 suggested that longer clinic hours could reduce missed appointments, while Participant 1 proposed easier medication access. The data reveals that limited service accessibility constrains adherence, and these findings are in line with those by McNabb et al. (72), who found that long travel distances and centralised services were key contributors to LTFU in South Africa.

Similarly, Park et al. (73) documented improved treatment outcomes following the implementation of integrated patient management and accessible services. Msoka et al. (39) also linked socio-geographic barriers to poor service utilisation in East Africa. Such findings reinforce that restructuring service delivery to meet patient realities is crucial for promoting adherence in TB care.

5.2.2.5 Sub-theme 5: Patient Counselling and Support

Participants expressed the need for emotional and psychological support through counselling. Participant 4 emphasised monthly counselling, while Participant 6 recommended support groups. The data reveals that counselling addresses internalised distress and improves adherence, and these findings are in line with those by Tola et al. (9), who linked psychosocial stressors to TB treatment non-adherence. Similarly, Opperman and Du Preez (32) identified a lack of emotional support as a factor in LTFU. Akeju et al. (40) noted that counselling created a space for TB patients to process their experiences, reducing default. Moreover, Makabayi-Mugabe et al. (50) found that integrated support mechanisms, including counselling, led to better treatment outcomes.

Counselling therefore plays a central role in managing the emotional demands of long-term treatment.

5.2.2.6 Sub-theme 6: Community Health Worker (CHW) Involvement

Participants advocated for CHW engagement to bridge gaps in care. Participant 1 noted their role in monitoring and motivating patients. The data reveals that CHWs serve as crucial mediators between health systems and patients, and these findings are in line with those by Sejie and Mahomed (49), who found that community TB care programs were effective in promoting adherence. Similarly, Tok et al. (33) and Wilder et al. (51) support the involvement of CHWs in delivering personalised care and reducing health system inefficiencies.

CHWs also feature in the work of Haldane et al. (75), who demonstrated that health workers in rural areas can bolster access and continuity of care. By offering logistical help, reminders, and social encouragement, CHWs are uniquely positioned to help patients navigate and complete TB treatment.

5.3 Summary of findings

The findings of the study on TB patients who were lost to follow-up in Oshakati District revealed a complex interaction of social, economic, psychological, and systemic factors that significantly undermine treatment adherence. Central to these experiences were financial constraints, which emerged as one of the most pressing barriers to completing the treatment regimen. Patients frequently reported that they had to prioritize immediate survival needs, such as securing food for themselves and their families, or finding money for basic household necessities, over the long-term goal of completing TB treatment. For many, the cost of transportation to health facilities proved to be particularly challenging. In situations where public transport was either unavailable or unaffordable, patients were forced to walk long distances, which often discouraged them from attending appointments or collecting medication. The cumulative effect of these financial struggles created a perception that treatment was less of a priority when compared to the daily fight for survival. Consequently, disengagement from care was not necessarily a matter of unwillingness, but rather a reflection of the socio-economic environment in which patients lived.

Beyond financial challenges, the issue of stigma was consistently highlighted as another major factor leading to treatment discontinuation. The fear of social ostracization was deeply rooted in cultural beliefs and communal interactions, where illness was not merely seen as a health condition but as something that diminished social standing. The internalization of this stigma left patients emotionally burdened and discouraged from seeking continued care, even when they understood the risks of abandoning treatment.

The absence of strong support systems further compounded the struggles faced by patients who were lost to follow-up. Many of the participants in the study expressed feelings of isolation, as they were left to manage demanding treatment regimens without adequate social or emotional assistance. Poverty and family neglect frequently worsened these circumstances, as some patients had no one to remind them to take their medication or accompany them to health facilities. The lack of family encouragement also meant that patients bore the psychological weight of the illness alone, which often resulted in frustration, despair, and eventual withdrawal from treatment. In households already struggling to meet basic needs, TB patients were sometimes regarded as a burden, further reinforcing their sense of exclusion. This absence of emotional and material support weakened resilience and made it more difficult for patients to adhere to the lengthy treatment process.

Another critical finding of the study was the overwhelming nature of the TB treatment regimen itself. Patients frequently described the pill burden as exhausting, with the daily intake of multiple tablets becoming physically and mentally draining over time. Added to this was the challenge of side effects, which ranged from mild discomforts such as nausea and fatigue to more severe and debilitating reactions. For some, the treatment felt more harmful than the disease itself, prompting them to discontinue their medication. These experiences illustrate how the structure and demand of the treatment program contributed directly to non-adherence, particularly in cases where side effects were poorly managed or inadequately explained by healthcare providers.

