EXPERIENCES OF PATIENTS DIAGNOSED WITH DRUG-SUSCEPTIBLE TUBERCULOSIS REGARDING LOST TO FOLLOW-UP IN ENGELA DISTRICT, OHANGWENA REGION

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ABSTRACT

Lost to Follow-Up (LTFU) amongst Tuberculosis (TB) patients is referred to as a patient diagnosed with TB who interrupts treatment for two consecutive months or more. LTFU has been cited as a major risk factor for the re-emergence of TB strains resistant to first-line anti-tuberculosis drugs. Namibia has been reporting increasing levels of patients LTFU over time, with some districts such as Engela reporting a 10% LTFU in quarter 4 of 2017 and 11% in quarter 1 of 2018 and constantly failing to attain the WHO recommended LTFU of below 5%. Patients diagnosed with drug-susceptible TB and registered for treatment after lost to follow up might have different experiences that can lead to them defaulting on treatment and being lost to follow up. Therefore, it was necessary to conduct a study aimed at exploring and describing the experiences of patients diagnosed with drug-susceptible and registered patients LFTU in Engela District, Ohangwena Region. Qualitative research with exploratory, descriptive and contextual designs were used in this study. The data was collected through in-depth interviews conducted at different sites in Ohangwena Region. A sample of 11 patients diagnosed with drug-susceptible TB and registered as patients LFTU were selected using a purposive sampling technique. The sample size was determined by saturation of data as reflected in repeating themes. Interviews were recorded and field notes were taken during the interview to ensure that all experiences of the participants were captured. The data was analysed using Tesch's eight steps of coding. The results showed that patients diagnosed with drug-susceptible TB had different experiences that led to the patients being lost to follow up on TB treatment. Some patients experienced physical malaise prior to being diagnosed with TB, while others experienced chest pain. The participants

became lost to follow up to their TB treatment for various reasons such as a lack of adequate information upon commencement of TB treatment and the importance of adherence to therapy, stigma at work and in the community, alcohol indulgence, a lack of proper nutrition and having travelled far away from the area where they initiated treatment.

The study recommends the development of holistic LTFU mitigation strategies/interventions aimed at improving organisational and administrative health system challenges impeding health education delivery to patients and the communities and provision of patient-centred care by health care workers. Further, it is important to look into addressing stigma issues and changing labour policies and laws that disadvantage sick people in the workplace and lead them to default therapy.

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AIDS	:	Acquired Immunodeficiency Syndrome
CHW	:	Community Health Worker
CNR	:	Case Notification Rate
DOTS	:	Directly Observed Treatment, Short-course
DR-TB	:	Drug-Resistant Tuberculosis
EPTB	:	Extrapulmonary Tuberculosis
HIV	:	Human Immunodeficiency Virus
HCWs	:	Health Care Workers
IPC	:	Infection Prevention and Control
LFTU	:	Lost To Follow-Up
LMICs	:	Low and middle-income countries
MDR	:	Multi-Drug Resistant
MOHSS	:	Ministry of Health and Social Services
NGOs	:	Non-governmental organisations
NTLP	:	National Tuberculosis and Leprosy Programme
PTB	:	Pulmonary Tuberculosis
RHZE	:	Rifampicin, Isoniazid, Pyrazinamide and Ethambutol
RHE	:	Rifampicin, Isoniazid and Ethambutol
SMS	:	Short Message Service
STIs	:	Sexually Transmitted Infections
TB	:	Tuberculosis
WHO	:	World Health Organization

XDR : Extensively Drug-Resistant

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- All the interviewed participants for agreeing to part take in the study.

DEDICATION

This thesis is dedicated to my late maternal grandfather Thomas Mayego ga Nameho.

Declaration

I, Teresia Kakunavali Venokulavo, hereby declare that the "Experiences of patients diagnosed with drug-susceptible tuberculosis regarding lost to follow up in Engela district, Ohangwena region", is a true reflection of my own work, and that all of the sources used have been acknowledged in the text and bibliography. This version is original work and has not previously been submitted in full or in part for a degree at any other university.

Teresia Kakunavali Venokulavo: Teresia K Venokulavo Date: 05-10-2022

CHAPTER ONE

INTRODUCTION AND BACKGROUND OF THE STUDY

1.1 Introduction

Lost to Follow-Up (LTFU) amongst Tuberculosis (TB) patients is defined as a patient diagnosed with TB who interrupts treatment for two consecutive months or more, and they were previously called defaulters (Ministry of Health and Social Services, 2017). Tuberculosis is a preventable, treatable and curable disease, despite that, it is still a major cause of high morbidity and mortality rates globally. TB is an infectious disease caused by the bacillus *Mycobacterium tuberculosis*. It mostly affects the lungs where it is known as Pulmonary TB (PTB) but can also affect other sites and is known as Extrapulmonary TB (EPTB). The disease is spread when people who are sick with pulmonary TB expel bacteria into the air, for example by coughing (Ministry of Health and Social Services, 2012).

There are two forms of TB, latent and active (pulmonary and/or extrapulmonary). Active TB disease can develop, following infection and facilitated by certain risk factors. Cough, fatigue, fever, night sweat, and weight loss are common symptoms associated with active pulmonary TB (Heymann, 2015). Latent TB occurs when a person has the TB bacteria within their body, but the bacteria are present in very small numbers. They are kept under control by the body's immune system and do not cause any symptoms (MoHSS, 2019).

TB treatment non-adherence and LFTU has been detected across several developing countries. According to a study conducted in Iran, the main factors associated with TB

treatment non-adherence and LFTU were socioeconomic factors: lack of transportation cost, lack of social support, and patients-health care worker poor communication. Numerous, socioeconomic, and behavioural factors were influencing TB treatment adherence and lost to follow-up. Therefore, understanding and minimising the effect of these associated factors is very important to enhance treatment adherence and follow up completion in developing countries (Tola, Tol, Shojaeizadeh, & Garmaroudi, 2015).

Patients LTFU from treatment are a major concern for TB programmes. It is even more challenging in programmes in urban informal settlements (slums) with large, highly mobile, impoverished populations. A retrospective study was conducted in Kibera, Kenya between July 2006 and December 2008 to determine the rate of LTFU from the TB programme and to assess associated clinical and socio-demographic factors. LFTU occurred in 146 (13%) of the 1094 patients registered, with male gender, no salaried employment, a lack of family support found to be significantly associated with LTFU. The most commonly cited reasons for LTFU were relocation from Kibera to 'up-country' rural homes and work commitments (Kizito, Kingori, Dunkley, & Reid, 2011).

A lack of knowledge among TB patients on the treatment aspects is a major concern highlighting the link between personal factors and health services factors. This link has negative implications on the management of TB patients and in general, the TB programme as it reflects on the quality of care provided to patients which promotes treatment defaulting. Furthermore, the link between socio-economic and health service factors negatively impacts the ability of patients to access care. Moreover, the lack of

integration of TB and Human Immunodeficiency Virus (HIV) care into normal health services has created an opportunity for stigma from society (Kakili, 2010). In contrast to other findings, a study conducted in Namibia by Mainga (2008) concluded that although the respondents seemed satisfied with the Directly Observed Treatment, Short-course (DOTS) system and health care providers, they still defaulted on their treatment.

Namibia as a middle-income country reported 9154 susceptible TB cases in 2016. Namibia's Ministry of Health and Social Services (MoHSS) like any other country in the world has adopted the Directly Observed Treatment (DOTS) strategy in order to effectively manage TB cases, but despite these strategies high lost to follow-up rate remains a challenge (MoHSS, 2015). Results from the study could provide insights for designing interventions aimed at reducing patient loss to follow-up during treatment for TB.

1.2 Background of the Study

According to the World Health Organization (WHO), TB is one of the top 10 causes of death worldwide (WHO, 2017). In 2015, 10.4 million people were infected with TB and 1.8 million succumbed to the infection with over 95% of TB deaths occurring in low and middle-income countries (WHO, 2017). In 2016, the largest number of new TB cases occurred in Asia, with 45% of new cases, followed by Africa with 25% of new cases (WHO, 2017). Namibia reports one of the world's highest incidence rates of TB and had a Case Notification Rate (CNR) of 436 per 100,000 in 2015.

The risk of transmission increases with close and prolonged contact with an infectious patient diagnosed with TB. In Namibia, the most frequent cause of progression of active TB disease is co-infection with HIV, as this coinfection reduces the immunologic control of TB infection. Early interventions with appropriate treatment reduce the time of infectiousness. Conversely, prolonged transmission occurs where TB goes unrecognised as well as when TB is diagnosed and treatment is initiated, but the treatment is inadequate due to improper medicine combinations, poor adherence, lower dosages and TB strains resistant to the prescribed medicines (MoHSS, 2015).

Lost to Follow-Up (LTFU) has been cited as a major risk factor for the re-emergence of TB strains resistant to first-line anti-tuberculosis drugs (Li et al., 2013). LTFU is defined as an interruption of TB treatment for at least 2 consecutive months (MoHSS, 2015). The Ministry attributes the gradual rise in the incidence of drug-resistant TB (DR-TB) and poor treatment outcomes (including death) as major barriers to ending TB in Namibia. Drug-Resistant (DR), Multi-Drug Resistant (MDR) and Extensively Drug-Resistant (XDR) forms of TB have been reported in Namibia since 2007 and incidences of these strains have been increasing over time. The incidence of LTFU among notified cases in Namibia increased from 4% in 2014 to 10% in the year 2015 (MoHSS, 2015). Findings from other studies done in other low and middle-income countries (LMICs) such as India and Malaysia estimate higher incidences of LTFU, of 19.2% and 24%, respectively (Heemanshu & Satwanti, 2016). In a study by Shah et al. (2017) in South Africa, a lack of education and knowledge and poverty were highlighted as factors leading to LTFU of TB patients.

According to the National Tuberculosis and Leprosy Programme (NTLP) report of 2018, Ohangwena Region reported the highest LTFU rate in Namibia of 14%, with the same report also indicating that the Ohangwena Region recorded the lowest success rate in Namibia. Among the 2015 cohort of TB patients, Namibia had a 6 % lost to follow-up, with Engela District alone having a 12% lost to follow-up amongst its susceptible TB cases in this cohort (MoHSS, 2015). Ohangwena Region has been failing to attain the set WHO target of 90% success rate in the past five years because of an increased lost follow-up in Engela District which is always above the WHO target of below 5% per quarter (MoHSS, 2017).

1.3 Problem Statement

The global target for TB treatment success rate is 90% and LTFU should be below 5% (WHO, 2017). Engela District has never attained these targets, Engela reported a 10% LTFU in Quarter 4 of 2017 and 11% in Quarter 1 of 2018. Despite the introduction and implementation of the DOTS in Engela, the district continues to fail to yield the desired outcomes. Lost to Follow-Up (LTFU) has been cited as a major risk factor for the re-emergence of TB strains resistant to first-line anti-tuberculosis drugs (Li et al., 2013).

According to two studies conducted on factors contributing to defaulting amongst patients on tuberculosis treatment in the Windhoek District, it was revealed that the major contributing factor was the lack of knowledge about TB treatment amongst patients (Mainga, 2008; Kakili, 2010). Mainga (2008) uses the quantitative research design, hence, the factors leading to LTFU could not be further explored or described in depth.

Additionally, although research has been done on this topic, it was only done in clinics in the Windhoek District of Khomas Region, and both studies were done within the same time frame 2008 and 2010, hence it yielded similar results. Engela being a rural district hospital located along the borders of Angola and Namibia, serves patients from both Angola and Namibia, hence the setting is different from previously conducted studies in Namibia due to the different geographic, social, economic and political dynamics. This identified gap then prompted the researcher to explore and describe in detail the experiences of patients diagnosed with susceptible TB who were lost to follow-up in this area.

1.4 Aim of the Study

This study aims to explore and describe the experiences of patients diagnosed with drug-susceptible tuberculosis who were lost to follow-up in Engela District, Ohangwena Region.

1.5 Research Objectives

The objectives of the study were to:

- Explore the experiences of patients diagnosed with drug-susceptible tuberculosis regarding lost to follow-up.
- Describe the experiences of patients diagnosed with drug-susceptible tuberculosis regarding lost to follow-up.

1.6 Theoretical Framework

To characterise factors associated with loss to follow-up during MDR TB treatment, the researcher followed a 5-level social ecologic model (Golden & Earp, 2012) that focuses on individual and environmental factors that affect health outcomes: 1) individual factors; 2) interpersonal factors; 3) healthcare setting factors, such as individual experiences with services and relationships within the setting; 4) diagnosis and treatment factors, and 5) social factors (Figure 2). To operationalise each category of factors and develop data collection forms, the researcher reviewed TB literature and solicited input from experts within the country. Tupasi et al. (2016) use a similar framework to identify factors associated with loss to follow-up during treatment for multidrug-resistant (MDR) tuberculosis (TB) in the Philippines and these included patients' higher self-rating of the severity of vomiting as an adverse drug reaction and alcohol abuse. Protective factors from this Philippines study included receiving any type of assistance from the TB program, better TB knowledge, and higher levels of trust in and support from physicians and nurses.

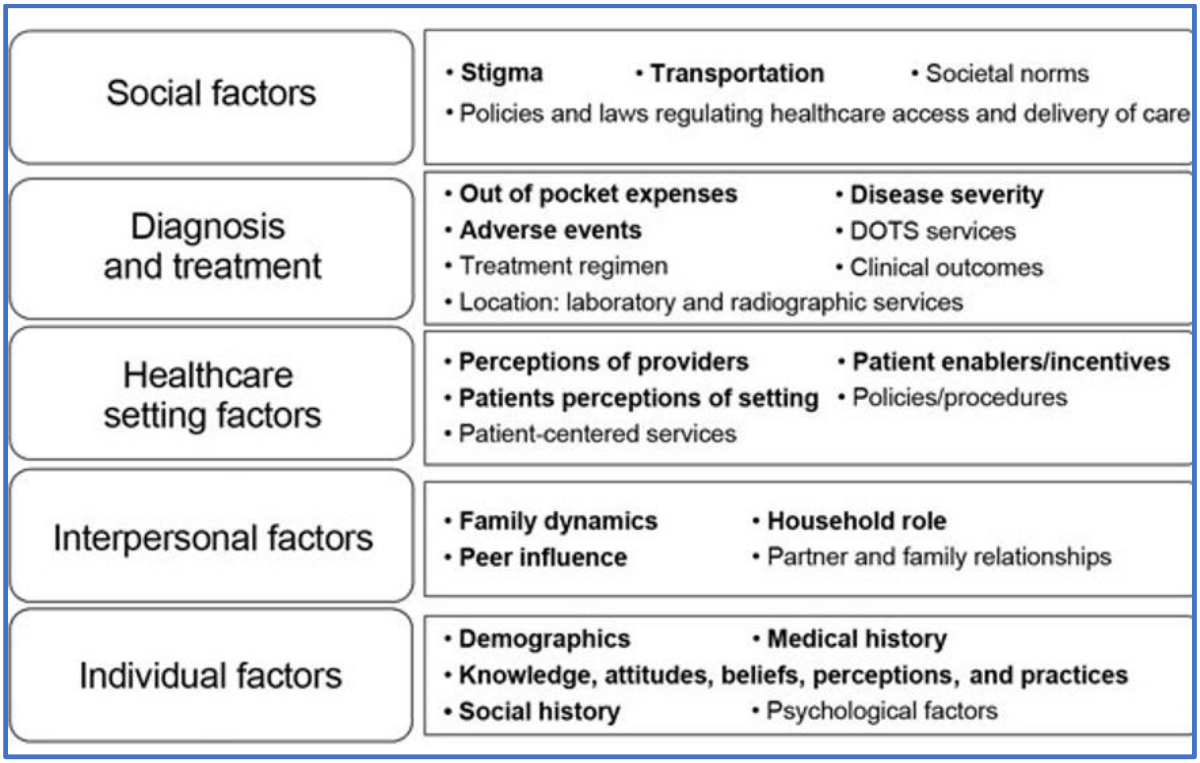


Figure 1. Social ecologic model

Adopted from (Tupasi et al., 2016).