Limited health literacy also featured prominently among the challenges encountered by patients lost to follow-up. The study found that many participants lacked a comprehensive understanding of tuberculosis, its transmission, and the importance of completing treatment. Misconceptions about the disease and doubts about the effectiveness of the medication undermined confidence in continuing care. Some patients expressed scepticism regarding whether the treatment would truly lead to a cure, while others believed that they were healed once their symptoms subsided and therefore saw no reason to continue taking medication. The absence of adequate health education contributed to these misconceptions, leaving patients poorly equipped to make informed decisions about their care. Without sufficient knowledge, motivation to adhere to the treatment regimen was significantly diminished, particularly when patients were already contending with stigma, side effects, and financial challenges.

In light of these findings, the study emphasized the need for strategies that directly address the structural and perceptual challenges faced by TB patients in Oshakati District. One of the key recommendations was the establishment of financial support programmes to mitigate the economic constraints that prevent patients from accessing care. Transport allowances and food assistance were identified as practical interventions that could reduce the burden of costs associated with treatment. By ensuring that patients did not have to choose between basic needs and healthcare, such initiatives could increase the likelihood of continuous treatment adherence. The study also underscored the importance of tackling stigma through targeted community education campaigns aimed at reshaping public perceptions of TB. Reducing stigma would not only alleviate patients' fear of disclosure but also create a more supportive environment for those undergoing treatment.

Improving health education was also highlighted as a vital strategy to enhance treatment adherence. By equipping patients with accurate information about tuberculosis and the necessity of completing the full course of medication, healthcare providers could strengthen patients' confidence in treatment and their personal motivation to persist. This could be achieved through regular counselling sessions, educational materials, and patient-centred communication that emphasizes the long-term benefits of adherence. Equally important was the call to improve the accessibility of healthcare services. Suggestions included extending clinic hours, decentralizing medication collection points, and creating flexible service delivery models that accommodate the diverse needs of patients. These measures would reduce structural barriers, normalize health-seeking behaviour, and foster continuity of care.

The provision of psychosocial support was also identified as a crucial component of improving treatment adherence. Counselling services, peer-support groups, and family-centred interventions could provide the emotional scaffolding necessary to help patients cope with the psychological and social burdens of TB treatment. By fostering a sense of belonging and shared experience, psychosocial support can empower patients to remain committed to their treatment journey. Additionally, the integration of Community Health Workers (CHWs) into TB programs was strongly recommended, recognizing their vital role in monitoring patients, providing reminders and motivation, and highlighting the need for them to be more visible within our society. Through their close proximity to patients, CHWs are able to identify challenges early and provide timely interventions that prevent treatment discontinuation.

5.4 Conclusion

The objective of this study was to explore the personal experiences of tuberculosis (TB) patients who were lost to follow-up during treatment and to identify strategies that could enhance treatment adherence. The results are important for pinpointing the experiences experienced by a patient and how there can be actionable strategies to improve the adherence to treatment. Several personal characteristics that affect adherence in TB patients are described in the study. The financial barriers were severe, with patients often prioritising immediate financial needs over their own health and treatment adherence. Stigma and social isolation compound the problem such that patients were unwilling to seek or follow treatment. Non-adherence was also contributed by failures in supporting systems, high pill burden, side effects and health education.

Based on the difficulty in addressing these challenges, the study further suggested several means to enhance adherence. Economic barriers were suggested to be alleviated with financial support programs. Reduction of stigma could be another strategy to improve TB treatment adherence, rather than focusing on addressing and mitigating the negative perceptions associated with TB, as an adverse perception on TB increases patients' negative outward appearance that can lead to patient feeling less comfortable with their treatment journey. The most important element to improve awareness on TB and the value of treatment completion was patient education. Providing healthcare services that take into consideration the components of time, space, communication, and context were proposed for improving healthcare access through longer clinic hours and decreasing waiting times. Attention was given to patient counselling and support services for psychological and emotional side of adherence. It also emphasized its view that essential strategies to support patients and improve adherence included involving community health workers as well as regular monitoring and follow up and reducing stigma.

In understanding how these strategies influence patient behaviour, it was the HBM that proved to be helpful. The emphasis of the HBM is on the patient’s perceptions of severity of the disease, susceptibility to the disease, value of action, and barriers to action. The purpose of the study was to address these perceptions and thereby improve patients’ adherence to TB treatment through the proposed strategies. For example, it is the case of increasing patient education, as a means of their better knowledge about the disease and its severity, of improving financial support and available healthcare access that would lessen the perceived barriers to compliance. Counselling and support services and stigma reduction efforts provide the patients with services so as to increase the emotional and psychological readiness for the patients to abide by and play their role with the treatment.

This study's findings highlight the multidimensional nature of TB treatment adherence and that multiple strategies should be addressed by a multifaceted approach that addresses the barriers found. The application of the recommended strategies will help healthcare providers in Oshakati District to provide better support to TB patients in line with the HBM, leading to better outcomes in treatment and less lost to follow up. Their insights provide a blueprint for the design of practical and psychological interventions to counteract these practical and psychological challenges and thus promote a more supportive context of TB patients.

5.5 Recommendations

5.5.1 Recommendations for the Ministry of Health and Social Services

- Develop and implement comprehensive educational programs on TB and treatment adherence.
- Expand clinic operating hours and reduce waiting times to facilitate easier access to care.
- Enhance the availability of healthcare services, including mobile clinics.
- Introduce financial aid and assistance programs to help cover the costs associated with TB treatment.
- Conduct community awareness and education campaigns to reduce stigma associated with TB.

- Involve community health workers to provide follow up care, support, and education.

5.5.2 Recommendations for nurses and Community Health Workers

- Provide clear, accessible, and culturally appropriate information to patients about their condition, the treatment process, and potential side effects, ensuring that they fully understand what to expect and how to manage it.Offer specialized psychological and emotional support for patients through regular counseling.
- Establish support groups of patients to commiserate and encourage one another.
- Develop a supportive environment for patients to access and remain in treatment.

5.5.3 Recommendations for future research

- For comparison purposes, similar studies may be replicated in other regions to determine the experiences of patients lost to follow up during TB treatment using a different or similar approach.

5.6 Limitations of the study

This study was subjected to some limitations, including:

5.6.1 Methodological limitation

The study included eleven (11) participants who were purposefully selected based on their lived experiences of being lost to follow-up during tuberculosis (TB) treatment in Oshakati District. While the sample size may not capture the full diversity of all patients lost to follow-up, it was sufficient for a qualitative study, as it allowed for in-depth exploration of individual experiences and the emergence of meaningful themes. This qualitative approach was well-suited for exploring the subjective experiences of patients, allowing for rich, in-depth insights into the factors contributing to loss to follow-up during TB treatment. Subjects had to recollect past exposures, possibly leading to recall bias as a result of memory loss. Conducting the study in one district may have missed variations in experiences across different healthcare settings.

5.6.2 Participant-related limitations

This study was conducted exclusively in Oshakati District and focused specifically on individuals who had defaulted from tuberculosis (TB) treatment. While this provided valuable insights into a specific context, it may limit the transferability of the findings to other regions of Namibia or settings with different socio-cultural dynamics. Additionally, the sensitivity of the topic may have influenced participants' openness during interviews. Some participants may have felt judged or stigmatised due to their treatment history, potentially leading them to withhold information or provide socially desirable responses rather than fully honest accounts.

5.6.3 Access challenges

The researcher had difficulty in locating some participants as their mobile phones were unreachable during the period of data collection. In some cases, participants who had initially agreed to take part in the study later became unreachable, such as by switching off their mobile phones, making follow-up and further contact impossible.

5.7 Chapter summary

Chapter five presented the conclusions of the study findings, recommendations, and the limitations of the study.