1.7 Paradigmatic Perspective

A study of this nature requires an interpretivist paradigmatic perspective, which is a worldview, an entire framework of beliefs, values and methods within which research takes place. Since the ontology of this study is mainly concerned with the human world of meanings and interpretations and the epistemological stance is mainly constructionist in nature, it is logically sequenced that interpretivism is the theoretical perspective underpinning this study. Due to the paucity of existing data on factors associated with LTFU among TB patients in the Namibian context, the researcher used a qualitative study

design that was exploratory, descriptive and contextual in nature, guided by a social ecologic model in order to answer the research question.

It is critical to ensure the trustworthiness of research findings and safeguard data integrity. Additionally, a balance needs to be struck between study participant meaning and researcher interpretation of the responses and clear communication of the study findings. In order to establish the trustworthiness of the qualitative research findings, the researcher applied the following four basic questions/assumptions to the study:

Ontological Assumptions: What is the nature of reality? Ontological assumptions are defined as the kind of world being investigated, taking into consideration the nature of existence and the structure of reality. Guba and Lincoln (2015) state that the ontological assumptions are those that respond to the question 'what is there that can be known? In this study, the researcher assumed that the area under investigation was populated by human beings who have their own thoughts, interpretations and meanings. The researcher, therefore, used a qualitative research method and structured in-depth interviews to interpret the study participants' feelings, experiences and inner thoughts. This reality/finding was also linked to existing findings from similar studies conducted on the same population of TB patients registered as a treatment after LTFU in different locations in the world (Tupasi, et al., 2016; Kizito, et al., 2011).

Epistemological Assumptions: How do you know something? Crotty (2013) defines epistemological assumptions as a way of understanding and explaining how we know what we know. Epistemology is also concerned with providing a philosophical grounding

for deciding what kinds of knowledge are possible and how we can ensure that they are both adequate and legitimate. In this study, the researcher searched existing literature, national reports and consulted subject experts on what is already known regarding the factors affecting LTFU TB cases and followed through with collecting data from patients registered as a treatment after lost to follow-up in Engela District through conducting in-depth interviews to gain insight and obtain sufficient and legitimate knowledge on the experience of the study participants.

Methodological Assumptions: How do you go about finding out knowledge? The methodology is the strategy, plan of action, process or design lying behind the choice and use of particular methods and linking the choice and use of the methods to the desired outcomes (Crotty, 2003). It aims to describe, evaluate and justify the use of particular methods. (Wellington, 2000). The methodology employed in this study is qualitative, exploratory, descriptive and contextual research methodology to gain insight and knowledge into the real-life experiences of patients diagnosed with drug-susceptible tuberculosis who are receiving their treatment after LTFU.

Axiological assumptions: This is also referred to as the role of values: The researcher's subjective values, intuition, and biases are important that they play a role in the dialogue of social construction and inform his or her interpretation of the data (Crotty, 2013). In this study, the researcher served as a research instrument by utilising in-depth interviews as the primary method of data collecting data objectively analysing this data to make valid study interpretations and conclusions.

1.8 The Significance of the Study

To Program Officers and Policymakers: the study findings might form the basis for policies and guidelines development that will be used to reduce lost to follow-up rate.

To Health Care Workers (HCWs): the study findings might enhance health care workers' knowledge on the challenges faced by TB patients this will then assist them in coming up with patient-centred interventions that could prevent patients from being lost to follow-up on their treatment.

To the Patients and Community: The study findings might help prevent the development of drug-resistant TB in communities and recurrence of the TB diseases.

1.9 Limitations of the Study

Limitation of a study is defined as influences that the researcher cannot control, they are shortcomings, conditions or influences that cannot be controlled by the researcher (Fox & Bayat, 2014). This study was conducted with patients diagnosed with drug-susceptible TB and registered as a treatment after lost to follow-up in Engela District. Therefore, the study findings will not be generalised to the broader population because the participants' geographical and cultural orientation may not be the same as that of patients in other regions. However, the researcher envisages that the study findings will be of use to other health care workers dealing with patients diagnosed with TB.

1.10 Delimitations of the Study

According to Fox and Bayat (2014), delimitations are choices made by the researcher and they describe boundaries set by the researcher for the study. In this study, the researcher

only collected data from patients registered as a treatment after loss to follow-up and not any other patient on TB treatment in Engela District.

1.11 Definition of Concepts

This study used several key terms. Hence, the following definitions of key concepts of the study:

Diagnosed: refers to an act of identifying the nature of an illness by examination of the symptoms, for whom a treatment, brief psychological intervention is required (Cambridge Dictionary, 2019). Thus, in this study, the general term of 'diagnosis', refers to the identification of the nature of the medical condition of a patient which is TB.

Drug-susceptible TB: means that if someone is infected with TB bacteria that are fully susceptible, all of the TB drugs will be effective as long as they are taken properly (World Health Organization, 2017). In this study, the terms still relate to the fact that this is the non-drug resistance TB and the first line drugs need to be taken together to provide effective TB treatment to the patient.

Infectious Disease: is a group of illnesses that include pneumonia, influenza, hepatitis, tuberculosis, sexually transmitted infections (STIs), pelvic inflammatory disease, and acquired immunodeficiency syndrome (AIDS) (Lix et al., 2012). In simple terms, in this study, infectious diseases refer to diseases that are transmitted between human beings.

Tuberculosis (TB): Tuberculosis is a disease that is acquired through infection from a *Mycobacterium,* specifically *Mycobacterium tuberculosis, Mycobacterium africanum, Mycobacterium canetti,* and *Mycobacterium bovis* (Lix et al., 2012). Thus, in this study, it is understood that TB is acquired through the infection with specific mycobacteria.

1.10 Structure of the Thesis

This thesis is divided into five chapters.

Chapter 1 presents the introduction and background to the central themes of the thesis. The research topic is introduced with its rationale. The research aim, objectives and significance are highlighted. Definitions of key concepts relevant to this thesis are provided.

Chapter 2 presents the research design and methodology adopted in this study. A motivation for qualitative, exploratory, descriptive and contextual designs are provided. The rationale for adopting a non-probability purposive sampling approach and the data analysis is also presented in this chapter.

Chapter 3 provides the analysis of data and literature control obtained through in-depth interview surveys as well as from documents such as official government reports and journal articles. Particularly the use of patients' experiences regarding Lost to Follow-Up (LTFU) is presented.

Chapter 4 contains the summary, conclusions and evaluation of the study. The evaluation assesses the practical, theoretical, and methodological contributions of the study. The focus of the summary is on the contribution of the thesis in the various chapters as well as the overall contribution in answering the research aim and objectives. The limitations of the study and suggestions for future research are also presented.

1.11 Summary of the Chapter

This chapter presented the introduction and background to the study. The introduction, including the problem statement, research aim, objectives and the significance of the

study are deliberated in this chapter. The chapter further provided context on the definitions of key concepts, limitations, delimitations, and structure of the thesis.

The next chapter focuses on the descriptions of the research design and methodology.

CHAPTER TWO

RESEARCH DESIGN AND METHODOLOGY

2.1 Introduction

This chapter comprises the research design and methodology. The research design, the population, the sample size and sampling methods used in this study are described and explained including the inclusion and exclusion criteria applied in the participants' selection process.

The chapter further includes the data collection subsection, where the aspects of the research instruments, the procedure for data collection, data integrity, trustworthiness and the pilot study are described and explained. Data analysis and the research ethics applied are also described and discussed in this chapter, ending with the chapter summary.

2.2 Research Design and Methodology

Qualitative, exploratory, descriptive, and contextual designs were used in this study. This was mainly to gain more insight into the experiences of lost to follow-up patients diagnosed with drug-susceptible tuberculosis, who are receiving their treatment at Engela Hospital.

2.2.1 Qualitative Design

Qualitative research enables the researcher to interpret the data. It allows the researcher to develop a description of an individual or setting, analyse data for themes and sub-themes, interpret or draw conclusions about meaning personally and theoretically, state

lessons learned, and offer further questions to be asked (Tappen, 2011). Since the researcher has little information regarding LTFU amongst TB patients, a qualitative design is a suitable design that gives the researcher a chance to find out more information in this area. The study used an explorative design to gain deeper insight into the experiences of patients diagnosed with susceptible TB. In addition, individual in-depth interview approach was employed, in order to get information directly from the participants, with the participants being able to describe their experiences in their own words. The study findings will only be understood within the context of patients diagnosed with drug-susceptible tuberculosis, who are receiving their treatment at Engela Hospital.

2.2.2 Exploratory Design

It is stated that exploratory research is conducted in order to gain insight into a specific situation (De Vos, Strydom, Fouche & Delport, 2011). In this study, exploratory design refers to gaining more insight from the experiences of LTFU patients diagnosed with drug-susceptible tuberculosis, who are receiving their treatment at Engela Hospital, Ohangwena Region, Namibia.

2.2.3 Contextual Design

The study's context refers to the environment and the conditions in which the study takes place as well as the participants' culture and location (Holloway & Wheeler, 2010). According to Pequegnat, Strover and Boyce (2010), a contextual study is any study wherein the phenomenon of interest is studied in terms of its immediate context. Context

refers to a particular setting in which a study is taking place, which can include the environment, people, and so forth. If the researcher understands the context, he can locate the actions and perceptions of individuals and grasp the meanings that they communicate, because in qualitative research the events and actions are studied as they occur in an everyday, real-life setting. It is, therefore, important for the researcher to be sensitive to the context of the research and immerse himself in the setting and situation because both personal and social context is important.

This study is contextual in nature because it was carried out in Engela District. There have been no studies conducted in this area and Engela being along the borders with Namibia and Angola and also being in a rural setting has a different cultural and social background as compared to Windhoek Namibia, an urban setting in central Namibia, where similar studies were conducted on the patients diagnosed with drug-susceptible tuberculosis. The aim of selecting a contextual design for this study was to maintain focus on the experiences of patients diagnosed with drug-susceptible tuberculosis, who are receiving their treatment at Engela Hospital. Understanding the day-to-day real-life experiences in the participants' geographical, social and cultural context allowed the researcher to get hold of the participants' perceptions and gain the meanings of their responses.

2.2.4 Descriptive Design

In qualitative studies, description is more likely to refer to an intensive examination of phenomena and their deeper meaning, thus, leading to a more detailed description (De

Vos et al., 2011). A descriptive study design was employed in order for the researcher to be able to describe the information that was obtained and observed during this study and answer the research question.

2.3 Population

Population refers to all the people that would fit into the group that is being considered by a particular study, a sample is then drawn from this population (Creswell, 2014). In this study, the population refers to all the patients diagnosed with drug-susceptible TB and registered as Treatment after Loss to Follow-Up (TALTFU) in Engela District Hospital between October 2018 and July 2019.

2.4 Sample and Sampling Method

A sample is defined as a subset of a population that fits the inclusion criteria, and is selected in order to research the population without having to collect data from its entirety (Creswell, 2014). Whereas, the term sampling method means selecting the group that the researcher will actually collect data from, for their research (Creswell, 2014). In this study, non-probability purposive sampling was used. Purposive sampling implies that the researcher makes own specific choices about which people, groups or objects to include in the sample (Bertram & Christiansen, 2014). A total of 11 study participants were purposively selected to participate in this study. The sample was decided upon based on the responses from the study participants during the data analysis process.

2.4 .1 Inclusion Criteria

Hulley, Cummings, Browner, Grady and Newman (2012) define the inclusion criteria as the key features of the target population that the investigators will use to answer their research question. Usual inclusion criteria include demographic, clinical, and geographic characteristics. In this study, only participants meeting the following inclusion criteria were selected:

- Patients diagnosed with susceptible TB and registered as a treatment after lost to follow-up.
- Patients aged 18 years old and above.
- Patients attending care at Engela District Hospital.

2.4.2 Exclusion Criteria

Contrary to inclusion criteria, the exclusion criteria are defined as features of the potential study participants who meet the inclusion criteria but present with additional characteristics that could interfere with the success of the study or increase their risk for an unfavourable outcome (Hulley, Cummings, Browner, Grady & Newman, 2012). Thus, in this study, the following exclusion criteria were applied:

- TB patients who are below the age of 18.
- TB patients registered as new or treatment after failure.
- Vulnerable people such as prisoners or mentally unfit patients.

2.5 Data Collection

2.5.1 Research Instrument

The researcher collected data by interviewing individual patients in the local Oshiwambo language. The following materials were used to collect data: a pen, a note pad and a voice recorder. An unstructured questionnaire was used by the researcher as an interview guide.

2.5.2 Interviews and Field Notes

Prior to going in the field the researcher called the Engela TB Clinic to assist in booking interviews with patients that are registered as LTFU. 8 out of the 11 interviews were conducted at the health facilities and 3 of the interviews were conducted at the participant's homes as per their preference, the interviews lasting for approximately 45 minutes. The interviews were conducted in a conducive room safe from noise and interruptions, the researcher employed different communication skills during the interviews such as reflection and clarification techniques which assists in understanding the participant's responses more clearly. The researcher collected the data using a questionnaire with in-depth open-ended questions. In-depth interviews are flexible ways of obtaining a wide range of detailed information when seeking to learn about people's experiences (Creswell, 2014). The researcher focused on taking field notes of the patients' experiences regarding TALTFU. In-depth interviews were chosen because they yield a high response rate and rich research data regarding the experiences of patients diagnosed with drug-susceptible tuberculosis, who are receiving their treatment at Engela Hospital.

2.5.3 Pilot Study

A pilot study is a trial run of an investigation conducted on a small scale to determine whether the research design and methodology are relative and effective. A pilot study makes it easy to correct areas of misunderstanding or confusion without wasting time or money (Fox & Bayat, 2014)**.** In this study, the researcher carried out a pilot study prior to the actual data collection process to assess feasibility methods and data collection processes. This was done on two patients who were not part of the actual data collection process, but are diagnosed with drug-susceptible tuberculosis, who are receiving their treatment at Engela Hospital. The pilot study yielded a positive expected response, which led to minor adjustments of the interview guide questions where gaps were identified.