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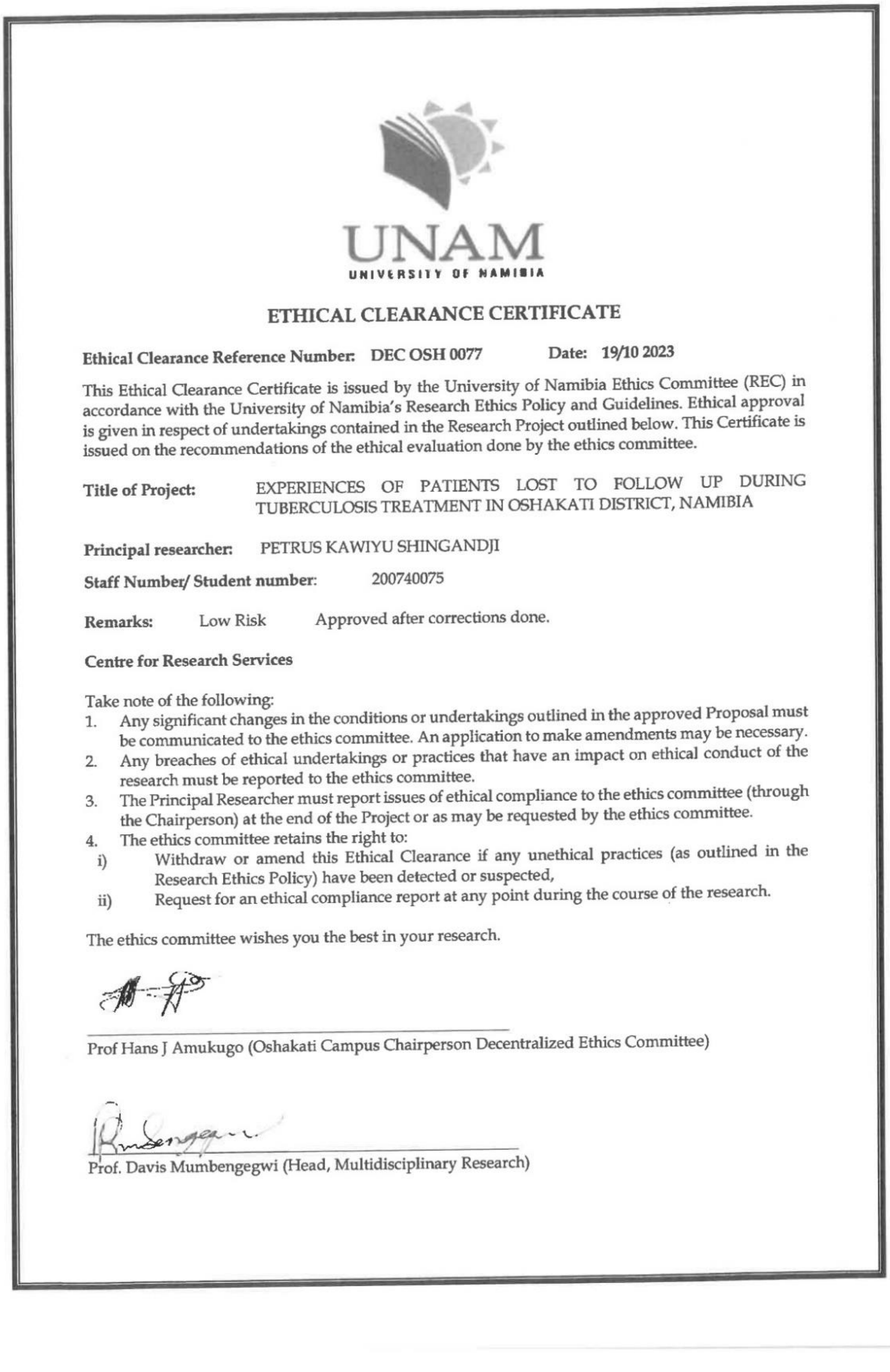
ANNEXURE A: ETHICAL CLEARANCE FROM UNAM



UNAM
UNIVERSITY OF NAMIBIA

ETHICAL CLEARANCE CERTIFICATE

Ethical Clearance Reference Number: DEC OSH 0077 **Date:** 19/10 2023

This Ethical Clearance Certificate is issued by the University of Namibia Ethics Committee (REC) in accordance with the University of Namibia's Research Ethics Policy and Guidelines. Ethical approval is given in respect of undertakings contained in the Research Project outlined below. This Certificate is issued on the recommendations of the ethical evaluation done by the ethics committee.

Title of Project: EXPERIENCES OF PATIENTS LOST TO FOLLOW UP DURING TUBERCULOSIS TREATMENT IN OSHAKATI DISTRICT, NAMIBIA

Principal researcher: PETRUS KAWIYU SHINGANDJI

Staff Number/ Student number: 200740075

Remarks: Low Risk Approved after corrections done.

Centre for Research Services

Take note of the following:

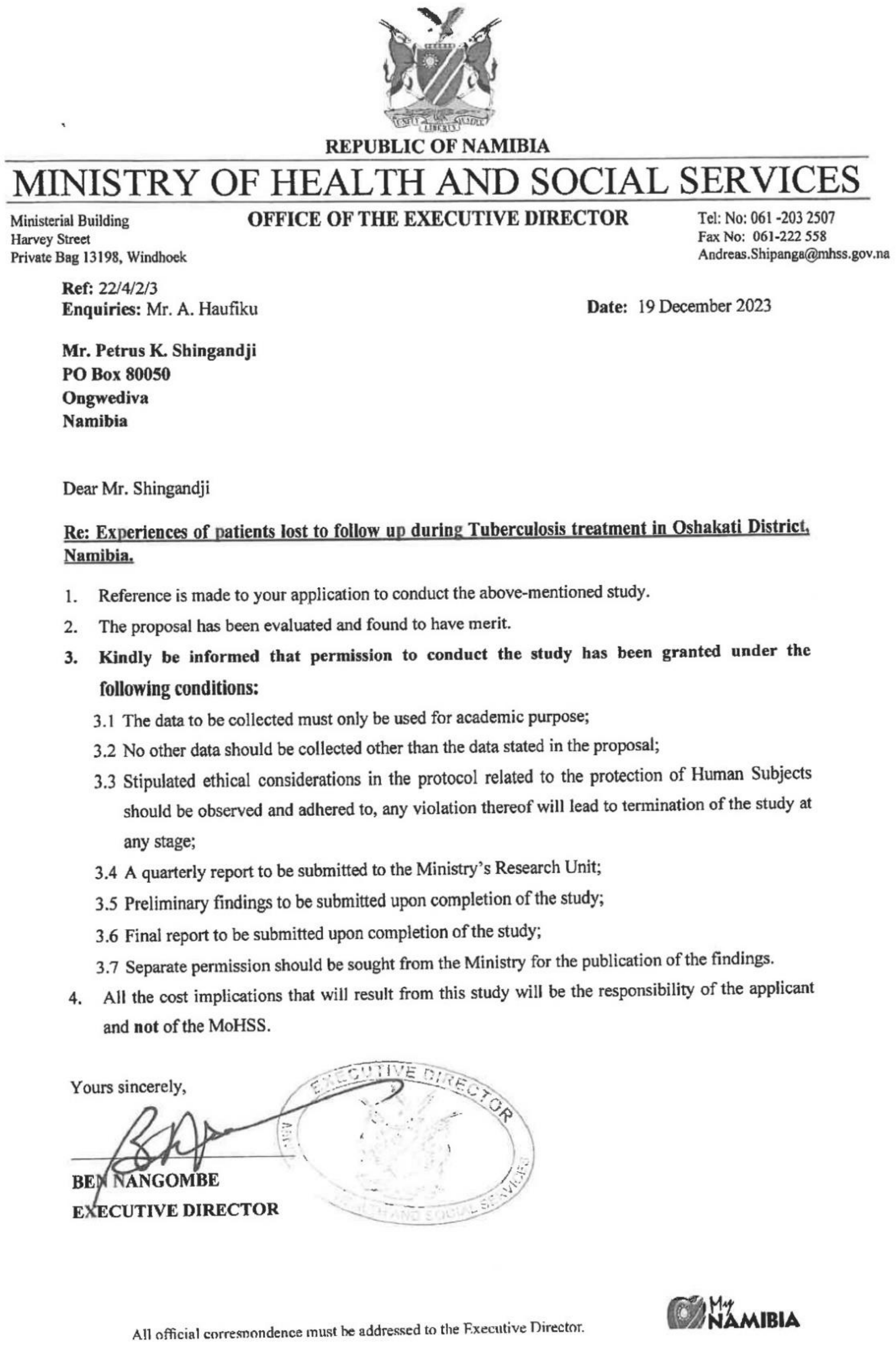
1. Any significant changes in the conditions or undertakings outlined in the approved Proposal must be communicated to the ethics committee. An application to make amendments may be necessary.
2. Any breaches of ethical undertakings or practices that have an impact on ethical conduct of the research must be reported to the ethics committee.
3. The Principal Researcher must report issues of ethical compliance to the ethics committee (through the Chairperson) at the end of the Project or as may be requested by the ethics committee.
4. The ethics committee retains the right to:
   i) Withdraw or amend this Ethical Clearance if any unethical practices (as outlined in the Research Ethics Policy) have been detected or suspected,
   ii) Request for an ethical compliance report at any point during the course of the research.

The ethics committee wishes you the best in your research.

Prof Hans J Amukugo (Oshakati Campus Chairperson Decentralized Ethics Committee)

Prof. Davis Mumbengegwi (Head, Multidisciplinary Research)

ANNEXURE B: PERMISSION LETTER FROM MOHSS



REPUBLIC OF NAMIBIA

MINISTRY OF HEALTH AND SOCIAL SERVICES

OFFICE OF THE EXECUTIVE DIRECTOR

Ministerial Building
Harvey Street
Private Bag 13198, Windhoek

Tel: No: 061 -203 2507
Fax No: 061-222 558
Andreas.Shipanga@mhss.gov.na

Ref: 22/4/2/3
Enquiries: Mr. A. Haufiku

Date: 19 December 2023

Mr. Petrus K. Shingandji
PO Box 80050
Ongwediva
Namibia

Dear Mr. Shingandji

Re: Experiences of patients lost to follow up during Tuberculosis treatment in Oshakati District, Namibia.