2.6 Data Analysis

Data analysis is a close or systematic study, or the separation of a whole into its parts, for the study. Data analysis consists of three flows of activity: data reduction, data display and conclusion drawing and verification (Bertram & Christiansen, 2014). In this study, qualitative data were analysed for 11 study participants diagnosed with drug-susceptible tuberculosis, who were receiving their treatment at Engela Hospital.

Demographic data were described and displayed in tabular format and Tesch's eight steps were used to analyse the participants' responses generating themes and subthemes. Below are the Tesch's eights steps followed.

Step 1: The researcher read the entire transcriptions carefully to get a general sense of the data.

Step 2: The researcher selected one interview transcription, asked herself a question "What is it about?", and considered the basic meaning of the data. The researcher wrote down her thoughts in the margin as they emerged.

Step 3: The researcher made a list of themes. Similar themes were grouped.

Step 4: The researcher applied the list of developed themes to the data. The themes were abbreviated as codes written next to the corresponding data segments. The researcher tested this preliminary organisational chart to see if new categories and codes emerge.

Step 5: The researcher looked for the most appropriate descriptive phrases for the themes and categorised them. Lines were drawn between categories to show relationships.

Step 6: The researcher made a final decision on the abbreviation for each category and the codes were arranged in alphabetical order.

Step 7: The data for each category was collected and a preliminary analysis was made. A preliminary analysis was then carried out.

Step 8: This step involves recoding of existing data if necessary, however, this was not done in this study.

2.7 Trustworthiness

Trustworthiness is a concept used by Guba and Lincoln (1994) for interpretivist research, which has become quite widespread. The usage of the concepts of credibility, transferability, dependability, confirmability (Bertram & Christiansen, 2014), were adopted and aligned to this study. The study adopted several qualitative research criteria for trustworthiness.

2.7.1 Transferability

Bertram and Christiansen (2014) define transferability as the degree to which the results of qualitative research can be transferred to other contexts or settings with other respondents. In this study, the researcher ensured that the study methodology and context were described in depth to ensure a robust study with credible and trustworthy study results that can be transferred to other settings outside Engela District.

2.7.2 Dependability

Dependability refers to the stability of research findings over time (Bertram & Christiansen, 2014). In this study, dependability was ensured because the researcher sent the preliminary research report, together with interview notes and recorded audios and the recommendations made to the study supervisors for verification and evaluation.

2.7.3 Confirmability

Confirmability refers to the degree to which the findings of the research study could be confirmed by other researchers (Creswell, 2014). In this study, confirmability is concerned with establishing that data and interpretations of the findings are not figments of the inquirer's imagination relating to patients diagnosed with drug-susceptible tuberculosis, but clearly derived from the data. The researcher retained the transcribed notes from the interviews as evidence of data collected and supporting interpretation of study findings.

2.7.4 Credibility

The researcher has vast experience in public health, having five years' experience in the field of TB, where the researcher worked as a district coordinator for TB activities and currently as a program officer responsible for TB activities in the whole region. The researcher's experience and good ethical conduct are important in establishing confidence in the data generated in this study.

2.8 Ethical Considerations

Ethical approval for the study was sought from the University of Namibia from the Research Ethical Committee and permission to conduct the study in the hospital was sought from the permanent secretary of the MoHSS. Given the sensitivity of this research, which requested some aspects of the private life experiences of participating patients diagnosed with TB, basic principles of human research ethics were safeguarded by the researcher. The researcher came up with an informed consent that was signed by all participants before participating in the study and the participants were clearly informed that participation is voluntary, and they could withdraw from the study at any time. Anonymity was ensured in a way that during the data collection process participants' identity was not used. The researcher ensured that no pain or harm was inflicted on the participants, as the interviews took place at the hospital premises in a private room. The audio recorded and field notes are strictly kept by the researcher in a safely locked cabinet that only the researcher has access to. The audios and field notes are kept safe until the research is finalised and destroyed only after the researcher gets permission to do so by the supervisors.

2.9 Summary of the Chapter

This chapter presented the context, explanations and descriptions of the research methodology. The research design, population, sample size and sampling methods used in this study were also described and explained. The chapter also detailed the data collection, analysis, and research ethics. Chapter Three details the data analysis and literature control of the study.

CHAPTER THREE

ANALYSIS OF DATA AND LITERATURE CONTROL

3.1 Introduction

This chapter focuses on the analysis of data and literature control of results that emerged from the data analysis process. The segments that contain similar meanings for each participant were grouped during the processing of listening to the recorded audios, re-reading through the notes taken during the interviews and repeatedly reading the transcripts. Results described in this chapter are based on verbatim transcriptions of the interviews, giving the researcher authentic insight into the participants' experiences.

The purpose of literature control is to expand the researcher's understanding of the phenomenon from multiple perspectives and to substantiate study findings with similar studies conducted in other parts of the world. This study's objective was to explore and describe the experiences of patients diagnosed with drug-susceptible tuberculosis who were lost to follow-up in Engela District.

3.2 Demographic Information of Participants

The researcher conducted in-depth interviews with 11 study participants. The interviews were conducted at different sites in Engela District depending on the participant's preference. Study participants were asked to report their primary reason for stopping treatment. The interviews were conducted at different sites in Engela District depending on the participant's preference, with the majority of the interviews being conducted at the health facility nearest to the participant's homestead. The participants interviewed were

aged between 28 and 62 years. Out of the 11 participants interviewed, nine were males and two were females, and all the participants were not formally employed with only two having attained secondary level education. Table 1 shows the demographic information of the interviewed study participants.

Table 3: Demographic information of participants

Participant (P)	**Age**	**Gender**	**Marital status**	**Level of education**	**Occupation**
P 1	34	Male	Single	Primary level	Unemployed
P 2	57	Female	Single	Primary level	Unemployed
P 3	57	Male	Single	None	Cattle herder
P 4	28	Male	Single	Primary level	Unemployed
P 5	60	Male	Married	Primary level	Retired
P 6	62	Male	Married	Primary level	Communal farmer
P 7	35	Male	Single	Secondary level	Unemployed
P 8	37	Male	Single	Secondary level	Unemployed
P 9	33	Female	Single	Junior secondary level	Unemployed
P 10	42	Male	Single	Primary level	Unemployed
P 11	55	Male	Single	None	Cattle herder

3.3 Data Analysis Themes and Subthemes

Preliminary data analysis occurred simultaneously with the data collection. Following verbatim transcription of the collected data, the researcher analysed the data guided by Tesch's eight steps of data analysis as described in Chapter 2. The following are themes and subthemes that emerged from the data analysis process.

Table 4: Themes and subthemes of the study

Themes	**Sub-themes**
3.3.1 Different experiences on being diagnosed with TB.	3.3.1.1 Body malaise due to various symptoms (cough, poor appetite and weight loss). 3.3.1.2 Pain (chest pain, rib pain).
3.3.2 Participants' experiences regarding TB health education from Health Care providers.	3.3.2.1 The duration of TB treatment. 3.3.2.2 The consequences of failing to adhere to TB treatment. 3.3.2.3 Collecting TB medication in another health facility when far away from the centre where treatment was initiated.

Themes	Sub-themes
3.3.3 Other rationales leading to Loss to Follow-Up	3.3.3.1 Travelling outside Namibia or away from the health facility area. 3.3.3.2 A lack of food/nutrition support. 3.3.3.3 Indulgence in alcohol. 3.3.3.4 Feeling of being healed. 3.3.3.5 Fear of losing jobs.

3.3.1 Different experiences of being diagnosed with TB

An experience is a specific instance of an encounter or personal experience with something (Kakili, 2010). This study refers to the experiences that different participants had prior to TB diagnosis, after diagnosis with the main focus being the experiences leading to LTFU. Participants' experiences of TB diagnosis and treatment after loss to follow-up varied from participant to participant and their experiences ranged from the symptoms they had before diagnosis to the social consequences because of TB diagnosis. This theme aligns with the diagnosis and treatment factors of the social ecologic model that the researcher used to guide this study.

A study conducted by Dodor (2012) in Ghana confirmed that most patients reported expressing various forms of emotions when they were told they had TB. Some of them said they were shocked, scared, confused and cried all night because they thought they were going to die. In this study, the researcher identified numerous experiences during the interview. These experiences included physical discomfort before TB diagnosis which

were due to various symptoms such as coughing, pain (chest pain, rib pain), loss of appetite and weight loss, and anxiety caused by fear of job loss as a result of the diagnosis as described in Table 3.2.

3.3.1.1 Various physical symptoms (malaise cough, poor appetite and weight loss)

Body malaise refers to fatigue, tiredness or weakness. According to Gebre-Mariam (2009), there are numerous possible causes of malaise; any time your body undergoes a disruption, such as an injury, disease, or trauma, you can experience malaise. It can be noted that body malaise is a symptom that can occur with almost any health condition. It may start slowly or quickly depending on the type of disease (Dodor, 2012). Ahmad, Stanikzai, Rahimy, Wasiq and Sayam (2021) note that due to body malaise various symptoms can be seen in affected patients expressed in ways such as cough, poor appetite, body pains, fever, chills and weight loss.

In this study, the researcher observed that all eleven participants had either experienced cough, poor appetite or weight loss at some point in time, and in some instances, some participants reported having experienced a combination or all of the stated symptoms. The following were some of the responses from the study participants regarding the symptoms they experienced before TB diagnosis:

"I developed a cough and I went to the hospital they gave me a bottle and told me to cough and spit sputum in that bottle, which then was tested and the health care workers later told me I had TB. [P1].

"I started having a cough which was not stopping at all and I decided to come to Ongha clinic to come to seek treatment" [P3].

"Later I just started to lose a lot of weight and my appetite kept becoming low." [P4].

"I started feeling feverish and thought it was malaria so I sent for drugs from the drug store. ...Later I started to cough…Then a time came that any time I ate, I vomited everything…Within days I grew very lean, so I decided to stop taking the drugs and go to the hospital" [P5].

"I was having a very bad cough; I was coughing non-stop especially during the night after some time I realized my appetite was poor and I even lost weight." [P10].

These findings are consistent with various existing studies associating early TB infection with coughing, fatigue, loss of appetite and vomiting, which include Dodor (2012) who studied the feelings and experiences of patients with Tuberculosis in Ghana, Lazarus et al. (2021) who note that some patients experienced fatigue more than coughing in the early stage, and a study by Ambaye and Tsegaye (2021) in selected treatment centres of the Amhara Region in Ethiopia which indicated that most patients with TB experience loss of appetite and vomiting during the early days after diagnosis with TB. A study conducted by Bhatnagar (2019) on the predictors and patterns of weight gain during treatment for Tuberculosis in the United States of America also found that most of the patients that were diagnosed with susceptible tuberculosis firstly presented with either weight loss or poor appetite.

In the local context and in line with this study findings where the majority of patients indicated that their appetite was affected by coughing as every time they want to eat food they would start coughing persistently and lose appetite, which they linked to weight loss, Ricks et al. (2012) note that in Namibia, the more common symptoms among TB were an unintentional weight loss, fatigue, fever and chills. Interestingly, MoHSS (2019) documented that a loss of weight is usually present for some weeks and it is caused by the general malaise associated with the TB disease leading to loss of appetite.

3.3.1.2 Pain

Silver (1958) describes pain in two different contents, in which pleural pain in tuberculosis is either superficial to diseased lung or is referred to a site of similar segmental nerve supply; and parasternal pain is the site of reference from the disease of the apical and posterior segments of the upper lobe of the lung. Another study reveals that some of the usual symptoms that occur with an active TB infection are generalised pain relating to chest pain, rib pain, tiredness or weakness (Srivastava, Gupta, Saxena, Sharma, & Midha, 2017). The experiences encountered by participants in this study show the aspect relating to pain (chest pain, rib pain) on being diagnosed with TB. Some of the participants of this study indicated that they experienced pain pre and post TB diagnosis and such experiences are highlighted in the quotes below:

"When I completed my pills for two weeks, I felt very better I did not have any chest pain and the cough was also gone" [P2].

"I was even having chest pain and that is when I decided to go back to the hospital" [P6].

"...painful in my chest so I came here at Engela hospital" [P11].

"I started feeling cold and I had a sharp pain on the left side of my chest and back, when I realized that the pain was not getting better, I came here at Okatope clinic the nurses referred me for TB test." [P9].

The responses by the participant in this study are not new, Kaeser et al. (2012) on Tuberculosis spondylitis presenting as severe chest pain found that patients with TB presented to the emergency room with severe chest pain and no history of trauma. Participants in this study indicated having either chest pain or rib pain, with some, experiencing the pain after coughing and others experiencing the pain without any associated coughing episodes. Chest pain is usually a result of inflammation of the pleura and lung infarction, usually associated with TB bacteria infiltration of the lungs (MoHSS, 2015). However, a study in Namibia by Seeling et al. (2014) reveals that in as much as chest pain is common among patients with tuberculosis, it is not primarily the main symptom that can be used to determine the symptoms or treatment changes of Tuberculosis in the lungs. Another study in the republic of Tanzania by Makori, Gichana, Oyugi, Nyale and Ransom (2021) shows that tuberculosis bacteria mainly grow in the lungs which could aggravate chest pain. This association of pain with TB infection even post-treatment initiation could have been a reason for some of the patients to default on treatment. Similarly, the absence of pain post treatment initiation (approximately 2 weeks from starting treatment), as described in the following sub theme where patients felt healed/relieved from the chest pains could also have led to patients stopping their medications as they perceived to have recovered from infection.

The National Tuberculosis Treatment Guidelines issued by the Department of Health and Human Services accounted that a person who develops signs and/or symptoms suggestive of Tuberculosis is referred to as a suspected case of Tuberculosis (MoHSS, 2012). The most common symptom of Tuberculosis is a productive cough that lasts for fourteen days and this can be accompanied by other respiratory symptoms (dyspnoea, chest pain and haemoptysis) and/or constitutional symptoms (inappetence, weight loss, fever, night sweats and fatigue). It should be noted that tuberculosis may be diagnosed based on the bacteriological confirmation or based on clinical findings, after which the health professional (clinician or another physician) decides on patient treatment with a full dose of anti-Tuberculosis drugs.

According to a World Health Organization report (WHO, 2017), people infected with TB bacteria develop active TB disease accompanied by symptoms (such as cough, fever, and night sweats poor appetite or weight loss) these symptoms may be mild for many months. The report states that weight loss among people with TB could be caused by several factors including reduced food intake due to loss of appetite, nausea, vomiting and abdominal pain.

3.3.2 Participants' various experiences regarding TB health education from Health Care providers

Health education is a combination of educational experiences designed to help individuals and communities improve their health by increasing their knowledge or influencing their attitudes. Health education should be patient-centred, meaning that each health education session should be designed to address the specific problems of the patient (MoHSS,

2015). This theme aligns with the health care setting factors of the social ecologic model that the researcher used to guide this study.

Most participants of this study indicated that they would have taken TB treatment more seriously only if the health professionals had provided them with comprehensive health education, especially on the duration of TB treatment and on the consequences of lack of adherence to therapy. These sentiments expressed by the participants are consistent with a study by Yadav et al. (2021) on the experiences of secondary school students with pulmonary TB in China, where it was found that most patients did not have sufficient information about the disease and in most cases could not even tell the researcher what the signs and symptoms of TB were. The participants in this study felt that the health providers did not give them the necessary information about the management of TB disease and treatment. In this study, participants felt that they were lost to follow-up because they were ill-equipped on the duration of their treatment, the consequences of not following the treatment and the possibility of collecting their TB medication at any one of the health centre's closest to them, even if it was in another region or district.