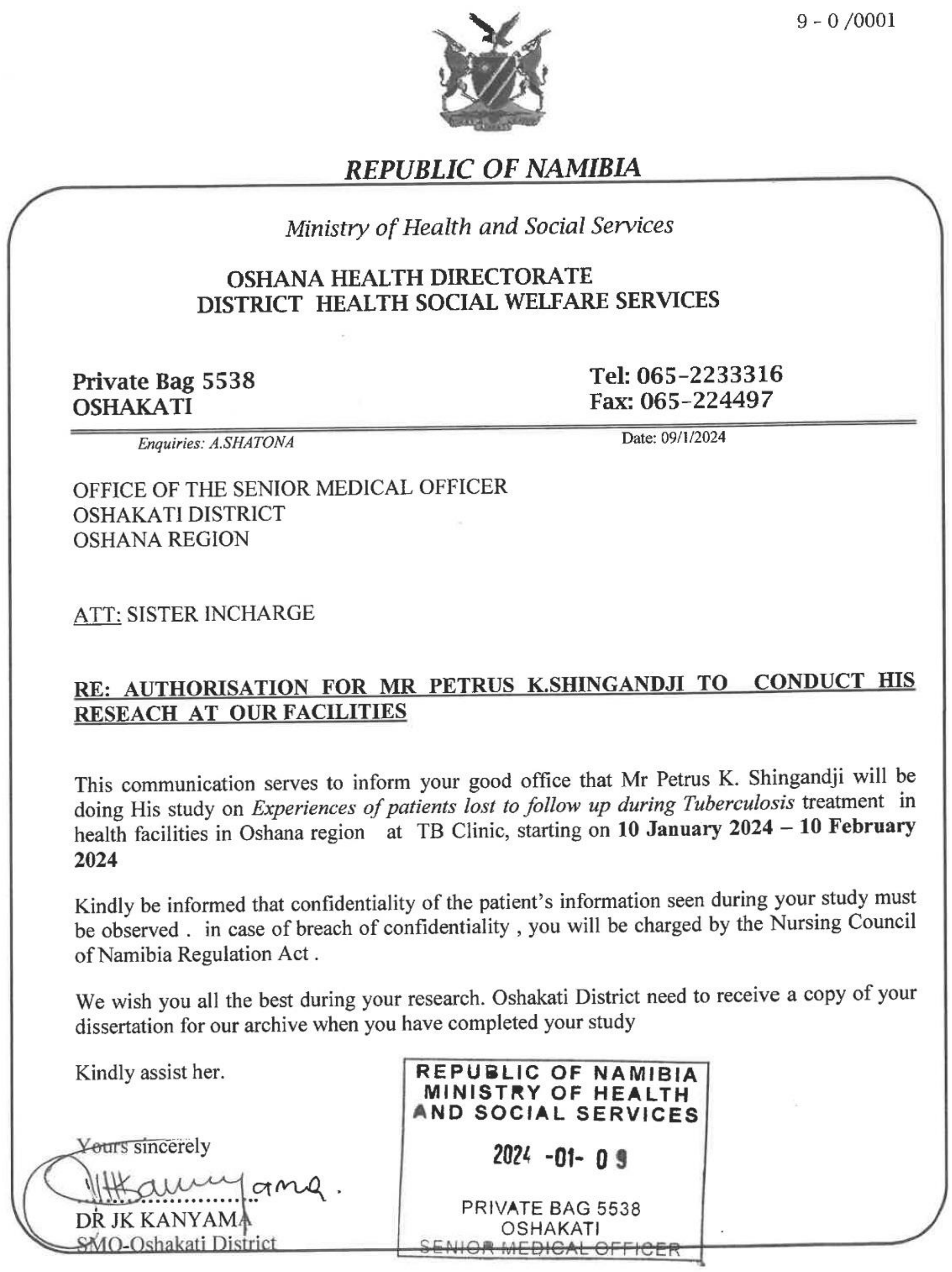
1. Reference is made to your application to conduct the above-mentioned study.
2. The proposal has been evaluated and found to have merit.
3. **Kindly be informed that permission to conduct the study has been granted under the following conditions:**
   - 3.1 The data to be collected must only be used for academic purpose;
   - 3.2 No other data should be collected other than the data stated in the proposal;
   - 3.3 Stipulated ethical considerations in the protocol related to the protection of Human Subjects should be observed and adhered to, any violation thereof will lead to termination of the study at any stage;
   - 3.4 A quarterly report to be submitted to the Ministry's Research Unit;
   - 3.5 Preliminary findings to be submitted upon completion of the study;
   - 3.6 Final report to be submitted upon completion of the study;
   - 3.7 Separate permission should be sought from the Ministry for the publication of the findings.
4. All the cost implications that will result from this study will be the responsibility of the applicant and **not** of the MoHSS.

Yours sincerely,

BEN NANGOMBE
EXECUTIVE DIRECTOR

All official correspondence must be addressed to the Executive Director.