It is therefore critical that TB health education to newly diagnosed TB patients covers a whole range of topics to include the duration of TB treatment, the consequences of not adhering to treatment and the side effects of TB drugs as well as advising patients to seek care at any nearest health care facility offering TB services even if it is not the original clinical of diagnosis where treatment was initiated etc. especially when the patient should return to the health centre for treatment follow-up. Non-governmental organisations (NGOs) and civil society organisations like in other countries can actually use a variety

of health education approaches to support the work of the Ministry of Health and Social Services in the Namibian communities.

3.3.2.1 The Duration of TB Treatment

When Mycobacterium tuberculosis enters the body and the immune system is unable to stop the bacteria from multiplying, the condition progresses to become TB disease and the body starts to experience different signs and symptoms of TB (MoHSS, 2019). Tuberculosis diagnosis requires that a patient be put on treatment to destroy the *Mycobacterium* TB. According to the MoHSS treatment guidelines (MoHSS, 2019), drug-susceptible TB is treated with the first-line regimen for 6 months, the initial phase of 2 months with Rifampicin, Isoniazid, Pyrazinamide and Ethambutol (RHZE) followed by the continuation phase of 4 months with Rifampicin, Isoniazid and Ethambutol (RHE).

In their responses to the interview, the study participants stated that the health care workers did not inform them on the duration of their treatment quoted below:

"When I started treatment, they never told me how long I was supposed to take the treatment" [P2].

"This time around they explained everything to me nicely that I will take my pills for 8 months even when I feel better, I should just continue drinking" [P6].

"The nurses never told me that I am supposed to take my TB treatment for 6 months, only now after I was lost to follow up that they gave all the clear information" [P11].

A study by Kamenye (2008) on TB knowledge, attitudes and practice in South Africa concluded that health education efforts be increased to ensure that patients receive

accurate information on the duration of TB treatment and to promote health knowledge and attitudes towards the disease among patients, which is in line with our findings where a lack of health education led to patients being lost to follow up. However, in contrast to the results of this study, a study by Chani (2010) on factors influencing adherence to TB treatment in Andara, Kavango, Namibia, 90% of respondents actually knew that treatment for drug-sensitive TB should be adhered to for six months without interruption.

As indicated earlier, there are many reasons why patients do not take their medication as recommended by the clinicians, for example, because they do not understand the instructions of the treating staff or sometimes the treating staff simply did not provide the patient with health education. In the instance of this study, some participants reported that they were not informed about following their TB medication for six consecutive months without interruption. Providing clear information and education to TB patients is important to ensure adherence to treatment and completing treatment for the indicated duration.

3.3.2.2 Ineffective health education on the consequences of failing to adhere to TB treatment

Tuberculosis treatment requires consistent adherence, meaning one needs to take their TB medication as advised by the health care workers without missing any dose. The consequences of not adhering to TB treatment can lead to the development of drug-resistant TB (Kateta, De Villiers, & Iita, 2018). The increasing number of reported cases of drug-resistant TB in different countries is a major global public health problem (Desta,

Masango, & Nkosi, 2018). It is understood that TB bacteria that are resistant to at least one first-line anti-TB drug cause drug-resistant TB (Brust, Gandhi, Carrara, Osburn, & Padayatchi, 2010). According to the WHO (2017), several factors contribute to the development of drug-resistant TB, some of which are: treating a person on monotherapy while they have active TB, inappropriate combination of drugs, an inadequate dose of drugs, not taking all TB drugs as prescribed, and discontinuation of treatment. Some leading factors are healthcare-related and others, such as discontinuation of treatment, are patient-specific and are often the result of poor health education about TB treatment.

Tuberculosis treatment monitoring is key in making sure the TB bacilli is completely killed off by the prescribed medication. The treatment monitoring is done with different methods such as a collection of follow-up sputum to be tested by the laboratory, measuring the weight and generally assessing how the patient is thriving on treatment to ensure that the patient does not become resistant to the anti-TB medications they are receiving (MoHSS, 2019). It is, therefore, important that when patients are commencing TB treatment, they are informed of the consequences of being non-adherent to TB treatment. Some participants in this study indicated that they were not informed about the consequences of non-adherence to their TB treatment, and this is substantiated by the quotes below:

"It is only now that they told me that I should take my treatment for 6 months because the TB can become resistant so they gave me pills again" *[P2]*.

"No, the nurses are good they do their job very well but maybe because of the overload of work and too many patients they sometimes forget to give us clear instructions because,

to be honest, me I can never miss my follow-ups or maybe to abscond from treatment, how can an old man like me do something like that, it is because of this pills that we are still strong like this they really help us"[P6]

"Only now that I restarted the treatment again that the nurses gave me clear health education, they even told me that TB can become resistant if I do not take my pills well" [P10].

The findings in this study are similar to the findings by Kamenye (2008) on the knowledge, beliefs and practices of patients diagnosed with tuberculosis in Katutura, Windhoek, where the study revealed that ineffective health education contributed to the poor knowledge of treatment by patients. According to Yu et al. (2012), despite having undergone several months of treatment, patients' understanding of TB knowledge remained unsatisfactory and they felt that the health education provided by health professionals was insufficient.

From these findings, it is therefore clear that in most cases, the health education provided by health professionals is not comprehensive enough to provide the basis for an appropriate treatment decision. It should be noted that when patients have accurate and sufficient information about their treatment, they can make more informed decisions about how they manage their condition.

Supporting evidence on the importance of health education was revealed in a report by WHO (2020) on TB-related knowledge, attitudes and practices in South Africa, where

respondents in this study generally had positive attitudes towards TB, possibly due to their knowledge of TB treatment.

3.3.2.3 Ineffective health education on collecting TB medication in other health facilities

It is necessary and considered very important that TB patients initiated on treatment in one health facility be referred to the health facility nearest to them for the continuation of their treatment without inconveniencing the patient. At times, such arrangements are initiated by the healthcare providers and sometimes, at the request of the patients themselves. Such inter-facility transfers may result in a new experience for the patient and may lead to failure to complete the TB treatment, therefore, constant monitoring of the patient is essential. On the other hand, and in most instances, such inter-facility transfer can result in a positive experience for the patient and facilitate good adherence to the TB treatment and completion of the duration of treatment.

Further, the TB Programme management in Namibia also allows patients in cases of emergency or unexpected travels to access TB treatment in any nearby facility without being formally referred, to avoid interruption of the TB treatment (WHO, 2020). A patient who intends to move to another district or region for any other reasons during their TB treatment should inform their current TB clinic health care workers of their intentions, for them to inform the health facility near to where they are going to include them in their monthly medication orders (MoHSS, 2012).

In this study, 8 out of 10 interviewees revealed that they were not aware that they could utilise other health care facilities nearest to them for care and they attributed this lack of knowledge to their lead to defaulting on therapy whenever they had travelled or were far from the clinic where they commenced therapy. Below are quotes from the study participants who felt they did not get sufficient information from the HCWs on collecting TB medication:

"No, when I started treatment, they never told me how long I was supposed to take the treatment, they only gave me pills for a week and later for two weeks. It is only now that they told me that I should take my treatment for 6 months because TB can become resistant so they gave me pills again" [P2]

"I asked because sometimes when I go collect my ARVs, nurses just give me ARVs and say nothing about the TB prevention medication even when they are finished. Am I supposed to remind them?" [P3]

"No, the nurses did not give me any health education and they also never told me how long I was supposed to take my TB treatment only now that I restarted, they explained everything nicely to me that I was supposed to drink my pills for six months even when I felt better I was still supposed to continue" [P4]

"No, we did not go into such a discussion at all, but later on during this treatment of mine, the HCW worker had a discussion with me and she taught me so much about TB" [P5]

"No, not at all, you know the nurses are very busy the clinics are always very full. I don't think they have time for these education sessions, and I really do not blame them as long as they give us our pills to get healed" [P6]

"*No, the HCWs did not give me any health education at all, but I am very much informed about TB because back in those years there were a lot of campaigns on TB they use to go on the radio and TV even house to house, but I do not see these programs happening anymore"* [P7]

"I used to take my pills very well for 3 consecutive months, I never missed any follow-up, the problem only came because I had to go plough at one of our fields that side of Okongo and while I was there, I never knew that I could collect my pills an any nearest clinic even if it is not where I started my treatment" [P9]

"Nothing, they just said I will start the pills and that I will drink the pills for six months and that I could always pick up my pills at the nearest clinic which is Odibo Clinic. They just said I should stop drinking alcohol if I do and that my next follow-up, I should go to Odibo Clinic" [P10]

The above sentiments are similar to the findings of a study by Adane, Alene, Koye and Zeleke (2013) on non-adherence to anti-tuberculosis treatment and determinant factors amongst patients with tuberculosis in Ethiopia. The Ethiopian study revealed that travelling to other places was amongst the most frequent reasons why people got lost to

follow up on TB treatment. Similarly, a study in Morocco on treatment default amongst patients with tuberculosis also found that the most common reason given by the respondents for being LTFU was relocation due to either finding a new job or visiting family members in another district (Ahmad et al., 2021). Results from the above studies are a clear indication that healthcare workers should constantly remind the patients that if they find themselves relocating or moving to a new place, they should inform the healthcare workers about their intentions to ensure continuity of treatment.

However, Kateta et al. (2018) explore that a lot of patients suffer a double-blow of stigma both from the health workers and the family and friends when they relocate or transfer to other health facilities resulting in patients shying away from obtaining TB Medication in most health facilities.

Health is a fundamental human right indispensable for the exercise of other human rights. Every human being is entitled to the enjoyment of the highest attainable standard of health conducive to living a life of dignity. According to the National Health Act, 2 of 2015, every human being in Namibia has the right to access health care at any health facility in Namibia regardless of their origin. It is imperative that when healthcare workers give health education to patients, they also include information about access to health care when patients find themselves in regions or districts where the initial diagnosis of conditions and therapy initiation was not made.

According to the MOHSS guidelines (MoHSS, 2015), TB is diagnosed in clinics and hospitals but thrives in the community, making community-based interventions central to the country's TB efforts. It is understood that being diagnosed with TB does not necessarily mean that the patient should start treatment immediately. It has been found that when patients start TB treatment without appropriate health education and without being provided with the right information in the language and form that the patient understands best, they are most likely going to default on treatment.

3.3.3 Other rationales leading to loss to follow-up

This theme aligns with individual factors of the social ecologic model that lead to LTFU among TB patients.

3.3.3.1 Travelling outside Namibia or away from health facility area

This study was conducted in Engela District Hospital, which is situated in northern Namibia in the Ohangwena Region. Engela District Hospital is along the Namibia-Angola border, hence, the catchment area for this hospital are patients, either living in villages bordering Angola or in Angola. It has been established that inhabitants of the Ohangwena Region, especially those living at the border villages have their crop fields in the neighbouring country Angola whose borders with Namibia are extremely porous, or they move their cattle there for better grazing.

Some of the respondents in this study indicated that they defaulted on their TB treatment and became LTFU because they had gone to Angola to cultivate their sorghum (mahangu) fields. The quotes below reflect this movement to Angola for one reason or the other:

"I don't have an Angolan sim card I only receive calls when I am here in Namibia," [P2].

"When the pills finished the ones I got during my third follow up I was unfortunately in Angola and I had stayed for a very long time there" [P5].

"It is very difficult to get transport going there because the cattle post is far in Angola" [P6].

In his study in South West Ethiopia, Ereso et al. (2021) reveal that travelling usually exposes people to complications of diseases such as tuberculosis and malaria because they tend to neglect their treatment during these travels.

Furthermore, Gobena et al. (2018) highlight the fact that in South-Western Ethiopia, health facilities should be responsible for the provision of anti-TB medicines, monitoring the patient's treatment (clinically and using sputum-smears), as well as tracing the patient who has missed an appointment. The Namibian guidelines state that the treating team which includes the assigned Community Health Worker (CHW) should discuss with the patient how best DOTS can be ensured at the patient's convenience (MoHSS, 2015). It is also the responsibility of the assigned CHW to ensure the patient is referred to the health facility nearest to their place of residence whenever they have travelled. It is very

important to strengthen and enforce these national TB guidelines across all health care centres providing TB services in Namibia.

3.3.3.3 Lack of food/nutrition support

Malnutrition is a risk factor for the development and progression of TB (Hasker et al., 2008). Malnutrition causes reduced proliferation of T-cells and impaired cell-mediated immunity, which in turn leads to increased susceptibility of the patient to infection (Ereso et al., 2021). Heemanshu and Satwanti (2016) stress the many factors that may play a role in the increase of TB worldwide which include socio-demographic factors such as the increase in the population, particularly in countries where the prevalence of TB is already high and many people are living in poverty as in the case of most under developed or third world countries. Consequently, an increase in the people living in poverty could result in overcrowded living conditions, indoor air pollution and malnutrition which increase susceptibility and transmission of TB. To illustrate this point, a participant in this study stated that:

"*I did not continue taking the TB medicine and the other pills because my family leaves me every week, then I couldn't continue to drink them on an empty stomach because no one gives me food and no one supports me at all."* [P8].

Mavenyengwa, Shaduka and Maposa (2017) claim that having a balanced diet improves TB outcomes and speeds up the treatment/recovery process, more so when the patient is on antiretroviral treatment. A balanced diet with high protein content is highly

recommended for TB patients (Sineke et al., 2019). TB patients with advanced HIV infection need additional support if they have gastrointestinal problems such as diarrhoea (MoHSS, 2019) and this is in line with the quoted response above where the patient stopped treatment because they could not take the medication on an empty stomach and also lacked family support.

It is important to note that pre-treatment screening is a crucial aspect in managing TB patients in order to establish whether the patient's socio-economic status will permit the patient to adhere to treatment or not. It is crucial to ensure that healthcare workers perform this screening before any TB patient commences treatment. It is recommended that the following information is obtained from the patient; family set up (number of family members including dependents), risk factors for TB, such as alcohol use, smoking, among others, and employment status and educational level. If the responses indicate an increased risk of socioeconomic instability, such patients are followed up, linked to assistance/care and closely monitored by a social worker within four weeks of commencing treatment for drug-susceptible TB.

3.3.3.4 Indulgence in alcohol

Alcohol use is a major contributing factor to adverse TB treatment outcomes; it is a key driver of poor TB treatment response. In comparison to patients who do not consume alcohol, those who consume alcohol and especially those who engage in heavy episodic drinking were shown to delay TB culture conversion and higher rates of treatment failure, LTFU, relapse and death (Myers, Bouton, Ragan et al., 2018).

In this study, participants quoted on indulgence in alcohol as a reason to LTFU as follow:

"*I started drinking a lot of alcohol which also became a problem"* [P4].

"I just felt better and got too much into alcohol and I missed my follow up" [P9].

The sentiments quoted above are in line with the findings by Ragan et al. (2021) whose study indicates that heavy alcohol use impacted retention in care and was associated with missed follow-ups to health facilities for collection of anti-TB medicines refills. The study by Chani (2010) was of the view that when one is under the influence of alcohol, they are likely to forget to take medication, and even if they do not forget the chances of developing side effects that may subsequently lead to poor compliance are high. Chronic alcohol use has a greater detrimental effect on the immune response to TB. Similarly and in line with this study findings, a study by Kamenye (2008) on the knowledge, beliefs and practice of patients diagnosed with tuberculosis in Katutura, Khomas Region in Windhoek revealed that patients on tuberculosis treatment engaged in behaviour such as drinking alcohol which might make them forget taking their medication as required. The researchers concluded that individual health education should be emphasised to increase awareness on refraining from unhealthy lifestyles to ensure treatment effectiveness (Koenig, 2012). However, regarding the study by Ereso et al. (2021) on factors that contribute to treatment defaulting amongst tuberculosis patients in the Windhoek District, it can be concluded that despite alcohol drinking being a problem, treatment defaulting was more of a behavioural attitude of the patient rather than pinning it on alcohol drinking alone.

TB is a social disease, thus, optimally managing people with TB depends on actions not only within the healthcare sector but outside the health sector as well. TB treatment and care, therefore, needs to be complemented with efforts to address the psychosocial and economic needs of TB patients and their families in a holistic manner (Thekkur et al., 2019). Rehabilitation is a set of interventions designed to optimise function and reduce addiction in individuals, through the interaction with their environment. Patients with drinking problems should be screened thoroughly for any risk of LTFU and they should be on strict directly observed treatment (Srivastava et al., 2017). Therefore, as an HCW, when attempting to rehabilitate defaulting patients who have drinking problems and any other social problems including malnutrition, it is important to take a holistic approach and implement targeted actions based on overall assessments of the affected patients.

3.3.3.5 Feeling of being healed

The feeling of being healed is experienced when one is free from injury, pain, or disease (Endjala, Mohamed, & Ashipala, 2017). According to the MoHSS guidelines (2012), susceptible tuberculosis treatment should be taken for a consecutive six-month duration without interruption to ensure that the TB mycobacterium is completely cleared from the system. The guidelines further state that during the intensive phase of treatment, patients might feel well and cured of the disease approximately within two weeks of beginning treatment and become non-infectious during this time, but this should not be taken as an indication for stopping treatment. Observations made in the Windhoek Central Hospital study (Endjala et. al, 2017) where patients stopped taking their medication once they

started feeling healed are similar to the findings in this study as evidenced in the quotes below:

"When I completed my pills for two weeks, I felt very better I did not have any chest pain and the cough was also gone so I just continue ploughing because I was healed with no complaints at all" [P2].

*"After I took the pills for some time I felt well and better and I just stopped coming to collect the pills" [*P3].

"I just felt better and got too much into alcohol and I missed my follow up" [P9].

The quotes above are also in line with a study conducted by Chani (2010) on factors affecting compliance to tuberculosis treatment in Andara, Kavango Region Namibia as Chani reveals that often when patients commence treatment, they will be very sick and may be inactive. The findings of Chani indicate that having a tendency of non-compliance to treatment once the patients started feeling well or relieved from pain was common with the majority of participants failing to complete TB medication as a result of this transition from pain to being pain-free.

More than half of the defaulters interviewed in this study reported that they defaulted treatment because they thought that they were cured when their health status improved. It is well known that as TB treatment progresses and the condition improves, TB symptoms start to regress, and the improvement in itself may become a barrier to the continuation of treatment. The patient might not see the need to continue with treatment when they are feeling better or well. Endjala et al. (2017) found that a lack of knowledge on TB treatment and the implications of defaulting on treatment was a factor that

influenced LTFU. This is an indication that either the information about the six-month duration of treatment was not given at the time of therapy initiation or that the information given by the health care provider was not well assimilated by the patients. It is very important for health care providers to ensure that the message around the importance of strict adherence to TB treatment for the entire prescribed duration is well understood by all TB patients initiating therapy.

3.3.3.5 Fear of losing jobs

Individual reactions to changing characteristics of job conditions or availability depend on several factors, such as labour market, individual character and level of education (Yadav, John, Allarakha, & Menon, 2021). The fear of job loss majorly originates from the anticipation of an involuntary job move, people who constantly worry about losing their jobs are usually suffering from some kind of disease. In this study, the majority (81.8%) of the participants had a very low level of education and for those of economically productive age, job insecurity was a challenge especially when accompanied by ill health and obligations of frequent hospital visits. Only two participants in the study were employed and both of them indicated that they feared losing their jobs hence they did not report their conditions to their bosses and ceased going to the hospital to collect their TB medications, their responses are quoted below:

"I use to work for a Chinese and I use to knock off very late and I never told him that I was diagnosed with TB so I could not get out of work to come to the follow-ups." [P4].

"I feared to report to my Boss as I feared that I might lose my job if he realises that I was diagnosed with tuberculosis" [P3].

The study findings are supported by Gyimah and Dako-Gyeke (2019), whose study on the perspectives of TB patients' care and support in Ghana, reveals that all the patients diagnosed with TB had to quit their respective jobs at the commencement of treatment due to unfavourable work policies, lack of strength and fear of stigma by colleagues. Furthermore, the majority of the participants were artisans and drivers who depended on physical strength to work similarly to our study where some of the participants were cattle herders. Thus, the physical weakness experienced during the illness and therapy phase incapacitated patients to continue working (Gyimah & Dako-Gyeke, 2019).

A similar study conducted by Thekkur et al. (2019) in India indicates that regular illness of patients with tuberculosis led to job losses in the formal and informal sectors. Workplace policies in India were restructured proposing that employers should not discriminate on recruiting individuals based on their disease/health status. It is envisaged that these policy changes will ensure treatment adherence and prevent further transmission of the infection. Additionally, the policy emphasises that the employers should consider the re-arrangement of working hours, opportunities for rest breaks, time off for medical appointments, flexible sick leaves and return to work arrangements (Heemanshu & Satwanti, 2016). These findings, similar to this study, imply an interruption of normal day to day work activities or the need to stop going to work as a serious social consequence of TB infection. This factor highlights the need for policy changes in Namibia to favour employees diagnosed with infections that may require them to frequently visit the health care centres for care.

3.4 Summary of the Chapter

This chapter presented and discussed the findings from the study. The researcher conducted eleven individual interviews altogether. The interviews were conducted at different sites in Engela District depending on the participant's preference. It was noted in the study that the study participants had different experiences pre and post TB therapy initiation. All the eleven participants interviewed indicated that they experienced at least one of the expected signs and symptoms of TB infection which include a cough, poor appetite, weight loss, pain (chest and/or rib pain) fever and chills on being diagnosed with TB.

Regarding factors that led to the participants defaulting on their TB treatment, the following factors were raised which include fear of losing jobs, insufficient health education on TB treatment from the attending healthcare providers, especially on the duration of treatment, consequences of defaulting on treatment and seeking care at any other health facility closest to the patient. Other factors were patients stopping the medication because they felt they had been healed, having travelled outside their area of health care, thus, not knowing how to seek care wherever they will be, a lack of food/adequate nutritional support and indulgence in alcohol. The following chapter unravels the study findings that will guide the conclusion and recommendations.

CHAPTER FOUR

CONCLUSIONS, RECOMMENDATIONS AND LIMITATIONS

4.1 Introduction

The previous chapter dealt with data analysis, discussions of findings and literature control. Data analysis was conducted using Tesch's eight steps. Three themes were identified from the experiences of patients diagnosed with drug-susceptible tuberculosis leading them to be lost to follow-up whereby both their positive and negative experiences were discussed.

This chapter will focus on conclusions, recommendations and limitations based on the study's findings. Conclusions drawn from the findings are related to the research's main aim which is to explore and describe the experiences of patients diagnosed with drug-susceptible tuberculosis regarding lost to follow-up. This study's recommendations emphasise the need for supportive care towards patients diagnosed with drug-susceptible tuberculosis as well as healthcare providers capacity building on active listening, health literacy, message-framing, motivational interviewing, communication skills for trust-building to enable them to provide comprehensive care for newly diagnosed TB patients initiating treatment.

4.2 Conclusions

The following section will discuss the conclusions of this study. The conclusions were derived from analysis of the study findings supported by existing literature, which will be discussed in line with the objectives achieved by the study.

Objective 1: Explore the experiences of patients diagnosed with drug-susceptible tuberculosis regarding loss to follow-up.

The researcher explored the experiences encountered by the study participants before TB diagnosis and post-diagnosis. The study findings revealed that before diagnosis was made at the various clinics, the majority of the participants had at some point in time experienced at least one or a combination of initial symptoms of TB infection which included episodes of coughing, pain (chest and rib pain), loss of appetite and weight loss.

Upon diagnosis, the participants of this study feared the stigma associated with TB diagnosis and those who were employed did not disclose the TB status to their employers for fear of losing their jobs as following up TB care would include frequent visits to the health care facilities for medication top-up and tests as well as possible repeated absenteeism due to ill health. This finding indicates serious social consequences faced by TB patients which may include career disruptions because of TB infection. In addition, most of the participants felt that they did not get adequate health education about TB management before they were initiated on therapy. The information that the participants felt could have helped them manage their conditions better and adhere to TB treatment included duration of treatment, accessibility of health care especially when they have travelled outside the area of the clinic where the initial diagnosis was made and the consequences of defaulting treatment. Considering that most of the participants had experienced symptoms of TB once they started taking the medication and the symptoms subsided, they felt they had been healed and some of them stopped taking medication as soon as they started feeling well. This indicates that either they did not receive

information from the attending clinicians on the importance of taking the medication continuously for a period of six months even if the symptoms were clear, or through the message was communicated it was not clearly understood by the patient.

It was concluded that as most patients indicated feeling pain prior to commencing treatment, some defaulted on therapy once they started feeling better or felt healed. Stigma and inadequate information on patient TB management were also major hindrances to TB treatment adherence. It is therefore critical to prioritise the provision of appropriate and patient-centred health education to TB patients prior to initiating treatment. The information provided by the health worker should be in a language and format that the patient understands best otherwise the lack of comprehension of the message by the patient would lead them to default on therapy. Strong emphasis on strict adherence to prescribed medication for the entire six months duration without ceasing should be made with constant follow-up by health workers in order to reduce the number of TB patients lost to follow-up.

Objective 2: Describe the experiences of patients diagnosed with drug-susceptible tuberculosis regarding lost to follow-up.

A description of experiences was done by analysing data according to Tesch's eight steps and the social ecologic model. The data were categorised into themes and sub-themes. Three themes emerged from this analysis namely the diagnosis and treatment factors where patients described their experiences upon TB diagnosis, health-care setting factors describing patients' views/perceptions regarding their attending healthcare providers, and

lastly, other rationales leading to LTFU including travelling outside the area of health facility they are receiving care, alcohol indulgence and a lack of proper nutrition and family support.

Participants expressed that before their diagnosis, they suffered from various symptoms of TB infection which caused them immense discomfort and affected their quality of life. However, after diagnosis and initiating TB treatment, some of them started feeling better and that effect of feeling healed led them to stop their medication. Others indicated that they feared the stigma associated with TB infection therefore they did not disclose their status to their employers for fear of losing their jobs because they could not be released from work for follow-up clinic visits and ended up defaulting on treatment.

The majority of the participants revealed that they did not get sufficient TB management health information from the health providers and this lack of knowledge on the serious effects of defaulting led them to stop their treatment for one reason or the other, more so, when they were relieved of the TB symptoms after some time of taking the medication. Other reasons for defaulting cited were having travelled to the neighbouring country Angola to farm or visit relatives in other areas, and once there, the patients did not know that they could access TB care at the nearest health care facility. Therefore, when they finished their medication supply, they discontinued treatment altogether. A lack of adequate nutrition and alcohol indulgence was also indicated as a cause of defaulting, especially among patients who lacked family or community support.

It can be concluded that constant health care provider, family and community support is essential to ensure TB patients adhere to their treatment and better manage their condition. The level of support needed by the TB patients includes physical, psychological, educational and financial support. To ensure that patients are not lost to follow up, it is essential to holistically assess TB patients for their different needs before therapy initiation in order to address the kind of support required for each case.

4.3 Recommendations

The recommendations set out below for this study are based on the conclusions drawn from the two objectives of this study: The recommendations were categorised into patient management, health education, future research and contribution to the body of knowledge. Based on the findings, the researcher makes the following recommendations:

4.3.1 Patient management

It is essential to develop evidence-based holistic interventions that address organisational and administrative health system barriers and change HCW attitudes towards TB patients. These interventions should aim towards making it easier for patients to manoeuvre the health system, educating HCWs so that they can educate the newly diagnosed patients prior to treatment initiation, and minimise the limitations that hinder HCWs from effectively executing their tasks. It is also recommended to decentralise treatment, that is to transfer care from a centralised TB treatment centre to a community DOTS facility. This will allow easy access to care for the patient and also an easier follow-up of TB patients by health providers e.g., community health workers allowing patient retention on

treatment. Adherence to TB treatment might also be improved through the provision of sufficient and timely financial assistance to patients in need (especially for transportation and food) by providing livelihood programs during and after TB treatment through strategic partnerships with NGOs and other stakeholders.

Creating an environment that cultivates a high degree of trust, good rapport, and support from providers is associated with patients' adherence to medical recommendations. Hence, this intervention is recommended for all health facilities offering TB diagnosis and treatment services. Lastly, the development and implementation of labour policies and laws that protect sick employees and enhance chances of treatment adherence are of great importance so that the employees do not fear disclosing their ill health and seeking health care at the appropriate times improving their chances of recovery and survival.

4.3.2 Health Education

Healthcare provider training concerning active listening, health literacy, message-framing, motivational interviewing, communication skills for trust-building and sensitivity should be seriously considered. This aspect is important in strengthening provider-patient mutual trust and respect. It is very important and necessary to educate TB patients and their caregivers on aspects around what causes TB infection, how it is transmitted, diagnosis of the disease, what the test results mean, the reasoning behind prolonged TB treatment, as well as the consequences of defaulting treatment and the anticipated side effects of the drugs. Ideally, all this information should be shared with

the newly diagnosed patients before treatment is initiated in order to avert defaulting during the treatment.

As community support has been shown to increase chances of patient adherence to therapy, a community-based health education program about TB Management can be introduced. Such a program can create awareness and knowledge in the community about the disease, and how to address the existing misconceptions about drug-susceptible tuberculosis that are likely to influence how patients manage their conditions. In order to make the community health awareness accessible to all without discrimination, visual infection prevention and control (IPC) materials can be prepared to accommodate those who are illiterate.

4.3.3 Future Research

Future studies may consider assessing the effectiveness of using standard screening tools prior to initiating treatment among TB patients to guide patient-centred care for example an assessment tool to screen for alcohol dependence as part of TB clinical services. Besides, assessing healthcare workers' knowledge, attitudes and practices regarding the management of patients diagnosed with drug-susceptible tuberculosis may be useful to establish the reason behind the communication disconnect between HCWs and TB patients. Lastly, another area that may be worth pursuing is expanding the scope of this study by retrospectively assessing the experiences of TB patients who were lost to follow-up but did not survive the illness, this will help better understand the various circumstances leading to poor prognosis culminating in death.