ANNEXURE C: PERMISSION LETTER FROM OSHAKATI DISTRICT



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REPUBLIC OF NAMIBIA

Ministry of Health and Social Services

OSHANA HEALTH DIRECTORATE
DISTRICT HEALTH SOCIAL WELFARE SERVICES

Private Bag 5538
OSHAKATI

Tel: 065-2233316
Fax: 065-224497

Enquiries: A.SHATONA

Date: 09/1/2024

OFFICE OF THE SENIOR MEDICAL OFFICER
OSHAKATI DISTRICT
OSHANA REGION

ATT: SISTER INCHARGE

RE: AUTHORISATION FOR MR PETRUS K.SHINGANDJI TO CONDUCT HIS RESEACH AT OUR FACILITIES

This communication serves to inform your good office that Mr Petrus K. Shingandji will be doing His study on *Experiences of patients lost to follow up during Tuberculosis* treatment in health facilities in Oshana region at TB Clinic, starting on **10 January 2024 – 10 February 2024**

Kindly be informed that confidentiality of the patient's information seen during your study must be observed . in case of breach of confidentiality , you will be charged by the Nursing Council of Namibia Regulation Act .

We wish you all the best during your research. Oshakati District need to receive a copy of your dissertation for our archive when you have completed your study

Kindly assist her.

Yours sincerely

DR JK KANYAMA
SMO-Oshakati District

REPUBLIC OF NAMIBIA
MINISTRY OF HEALTH
AND SOCIAL SERVICES
2024 -01- 09
PRIVATE BAG 5538
OSHAKATI
SENIOR MEDICAL OFFICER

ANNEXURE D: INFORMED CONSENT FORM

Dear Participant

My name Petrus Kawiyu Shingandji (200740075). I am studying towards a Master's in Public Health degree at the University of Namibia (UNAM), and I am conducting a study titled: Experiences of patients lost to follow up during Tuberculosis treatment in Oshakati District, Namibia.

The purpose of the study is to explore and describe the lived experiences of patients lost to follow up during TB treatment in Oshakati District. No harm is anticipated from this study. There will be no payment for participating in the study. I have selected you to participate in my study, because you belong to the group of people I want to include for my research. I would therefore like to invite you to participate in the interview.

The research I am conducting has been approved by the UNAM Research Ethics Committee and I have permission from MoHSS to conduct this study. I would like to assure you of the following: You do not have to participate if you do not want to. You can stop participating at any time if you want to, and there will be no negative consequences for you. Your participation is completely anonymous, your personal information will not be known. The information collected will not be shared with anyone, only authorized University officials, my supervisor and I will have access to it. The interview may take about 20 – 30 minutes.

If you have any questions about this study, or if you do not understand some things please feel free to ask me, and I will be happy to explain it to you. You can reach me on my cell phone at (+26481271109), or send an e-mail to (petrinho09@gmail.com).

If you want to contact the UNAM Centre for Research Services for more information or because you have a comment or complaint about this research or about me, please call +264 61 206 4673, or write an e-mail to research@unam.na. Please provide specific information.

Thank you very much for your willingness to participate in this study!

Participant signature……………………… Date………………………

ANNEXURE E: INTERVIEW GUIDE

Topic: Experiences of patients lost to follow up during Tuberculosis treatment in Oshakati District, Namibia

Researcher name: Petrus Kawiyu Shingandji, 200740075

Procedure:

- Greeting participants.
- Introduce self.
- Explain the aim and objectives of the study.
- Obtain informed consent.
- Inform participants of the duration of the interview.
- Reassure participants of the ethical considerations in research.

The following questions served as a guide in the exploration of experiences of patients lost to follow up during Tuberculosis treatment:

Main questions:

1. Briefly, tell me about your experience regarding lost to follow up during Tuberculosis treatment.
2. What are your suggestions on strategies that could help you sustain adherence to TB treatment?

Possible probing questions:

3. What was your experience when you were first diagnosed and initiated on Tuberculosis treatment?
4. Prior to the initiation of Tuberculosis treatment, what did the healthcare worker say regarding health education?
5. Tell me, what were the reasons you got lost to follow up during TB treatment?

Thank you for taking time to answer these questions and have a pleasant day ahead.

INTERVIEW TRANSCRIPT

EXPERIENCES OF PATIENTS LOST TO FOLLOW UP DURING TUBERCULOSIS TREATMENT IN OSHAKATI DISTRICT, NAMIBIA

Respondent 01 (R01)

Age: 29 years

Gender: Male

Employment status: Employed

Education level: Grade 8

Drug susceptible or drug-resistant TB: Drug susceptible TB

Interviewer: My name is Petrus Shingandji, a nurse by profession and a student at the University of Namibia, pursuing a Master of Public Health. At the beginning, I would like to thank you for availing yourself and agreeing to participate in this interview. I am conducting a research study on Experiences of patients lost to follow up during Tuberculosis treatment in Oshakati District. Before we proceed with the interview, I would like to inform you the following: our engagement will last for 20 minutes on average, and in case you have more to say, it may extend to 30 minutes. I would like to inform you that confidentiality shall be maintained. Your name will not be attached to this interview, hence, I am not expecting you to mention your name throughout the interview. Your participation is entirely voluntary, therefore, you may withdraw your participation at any stage without experiencing any punishment. Please note, there are no monetary benefits associated with your participation in this study. Moreover, you are not compelled to answer any question that you may wish not to answer and you are welcome to seek for clarity for any unclear questions. To ensure that I capture all the information you provide, I would like to request for permission to use an audio recorder. Would you continue with your participation and allow me to record this interview?