4.3.4 Contribution to the Body of Knowledge

Understanding the driving forces leading to LTFU among TB patients is critical in devising policies in Namibia and other countries facing similar challenges promoting adherence to therapy, therapy counselling and buddies and support services for patients initiating TB treatment. The scientific evidence gained will help policymakers and healthcare services in decision making, legal protection of TB patients especially working patients and changing societal norms. Improved communication/health education talks on TB management are needed for patients with TB, their families, community members and healthcare providers. These study findings may inform patient-centred interventions that may be applied to various groups of TB patients of different social statuses to reduce loss to follow-up during TB treatment in Namibia.

4.4 Limitations of the Study

The study was subject to several limitations which include:

Population effect: The researcher had a small sample size making it difficult to determine if our study outcomes were true findings. The study setting was only limited to Engela District which has a different geographical, social and cultural orientation to some of the districts in the country, therefore, it may be difficult to generalise our findings to the Namibian population as well as those of other countries, unlike, if the researcher had covered more districts in Namibia allowing generalisability. This study also used non-probability purposive sampling data sampling methods, thus, it is impossible to know how well the researcher represented the population.

Data Collection and data analysis effects: Translation of study concepts and questions from English to the local Oshiwambo language may have affected the way the researcher delivered the interview as this was a rural setting where most of the participants had not attained secondary level education, thus, making it difficult for them to fully understand English. The local language responses from the participants also had to be translated back to English to allow for data analysis, the translation could have introduced some mistakes/gaps affecting study outcome. Another element that could have affected the outcome of the study was the selective memory (recall bias) and exaggeration bias etc. that could have been introduced through the self-reported data that was collected from the participants through interviews.

Participant's effects: The researcher being a nurse that was well known in the area of study may have affected the way that the participants responded to the questions due to the researcher unconsciously behaving in certain ways to participants that will elicit particular responses. Patients usually tend to respond in a manner that they know the clinician would want to hear. Interview responses may reflect socially desirable answers rather than true thoughts and experiences.

Despite these limitations, this study provides useful data as the interviews conducted captured patients' perspectives and provided distinctive meanings that retrospective cohort studies lack.

4.5 FINAL CONCLUSION

In this qualitative study, it was found that LTFU of TB patients is an intricate problem involving a wide array of factors leading to patients discontinuing treatment before the prescribed duration of six months. The most common finding was the role of health care providers in failing to provide adequate information to TB patients on TB treatment and the importance of adherence to therapy at all costs. Other contributing factors such as stigma at work and in the community, alcohol indulgence, a lack of proper nutrition and having travelled far away from the area where they initiated treatment were also linked to defaulting therapy.

It is critical and essential to develop holistic LTFU mitigation strategies/interventions aimed at improving organisational and administrative health system challenges impeding health education delivery and provision of patient-centred care by healthcare workers. This approach to address identified gaps in the health care delivery system requires a collaborative effort from all relevant stakeholders including clinicians (nurses and doctors), policymakers, government and political leaders, implementing partners (NGOs etc.), patients and the community at large.

In addition to addressing healthcare delivery challenges, it is also important to look into changing labour policies and laws that disadvantage sick people in the workplace. Employees should be allowed to take sick leave when feeling ill and unable to carry out their work duties, be assigned to tasks that will not pose danger to their vulnerable health status, time off for medical appointments. re-arrangement of working hours, opportunities

for rest breaks etc. Implementing such measures will reduce the stigma associated with having TB or any other deadly infection and lower the chances of affected employees being lost to follow-up for treatment.

The researcher believes that this study will significantly contribute to alleviating the effects of the TB scourge and the development of drug-resistant TB strains, leading to better recovery and survival rates of TB patients.

REFERENCES

Adane, A. A., Alene, K. A., Koye, D. N., & Zeleke, B. M. (2013). Non-adherence to anti-tuberculosis treatment and determinant factors among patients with tuberculosis in Northwest Ethiopia. *PloS one, 8*(11), e78791.

Ahmad, M., Stanikzai, M. H., Rahimy, N., Wasiq, A. W., & Sayam, H. (2021). Diagnostic accuracy of Ziehl-Neelsen smear microscopy in comparison with GeneXpert in pulmonary tuberculosis: A Multi-center study in Kandahar Province, Afghanistan. *Culture, 6*, 9-12.

Ambaye, G. Y., & Tsegaye, G. W. (2021). Factors associated with Multi-drug resistant tuberculosis among TB patients in selected treatment centers of Amhara Region: A case-control Study. *Ethiopian Journal of Health Sciences, 31*(1).

Bhatnagar, H. (2019). User-experience and patient satisfaction with quality of tuberculosis care in India: A mixed-methods literature review. *Journal of Clinical Tuberculosis and other Mycobacterial Diseases, 17*, 100127.

Bertram, C., & Christiansen, I. (2014). *Understanding research*. Pretoria: Van Schaik Publishers.

Brust, J. C., Gandhi, N. R., Carrara, H., Osburn, G., & Padayatchi, N. (2010). High treatment failure and default rates for patients with multidrug-resistant

tuberculosis in KwaZulu Natal, South Africa, 2000–2003. *The International Journal of Tuberculosis and ung Disease, 14*(4), 413-419.

Cambridge Dictionary. (2019). Definitions of terms (Online). Retrieved from: https://dictionary.cambridge.org/dictionary/english/diagnose [accessed 15 November 2020].

Centers for Disease Control and Prevention. Colorectal Cancer Control Program. Social ecological model of health promotion [cited 2014 Jan 8]. http://www.cdc.gov/cancer/crccp/sem.htm

Chani, K. (2010). *Factors affecting compliance to tuberculosis treatment in Andara Kavango Region Namibia.*

Creswell, J. (2014). *Research Design* (4th ed.). California: Sage Publications.

Creswell, J. W., & Poth, C. N. (2016). *Qualitative inquiry and research design: Choosing among five approaches*: Sage publications.

Crotty, M. (2013). *The foundations of social research: Meaning and perspective in the research rocess*. London; Thousand Oaks, Calif: *Sage Publications*.

Desta, K. T., Masango, T., & Nkosi, Z. Z. (2018). Performance of the national tuberculosis control program in the post conflict Liberia. *PloS one, 13*(6), e0199474.

De Vos, A. S., Strydom, H., Fouche, C. B., & Delport, C. S. L. (2011). *Research at grass roots: For the social sciences and human service professions* (4th ed.). Pretoria: Van Schaik.

Dodor, E. (2012). The feelings and experiences of patients with tuberculosis in the Sekondi-Takoradi metropolitan district: Implications for TB control efforts. *Ghana Medical Journal, 46*(4), 211.

Edmonds, W. A., & Kennedy, T. D. (2013). *An applied reference guide to research design: Quantitative, qualitative, and mixed methods*. United States of America: Sage Publications.

Endjala, T., Mohamed, S., & Ashipala, D. O. (2017). Factors that contribute to treatment defaulting amongst tuberculosis patients in Windhoek District, Namibia. *Clinical Nursing Studies, 5*(4), 12.

Ereso, B. M., Sagbakken, M., Gradmann, C., & Yimer, S. A. (2021). Treatment outcomes of patients with drug-sensitive tuberculosis under community-based versus

facility-based directly observed treatment, short course strategy in Southwest Ethiopia: A prospective cohort study. *BMJ Open, 11*(7), e048369.

Fox, W., & Bayat, M. (2014). *A guide to managing research.* Cape Town: Juta & Co Ltd.

Guba, E. G., & Lincoln, Y. S. (1994). Competing paradigms in qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research (pp. 105-117)*. Thousand Oaks, CA: Sage.

Gebre-Mariam, M. K. (2009). *Adherence to treatment of Tuberculosis in patients with TB/HIV Co-infection on concomitant treatment in Addis-Abeba, Ethiopia.*

Gobena, D., Ameya, G., Haile, K., Abreha, G., Worku, Y., & Debela, T. (2018). Predictor of multidrug resistant tuberculosis in southwestern part of Ethiopia: A case control study. *Annals of Clinical Microbiology and Antimicrobials, 17*(1), 1-7.

Golden S. D, & Earp, J. A. L. (2012). Social ecological approaches to individuals and their contexts: twenty years of health education & behavior health promotion interventions. Health Educ Behav.;39:364–72. DOIExternal LinkPubMedExternal LinkGoogle ScholarExternal Link

Guba, E. G., & Lincoln, Y. S. (2015). *Fourth generation evaluation*. Newbury Park, CA: Sage.

Gyimah, F. T., & Dako-Gyeke, P. (2019). Perspectives on TB patients' care and support: a qualitative study conducted in Accra Metropolis, Ghana. *Globalization and Health, 15*(1), 1-9.

Hasker, E., Khodjikhanov, M., Usarova, S., Asamidinov, U., Yuldashova, U., van der Werf, M. J., & Veen, J. (2008). Default from tuberculosis treatment in Tashkent, Uzbekistan. Who are these defaulters and why do they default? *BMC Infectious Diseases, 8*(1), 1-7.

Heemanshu, A., & Satwanti, K. (2016). Determinants of lost to follow up during treatment among tuberculosis patients in Delhi. *Int J Med Res Health Sci, 5*(1), 145-152.

Heymann, D. (2015). *Control of communicable diseases.* London: APHA Press.

Holloway, S., & Wheeler, I. (2010). *Qualitative research in nursing and healthcare* (3rd ed.). Malaysia: Vivar Printing.

Hulley, S. B, Cummings, S. R, Browner, W. S, Grady, D. G, & Newman, T. B. (2012). *Designing clinical research*. PA: Lippincott Williams & Wilkins.

Kaeser, M. A., Kettner, N. W., Albastaki, U., Kotb, H. A., Eldesouky, I., & Pierre-Jerome, C. (2012). Tuberculous spondylitis presenting as severe chest pain. *Clinics and Practice, 2*(2), 100-103.

Kakili, T. (2010). Factors that contribute to treatment defaulting amongst tuberculosis patients in Windhoek district, Namibia.

Kamenye, E. (2008). *A study on the knowledge, beliefs and practices of patients diagnosed with tuberculosis in Katutura, Khomas Region, Namibia.* Citeseer,

Kateta, E., De Villiers, J., & Iita, H. (2018). *Knowledge, attitudes and practices of patients diagnosed with Tuberculosis related to Tuberculosis treatment adherence in Keetmanshoop district, Namibia.* University of Namibia,

Kizito, K., Kingori, M., Dunkley, S., & Reid, T. (2011). Lost to Follow up from Tuberculosis treatment in an urban informal settlement (Kiberia) Nairobi, Kenya. *Transactions of the Royal Society of Topical Medicine and Hygiene*. Nairobi, Kenya.

Koenig, H. G. (2012). *Spirituality and health research: Methods, measurements, statistics, and resources*: Templeton Foundation Press.

Kuhn, T. (2012). *The structure of scientific revolutions*. Chicago, IL: University of Chicago Press.

Lazarus, G., Tjoa, K., Iskandar, A. W. B., Louisa, M., Sagwa, E. L., Padayatchi, N., & Soetikno, V. (2021). The effect of human immunodeficiency virus infection on adverse events during treatment of drug-resistant tuberculosis: A systematic review and meta-analysis. *PloS one, 16*(3), e0248017.

Leedy, P. D., & Ormrod, J. E. (2010). *Practical research: Planning and design* (9th ed.). New York: Pearson Education.

Li, M. S., Musonda, P., Gartland, M., Mulenga, P. L., Mwango, A., Stringer, J. S., & Chi, B. H. (2013). Predictors of patient attrition according to different definitions for loss to follow-up: a comparative analysis from Lusaka, Zambia. *Journal of Acquired Immune Deficiency Syndromes (1999), 63*(3), e116.

Lix L, Smith, M., Azimaee, M., Dahl, M., Nicol, P., Burchill, C., … Bailly, A. (2012). *A Systematic Investigation of Manitoba's Provincial Laboratory Data*. Winnipeg, MB: Manitoba Centre for Health Policy.

LoBiondo-Wood, G., & Haber, J. (2010). *Nursing research: Methods and critical appraisal for evidence-based practice* (7th ed.). China: Elsevier.

Makori, L., Gichana, H., Oyugi, E., Nyale, G., & Ransom, J. (2021). Tuberculosis in an urban hospital setting: Descriptive epidemiology among patients at Kenyatta National Hospital TB clinic, Nairobi, Kenya. *International Journal of Africa Nursing Sciences*, 100308.

Mavenyengwa, R. T., Shaduka, E., & Maposa, I. (2017). Evaluation of the Xpert® MTB/RIF assay and microscopy for the diagnosis of Mycobacterium tuberculosis in Namibia. *Infectious diseases of poverty, 6*(1), 1-5.

MoHSS (2012). *National Guidelines for the Management of Tuberculosis.* Windhoek: Namibia.

MoHSS (2015). *National Tuberculosis and Leprosy Programme Summary Report 2014-15*. Windhoek, Namibia

MoHSS (2019). *National Guidelines for the Management of Tuberculosis*. Windhoek, Namibia.

Nawa, E., Tjijenda, V., Moyo, S. R., & Hamatui, N. (2020). Evaluating risk factors associated with pulmonary tuberculosis among Namibian health care workers.

Ministry of Health and Social Services (2012). *National Guidelines for the Management of Tuberculosis.* Windhoek, Namibia.

Ministry of Health and Social Services (2015). *Tuberculosis Annual Report.* Windhoek, Namibia.

Ministry of Health and Social Services. (2017). *Guidelines for the Management of Drug-Resistant Tuberculosis in Namibia* (2nd ed.). Windhoek, Namibia.

Park J, Lee J, Lee Y, et al. (2016). Serum levels of antituberculosis drugs and their effect on tuberculosis treatment outcome. *Antimicrob Agents Chemother*, *60*(1), 92-98. doi:http://dx.doi.org/10.1128/AAC.00693-15.

Pequegnat, W., Strover, E., & Boyce, C. A. (2010). *How to write a successful research grant application: A guide for social and behavioural scientist*? New York: Springer.

Ragan, E. J., Gill, C. J., Banos, M., Bouton, T. C., Rooney, J., Horsburgh, C. R., Jacobson, K. R. (2021). Directly observed therapy to measure adherence to tuberculosis medication in observational research: Protocol for a prospective cohort study. *JMIR Research Protocols, 10*(6), e24510.

Ricks, P. M., Mavhunga, F., Modi, S., Indongo, R., Zezai, A., Lambert, L. A., . . . Holtz, T. H. (2012). Characteristics of multidrug-resistant tuberculosis in Namibia. *BMC Infectious Diseases, 12*(1), 1-8.

Seeling, S., Mavhunga, F., Thomas, A., Adelberger, B., & Ulrichs, T. (2014). Barriers to access to antiretroviral treatment for HIV-positive tuberculosis patients in Windhoek, Namibia. *International journal of mycobacteriology, 3*(4), 268-275.

Shah, N. S., Auld, S. C., Brust, J. C., Mathema, B., Ismail, N., Moodley, P., & Mthiyane, T. (2017). Transmission of extensively drug-resistant tuberculosis in South Africa. *New England Journal of Medicine, 376*(3), 243-253.

Silver, C. (1958). Tuberculous infection in East London school children. *Tubercle, 39*(4), 206-212.

Srivastava, K., Gupta, A., Saxena, R., Sharma, R., & Midha, T. (2017). Patient's satisfaction regarding directly observed treatment short course under RNTCP in a district of North India. *Int J Commun Med Public Health, 4*(5), 1536-1541.

Tappen, R. M. (2011). *Advanced nursing research: From theory to practice*. United States of America: Sudbury.

Tesch, R. (2019). Computer software and qualitative analysis: A reassessment. In *New technology in sociology* (pp. 141-154): Routledge.

Thekkur, P., Kumar, A. M., Chinnakali, P., Selvaraju, S., Bairy, R., Singh, A. R., Shastri, S. (2019). Outcomes and implementation challenges of using daily treatment regimens with an innovative adherence support tool among HIV-infected tuberculosis patients in Karnataka, India: a mixed-methods study. *Global health action, 12*(1), 1568826.

Tola, H., Tol, A., Shojaeizadeh, D., & Garmaroudi, G. (2015). Tuberculosis treatment non-adherence and lost to follow up among TB patients with or without HIV. *Iranian Journal of Public Health*.

Tupasi, T. E., Garfin, A. G., Kurbatova, E. V., Mangan, J. M., Orillaza-Chi, R., Naval, L. C....Sarol, J. N. (2016). Factors associated with loss to follow-up during treatment for multidrug-resistant tuberculosis, the Philippines, 2012–2014. *Emerging Infectious Diseases*, *22*(3), 491-502. https://dx.doi.org/10.3201/eid2203.151788.

World Health Organization. (2017). Treatment of tuberculosis: Guidelines for treatment of drug-susceptible tuberculosis and patient care (Online). Retrieved from: https://apps.who.int/iris/bitstream/handle/10665/255052/9789241550000-eng.pdf?sequence=1 [accessed 16 November 2020].

WHO (2017). Guidelines for treatment of drug-susceptible tuberculosis and patient care.

WHO (2020). Health policy and system support to optimize community health worker programmes for HIV, TB and malaria services: an evidence guide.

Yadav, J., John, D., Allarakha, S., & Menon, G. R. (2021). Rising healthcare expenditure on tuberculosis in India: Can India achieve the End-Tb goal? *Tropical Medicine & International Health*.

Yu, X., Prados-Rosales, R., Jenny-Avital, E. R., Sosa, K., Casadevall, A., & Achkar, J. M. (2012). Comparative evaluation of profiles of antibodies to mycobacterial capsular polysaccharides in tuberculosis patients and controls stratified by HIV status. *Clinical and Vaccine Immunology, 19*(2), 198-208.

APPENDIXES

Appendix A: Ministry of Health and Social Services Namibia, Permission to Conduct Study

ID.10496

REPUBLIC OF NAMIBIA

Ministry of Health and Social Services

Private Bag 13198
Windhoek
Namibia

Ministerial Building
Harvey Street
Windhoek

Tel: 061 – 203 2507
Fax: 061 – 222558
E-mail: jtashipu87@gmail.com

OFFICE OF THE EXECUTIVE DIRECTOR

Ref: 17/3/3 KV
Enquiries: Mr. A. Shipanga

Date: 19 September 2019

Ms. Kakunavali Venokulavo
PO Box 120
Oshakati
Namibia

Dear Ms. Venokulavo

Re: Experiences patients diagnosed with drug susceptible Tuberculosis regarding lost-to-Follow-up in Engela district, Ohangwena region, 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;

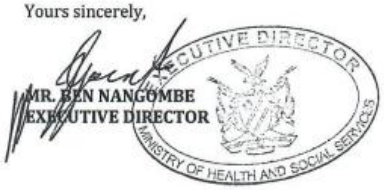
3.5 Preliminary findings to be submitted upon completion of the study;

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.

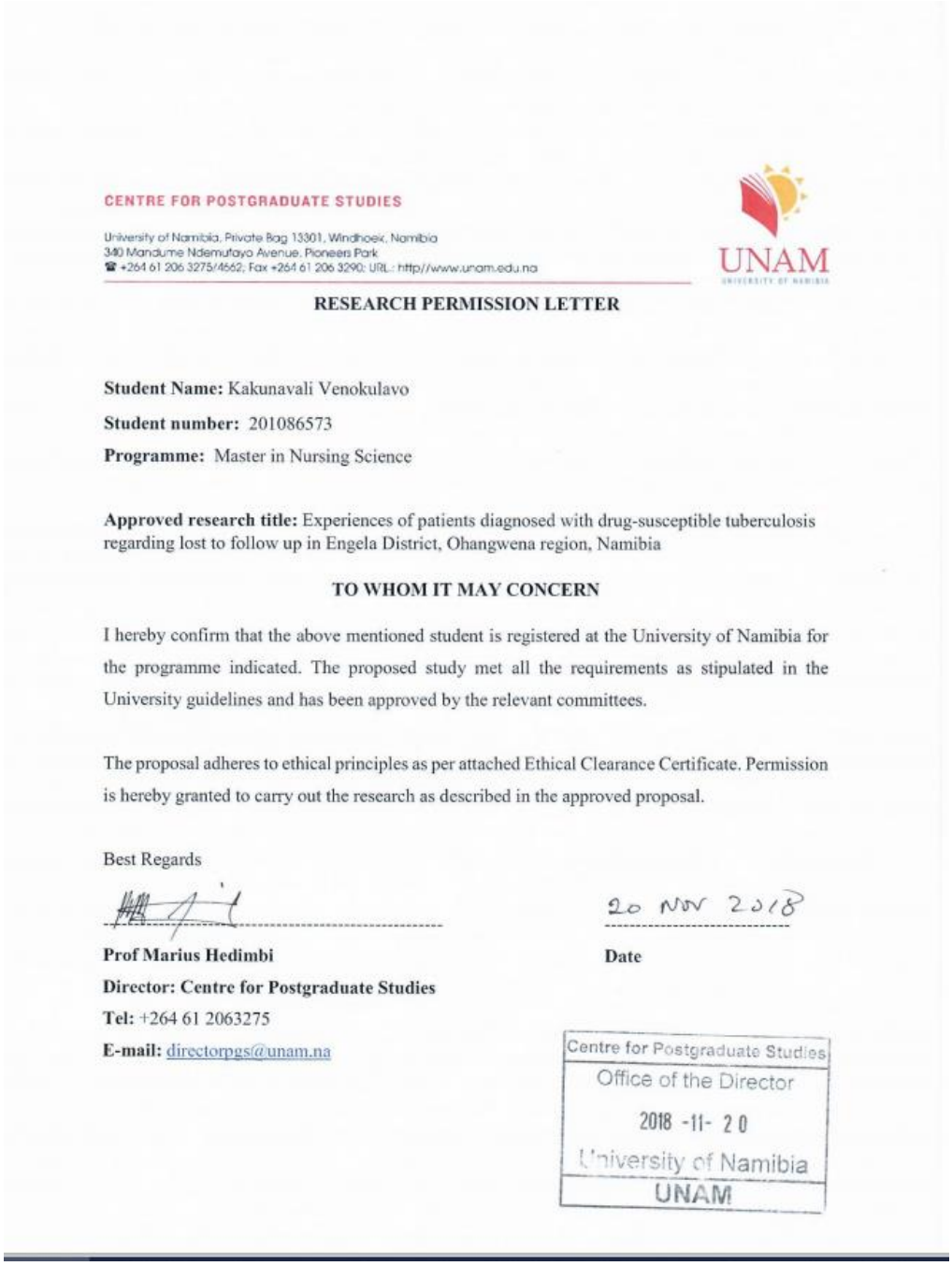
Yours sincerely,



MR. BEN NANGOMBE
EXECUTIVE DIRECTOR

"Health for All"

Appendix B: Permission letter from University of Namibia postgraduate committee to conduct a research study



CENTRE FOR POSTGRADUATE STUDIES

University of Namibia, Private Bag 13301, Windhoek, Namibia
340 Mandume Ndemufayo Avenue, Pioneers Park
☎ +264 61 206 3275/4662; Fax +264 61 206 3290; URL: http://www.unam.edu.na

UNAM
UNIVERSITY OF NAMIBIA

RESEARCH PERMISSION LETTER

Student Name: Kakunavali Venokulavo

Student number: 201086573

Programme: Master in Nursing Science

Approved research title: Experiences of patients diagnosed with drug-susceptible tuberculosis regarding lost to follow up in Engela District, Ohangwena region, Namibia

TO WHOM IT MAY CONCERN

I hereby confirm that the above mentioned student is registered at the University of Namibia for the programme indicated. The proposed study met all the requirements as stipulated in the University guidelines and has been approved by the relevant committees.

The proposal adheres to ethical principles as per attached Ethical Clearance Certificate. Permission is hereby granted to carry out the research as described in the approved proposal.

Best Regards

20 NOV 2018

Prof Marius Hedimbi
Director: Centre for Postgraduate Studies
Tel: +264 61 2063275
E-mail: directorpgs@unam.na

Date

Centre for Postgraduate Studies
Office of the Director
2018 -11- 20
University of Namibia
UNAM

Appendix C: UNAM Ethical Clearance Letter

UNAM
UNIVERSITY OF NAMIBIA

ETHICAL CLEARANCE CERTIFICATE

Ethical Clearance Reference Number: SON /559/2020 **Date: 6 February, 2020**

This Ethical Clearance Certificate is issued by the University of Namibia Research Ethics Committee (UREC) 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 Faculty/Centre/Campus Research & Publications Committee sitting with the Postgraduate Studies Committee.

Title of Project: Experiences Of Patients Diagnosed With Drug-Susceptible Tuberculosis Regarding Lost To Follow Up In Engela District, Ohangwena Region, Namibia

Researcher: KAKUNAVALI VENOKULAVO

Student Number: 201086576

Supervisors: Dr E. Kamenye (Main) Ms. O. Tuhadeleni (Co)

Faculty: School of Nursing
Take note of the following:

(a) Any significant changes in the conditions or undertakings outlined in the approved Proposal must be communicated to the UREC. An application to make amendments may be necessary.
(b) Any breaches of ethical undertakings or practices that have an impact on ethical conduct of the research must be reported to the UREC.
(c) The Principal Researcher must report issues of ethical compliance to the UREC (through the Chairperson of the Faculty/Centre/Campus Research & Publications Committee) at the end of the Project or as may be requested by UREC.
(d) The UREC 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.

UREC wishes you the best in your research.

Dr. J.E. de Villiers: Chairperson

Ms. P. Claassen: Secretary

Appendix C: Consent Form

TITLE: EXPERIENCES OF PATIENTS REGISTERED AS TREATMENT AFTER LOST TO FOLLOW-UP AMONGST PATIENTS DIAGNOSED WITH DRUG-SUSCEPTIBLE TUBERCULOSIS IN ENGELA DISTRICT, OHANGWENA REGION

Researcher: Kakunavali Venokulavo

Dear participant

My name is Kakunavali Venokulavo, a registered student with the University of Namibia, doing a Master's Degree in Nursing. I wish to conduct a research study project titled: Experiences of patients registered as treatment after lost to follow-up amongst patients diagnosed with drug-susceptible tuberculosis in Engela Hospital. The purpose of the research is to explore and describe the experiences of patients registered as treatment after lost to follow-up amongst patients diagnosed with drug-susceptible tuberculosis in Engela District.

The objectives of this study are to:

1. Explore the experiences of patients registered as treatment after lost to follow-up amongst patients diagnosed with drug-susceptible tuberculosis.
2. Describe the experiences of patients registered as treatment after lost to follow-up amongst patients diagnosed with drug-susceptible tuberculosis.

Your participation will provide information that might enable decision-makers to assist in this regard, which will also help to improve the situations of lost to follow-up in Engela District. Participation in this study will take approximately 20 minutes. The procedure includes responding to questions on demographics, your current and previous experiences with your treatment.

Your participation in this research project is voluntary. There are no risks to participation. Your response will remain confidential and anonymous. No one other than the researcher will know your individual answers to this interview. The researcher and the supervisors are the only people who will have access to the data collected.

Should you agree to participate, please sign your consent with a full understanding of the purpose of the study.

If you have any questions or concerns about the research, please feel free to contact Ms Kakunavali Venokulavo at 0813393835 or email at kakunavenokulavo123@gmail.com. The main supervisor Dr E Kamenye E-mail: ekamenye@unam.na and co-supervisor Mrs O Tuhadeleni at otuhadeleni@unam.na.

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims or rights because of your participation in this research study.

Should you agree to participate, please sign the consent provided. If you have any questions that need clarification you are welcome to contact me.

I……

Agree to participate in this research project on my own will.

Signed at ……..

……. …….
Participant signature Date

Appendix D: Interview Guide

Interview Guide

TITLE: EXPERIENCES OF PATIENTS DIAGNOSED WITH DRUG-SUSCEPTIBLE TUBERCULOSIS REGARDING LOST TO FOLLOW-UP IN ENGELA DISTRICT, OHANGWENA REGION

Items needed:

- Notepad
- Pen
- Consent form
- Interview Guide
- Audio recorder/Cell phone

Introduction:

- Greet the participant.
- Introduce myself.
- Explain the reason for the research.
- Explain the aim of the interview and that it will be recorded.
- Explain the focus of the study.
- Talk about the time frame for the interview.
- Emphasise on ethical aspects of research which are
    - ✓ Privacy and confidentiality
    - ✓ Autonomy- voluntary withdrawal at any time from the study.
    - ✓ Anonymity- their identity is going to be a safeguard.
- Sit in a quiet and private room.
- Start the tape recorder and start with the interview.

Main Question

1. **Tell me about your experiences regarding TB treatment lost to follow-up?**

Possible Probing questions

- Can you tell me briefly what the healthcare workers told you during the health education given to you prior to your TB treatment initiation?

- Can you tell me the reasons why you could not complete your treatment the last time?

Thank you very much for your time and participation, have a good day!

Appendix E: Interview Transcripts

Participant 1

Sex: Male

Age: 34

Education: Primary

Occupation: Unemployed

Marital Status: Single

Researcher: Tell me about your whole TB treatment experience from being diagnosed until the time when you defaulted on your treatment.

Participant: I was diagnosed with TB a long time back in 2015 and I was hospitalised for about a month in Engela Hospital.

Researcher: Before being diagnosed with TB, what symptoms did you have that made you go to the hospital?

Participant: I develop a cough and I went to the hospital and at hospital they gave me a bottle and told me to cough and spit sputum in that bottle, which then was tested and the healthcare workers later told me I had TB, I started my treatment which I completed within 6 months.

Researcher: In the facility records it shows that you had been lost to follow-up on your TB treatment for some time.

Participant: I have never missed my TB treatment I was told that I would drink my medications for 6 months and that is what I did until I fully completed the TB treatment.

Researcher: Was there never a time that you perhaps did not come to collect your medication or probably came late like maybe late with some days or weeks.

Participant: No, not at all, the only treatment that I missed for some time was my ARVs not TB at all.