R01: Yes, I have no problem.

Interviewer: Thank you for agreeing to participate in the study and for assenting to the use of an audio recorder. I, therefore, invite you to this interview and, request that you keep your phone on silence for the period of our engagement. To begin with, briefly, tell me about your experience regarding lost to follow up during Tuberculosis treatment.

R01: It was a very challenging experience though. At the beginning, I was committed to following the treatment. I knew it was important because the nurses kept emphasizing that TB could be cured if I adhere to my medication. To be honest, once I started feeling better, I did not see the need to continue the treatment as strictly as I did at first.

Interviewer: Thank you. When you were first diagnosed and initiated on Tuberculosis treatment, what was that experience like for you?

R01: Well, I had TB before. I think it has been some eight years ago since I was first told I had TB. Hence, I was feeling a little down as I was diagnosed with TB again. There were mixed feelings as TB can be a little deadly. On the other hand, I was familiar with the disease and it is treatment process.

Interviewer: You mentioned that TB can be a little deadly, could you explain further what does that mean?

R01: TB is a treatable disease, however, if left not treated it may cause death.

Interviewer: Prior to the initiation of tuberculosis treatment, what did the healthcare worker say regarding health education?

R01: They did their best to explain things to me, I think. The nurse spoke about how TB spreads and why it is important to complete the treatment. They said that if I did not finish the treatment, the TB could become resistant to the drugs. They have also explained the side effects of the medication, like nausea and dizziness, and advised me on what to do if I experienced them. But honestly, a lot of it went over my head because I was still in shock from the diagnosis.

Interviewer: Did you feel adequately informed?

R01: I think I understood the basics, but there were things I did not fully grasp, especially about what would happen if I missed doses or stopped taking the medicine.

Interviewer: I see. Can you tell me more about the specific reasons you got lost to follow up during your TB treatment?

R01: There were a few reasons. First, the cost of getting to the clinic was a big problem. I do not have a steady income, and sometimes I just did not have the money to pay for taxi fare. Also, after a few months on the medication, I started to feel much better. I thought that may be I did not need to continue taking the pills because the worst seemed to be over. Another issue was the side effects. The medicine made me feel nauseous, and I had headaches almost every day. There were times when I did not take the pills because I could not handle the side effects and I felt better.

Interviewer: You mentioned earlier that this is not your first experience with TB and that during a previous instance you completed your treatment. However, with the current TB experience, after taking the medication for several months and feeling better, you decided to stop treatment before considered as having completed your treatment by healthcare workers. Could you explain what influenced your decision to discontinue the treatment prematurely, especially since you had successfully completed treatment in the past?

R01: At that time, I was free from symptoms not like in the previous instance when symptoms were persistent. It was also a little challenging keeping up with the treatment routine having to follow another 6 months of treatment. I thought having completed 3 months, would have been sufficient.

Interviewer: It sounds like there were multiple factors contributing to your decision to stop the treatment. Did you ever try to seek help or talk to someone about the difficulties you were facing?

R01: Not really. As indicated before, I thought not having symptoms means that the disease has cleared.

Interviewer: Thank you for sharing that. Looking back, is there anything that could have been done differently to help you stay on track with your treatment?

R01: I think if there had been more support, may be someone to check in on me regularly, or if I could have talked to someone who went through the same thing it would have helped. Making healthcare services more readily available and accessible would support better treatment adherence. Perhaps they can consider boxes that can be accessed by patients at their convenience just like other people who collect monthly medications.

Interviewer: Thank you. As we draw towards the end of our interview, is there anything you would like to suggest that may be will assist patients to keep up with their treatment?

R01: May be if the healthcare workers could explain things in a simpler way, I would have understood the importance of sticking with the treatment better. The pills were huge, and sometimes I struggled to swallow them. I had to take a handful of medicine. I just hope that in future they will introduce one tablet.

Interviewer: In what specific ways do you think the presence and involvement of Community Health Workers could be made more prominent during TB treatment to better support patients like yourself?

R01: We appreciate the role of Community Health Workers in our society as they play a crucial role in monitoring patients and providing reminders and encouragement, however, their presence needs to be more prominent.

Interviewer: Thank you for all your responses. Do you perhaps have any questions sir?

R01: No, thank you, I think I have said it all.

Interviewer: Thank you for taking time to share your experiences with me. We have come to the end of our interview and I wish you a pleasant day ahead.

R01: Thank you.