Researcher: Okay, then I think we have the wrong person because this study is focusing on people who were lost to follow-up on their TB treatment and I thought you are one of them because that is indicated like that in the facility records.

Participant: No, I have never been lost to follow-up on TB treatment.

Researcher: Okay, thank you so much for responding to my call and coming for this interview even though you are not amongst the patients I am looking for, thank you so much and have a good day.

Participant 2

Sex: Female

Age: 57

Education: Primary

Occupation: Unemployed

Marital Status: Single

Researcher: Tell me about your whole TB treatment experience from being diagnosed until the time when you defaulted on your treatment.

Participant: It all started with a cough, after coughing for some time I then decided to go to our local clinic Ondobe clinic. At the clinic, I was treated and given medication but the cough was just not getting better, so I decided to go back to the clinic and then the HCWs gave me some bottle to cough in some sputum for it to be tested.

Researcher: Where do they test the sputum?

Participant: They told me that they would send the bottles to Engela Hospital that is where they will do the testing, after 3 days I received a call that I should report myself at Ondobe clinic, when I arrived there, I was told that my results have been received and I have tested positive for TB. Upon receiving my results, they told me that TB is curable and they will give me medications, they gave me pills enough for one week and told me to come back after a week, that is what I did I went home drank my pills and came back after a week when I returned after a week this time around they gave me treatment for two weeks, I got my pills for two weeks before the two weeks ended the fieldwork of ploughing also started and I had to go to my mahangu field which is very far in Angola, I continued ploughing my field and drinking my pills at the end of two weeks my pills were finished and I felt very better I didn't even have any chest pains anymore, (Phone ringing non-stop)

Researcher: Your phone is ringing nonstop is it probably not the people you said you are expecting? We can pause for you to answer them.

Participant: The people need directions, these people don’t wait they are coming to fix the water, I am so sorry for answering the phone.

Researcher: No madam it is not a problem at all you needed to direct the people, we can continue now. We paused when you were saying you went to the field after being given treatment for two weeks.

Participant: Yes, when I completed my pills for two weeks I felt very better I did not have any chest pain and the cough was also gone so I just continues ploughing because I was healed with no complaints at all, after a month and a half I came back because I was done ploughing, I found a message at home that the nurses of Ondobe clinic were looking for me I than went to the clinic when I arrived at the clinic the nurses were then asking me why I was lost to follow-up on my TB treatment.

Researcher: Is your mahangu field far from the hospital?

Participant: The field is in Angola.

Researcher: Did the HCWs not call you?

Participant: The phones, the other side don't really work the networks there are different from the ones here and I don't have an Angolan sim card I only receive calls when I am here in Namibia, unless if a message is sent through someone coming that side. I was shocked to be informed that I was lost to follow-up on my TB treatment, because how am I lost to follow-up if the pills I drank cured me and they said apparently I was supposed to just continue drinking even when I felt better?

Researcher: So, when they said you were supposed to drink even when you felt better when you started treatment did they tell you how long you are supposed to take the TB treatment?

Participants: No, when I started treatment, they never told me how long I was supposed to take the treatment, they only gave me pills for a week and later for two weeks.

Researcher: After receiving your results did you and the HCW not have a discussion on what TB is and how your treatment should be taken and for how long?

Participant: No, that day I did not spend much time with the HCW, she just said TB is curable and they will give me pills for a week and I should come back after a week.

Researcher: So, now they said how long should you take this current treatment?

Participant: It is only now that they told me that I should take my treatment for 6 months because TB can become resistant so they gave me pills again.

Researcher: Now that you have restarted with the TB treatment, who do you stay with at home taking care of you and reminding you to take your pills?

Participant: Aaah, there is a shortage of people nowadays I only stay with my little grandchildren, so I only remind myself.

Researcher: How is your relationship with the HCWs and their treatment towards you?

Participant: These are our usual HCWs at Ondobe clinic and they assist us very well, except for the fact that they did not inform me very well that I was supposed to drink my pills for 6 months even when I felt cured.

Researcher: Are you on any other treatment apart from the TB ones

Participant: No,

Researcher: Do you have any questions, comments or maybe recommendations towards the treatment of TB?

Participant: The only thing that I see needs change is there is too many follow-ups going up and down to the clinic, if only they could give us enough pills like we hear some conditions people get treatment for 3months, just for them to relieve us from this up and down of going to the clinic, it is not easy

Researcher: Do you have a question meekulu?

Participant: No, that is all I had to say.

Researcher: Thank you so much for participating in this study and welcoming me into your house, if there is nothing else, this is the end of our interview thank you so much.

Participant: I am also thankful. We are always grateful when the youth come to ask us questions, we also learn something.

Participant 3

Sex: Male

Age: 57

Education: None

Occupation: Cattle herder

Marital Status: Single

Researcher: Tell me about your whole TB treatment experience from being diagnosed until the time when you defaulted on your treatment.

Participant: I started having a cough which was not stopping at all and I decided to come to Ongha Clinic to come seek treatment. Here at Ongha Clinic the nurses collected my sputum and told me to come back after 3 days, after I came back the nurses told me that my results came and I am TB positive so they said I will have to go to Engela Hospital to start treatment there.

Researcher: Why did they say you must go to Engela? Do they not give TB pills here at Ongha or were you admitted.

Participant: No, they do give pills here also, but I think when you start for the first time you first need to start at the big hospital but later, I transferred back here and I continued getting my pills here at Ongha.

Researcher: In the records, it shows that you were taking your treatment very well but at some stage, you became lost to follow up on your TB treatment.

Participant: I really use to take my pills well I started at Engela and came to continue here at Ongha. I never missed any of my follow-ups but after I took the pills for some time I felt well and better and just stopped coming to collect the pills.

Researcher: You mention that you stopped collecting your pills because you felt better and well, did the HCWs not tell you how long you were supposed to take your medication.

Participant: The other reason why I also missed my follow-ups is because I went to the cattle post and the cattle post is very far, so when I came back from the cattle post I was feeling healed hence I never went back to the clinic.

Researcher: Before you started your TB, treatment did the HCWs not give you some health education on TB including the consequences of being lost to follow-up on your treatment.

Participant: They told me that I should take my pills for 6 months that is all they told me and also that it is not good to smoke when you are on TB treatment.

Researcher: How was your relationship with health care workers?

Participant: It is very good, no complaint. Now I am taking my medication in order.

Researcher: Summing up your reasons for defaulting your TB treatment, you said that you were away right? Any other reason?

Participant: Yes, only that I went to the cattle post and I delayed coming back and I felt healed when I came back.

Researcher: So, while on treatment who takes care of you in terms of preparing food and reminding you to take your medication?

Participant: I just take care of myself.

Researcher: Okay thank you so much for your participation in this study, do you perhaps have a question or addition.

Participant: Yes, I have a question regarding the prevention pills that I am currently taking. Do I have to take them until I am told to stop?

Researcher: Absolutely. You have to take them until health care workers inform you to stop taking them.

Participant: I asked because sometimes when I go collect my ARVs, nurses just give me ARVs and say nothing about the TB prevention medication even when they are finished. Am I supposed to remind them?

Researcher: Are you on ARV treatment as well?

Participant: Yes.

Researcher: Yes, it is vital that you feel free to ask the nurses and inform them about any other treatment you are supposed to get. Because sometimes the nurses are too busy and they also forget, so it is very important to always remind them about any other treatment you are on, any other question

Participant: No.

Researcher: Okay, thank you for your time and participation sir

---

Participant 4

Sex: Male

Age: 28

Education: Primary

Occupation: Unemployed

Marital Status: Single

Researcher: Tell me about your whole TB treatment experience from being diagnosed until the time when you defaulted on your treatment.

Participant: I firstly started having a terrible cough, the people use to force me to go to the hospital but I was always refusing. Later I just started to lose a lot of weight the cough was not getting better and my appetite kept becoming low, that is when I realised that I was really sick and I decided to go to the hospital so at the hospital they tested me for TB and the results came that I have TB.

Researcher: When you were told that you were TB positive what happened thereafter?

Participant: The nurses told me that the TB that I have is not a resistant one so they will give me some pills and come back again when the pills are finished and that is what I continued doing all the time.

Researcher: In the hospital records, it shows that you were lost to follow-up on your treatment. What caused that?

Participant: You know, I use to work for a Chinese and I use to knock off very late and I never told him that I was diagnosed with TB so I could not get out of work to come to the follow-ups and after I took the medication for some time I really felt very healthy so I thought it is no more necessary for me to continue taking the pills. I also started drinking a lot of alcohol which also became a problem.

Researcher: So, how did you restart your TB treatment again?

Participant: I started getting sick again and I came back to the hospital, that is how I restarted on the TB treatment again.

Researcher: Before starting your initial TB treatment that you became lost to follow-up on TB treatment, did the nurses not give you health education on TB and how you should take your pills and the duration?

Participant: No, the nurses did not give me any health education and they also never told me how long I was supposed to take my TB treatment only now that I restarted they explained everything nicely to me that I was supposed to drink my pills for six months even when I felt better I was still supposed to continue.

Researcher: Generally, how was your relationship with the HCWs?

Participant: The relationship I have with the nurses is really good and they treat me well even when I came back after being lost to follow-up, they did not yell at me at all, they just assisted me very well. I am the only one who was at fault because I stopped coming and I got mixed up in alcohol.

Researcher: Before we come to the end of the interview, do you perhaps have a question or addition or even a recommendation?

Participant: I just want to say that the follow-ups for TB treatment are a lot and sometimes costly when it comes to transport if they could at least give us enough pills that can give us enough time to get transport money it would be better.

Researcher: Okay, thank you for that recommendation, if there is nothing, I would like to thank you for participating in this study.

Participant 5

Sex: Male

Age: 60

Education: Primary

Occupation: Retired

Marital Status: Married

Researcher: Tell me about your whole TB treatment experience from being diagnosed until the time when you defaulted on your treatment.

Participant: In the beginning, I had a cough and I visited a private doctor in Oshakati, the doctor then said he will send me to get an X-ray, after the X-ray was taken he told me to come back after some days, before I could go back he called me and told me that I have TB. The doctor then gave me some pills to drink and said I should go back again I went there for 3 consecutive follow-ups and on the third follow-up he gave me different pills from the first two follow-ups when the pills finished the ones I got during my third follow up I was unfortunately in Angola and I had stayed for a very long time there

Researcher: When you came back from Angola what happened?

Participant: While in Angola I felt very well and thought I was cured because the cough was gone and I was no more feeling dizzy, so upon returning from Angola, I did not go back to the doctor because I thought I was cured of TB. After some time, I started to get sick again then I came here at Ongenga Clinic, when I arrived here the nurses asked me if I was treated with TB before than I told them that yes I was diagnosed with TB by a private doctor I only received treatment from the doctor three times then I went to Angola where I spend a long time and I never went back to the doctor because I felt well when I came back from Angola.

Researcher: What did the nurses then do or say?

Participant: No, the nurses then said that they could not give me TB pills without consulting my private doctor because they are not sure if I really had TB and on that same day, they gave other sputum bottles again to put in the sputum, I also gave them my private doctor's number so they could call him

Researcher: You said the nurses here at Ongenga clinic gave you sputum bottles again, were you given sputum bottles already before?

Participant: Yes, at my private Dr he gave me some sputum bottles also.

Researcher: So, after you gave the sputum bottles here at Ongenga what happened?

Participant: The sputum bottles were sent to Engela for testing and after some days the HCWs here at Ongenga called me and they informed me that they received my results and it shows that I still have TB. They also told me that they managed to get hold of my private doctor and he told them that I am lost to follow-up on TB treatment so from there I restarted my treatment again.

Researcher: Before restarting your treatment did you and the HCWs have a discussion about what TB is and how it spreads including the common signs and symptoms?

Participant: No, we did not go into such a discussion at all.

Researcher: Even at your private doctor?

Participant: No not at all, but later on during this treatment of mine, the HCW worker had a discussion with me and she taught me so much about TB.

Researcher: Who do you stay with taking care of you and reminding you to take your pills?

Participant: I stay with my wife, children, nieces and nephews so they always prepare food and Oshikundu for me.

Researcher: How is your relationship with the HCWs and how do they treat you?

Participant: No, the nurses here are good and they treat us all very well, they are really working very hard.

Researcher: So, in conclusion, if I was to ask you what was the real reason that you were lost to follow-up on your TB treatment?

Participant: No, the main reason is just that, to be honest, I was away in Angola and I really felt I was cured even when I got back, I did not see it necessary for me to go back to the doctor because I thought I am cured.

Researcher: Do you have any questions or maybe comments?

Participant: No question really just to say I am really grateful to the nurses here at Ongenga and how they taught me more about TB because I always thought that once you get TB it can never be cured it stays in your body like HIV but they taught me that no it can get cured.

Researcher: Thank you so much sir for agreeing to take part in this study.

Participant: It is not a problem, the other thing I want to add is that the MoHSS should start again with those campaigns they use to conduct many years ago about TB because really the community needs to be educated and encouraged because many people still think TB is a death sentence and you can never get cured of it.

Researcher: Thank you so much, sir, I will definitely add that into the recommendations.

Participant 6

Sex: Male

Age: 62

Education: Primary

Occupation: Communal Farmer

Marital Status: Married

Researcher: Tell me about your whole TB treatment experience from being diagnosed until the time when you defaulted on your treatment?

Participant: Myself, this is not the first time I suffered from TB, I had TB in 1996 when I was still working at a Mine in Arandis. So last year I started having a cough, it started like a small dry cough but the problem is it was just not stopping so after coughing for more than two weeks I decided to go to Engela Hospital to get treatment for this cough. I went to Engela, the nurses treated me and gave me a bottle to put in sputum but I was not producing any sputum, after some time I started having chest pain.

Researcher: Sorry sir, you said the nurses gave you a bottle to put in sputum but you did not produce any so what happened after you did not produce the sputum?

Participant: No, when I saw that I did not produce any sputum I just did not go back to the hospital I just drank the pills that they gave me but even after finishing those pills the cough was still there and now I was even having chest pain and that is when I decided to go back to the hospital. So when I came back to the hospital the nurses send me to the doctor and the doctor send me to the X-ray department so with the X-ray Image the doctor then said the image showed that I have TB, I was then sent to the TB clinic to start with the TB treatment.

Researcher: When you arrived at the TB clinic what happened, what did the nurses say to you?

Participant: No, the HCWs just said I have TB and told me they will give me pills for two weeks and that I could continue getting my pills at the nearest clinic to me which is Ohalushu Clinic.

Researcher: What else did the HCWs tell you? Did you not go into a health education discussion on what TB is and how it is spread and how you should take your treatment and for how long etc.?

Participant: No, no like I said they just said I have TB and I will get pills for two weeks and that the rest I will get from Ohalushu, but I asked them that how will Ohalushu HCWs now what pills I am drinking and then they said they will call them, but by that time I had already called my wife to inform her that I will be admitted because I know the other time I had TB I was admitted in the Swakopmund Hospital, but I don't know this nowadays TB you just get your pills and go home.

Researcher: So, sir, after the pills finished did you go get the pills at Ohalushu clinic and did they assist you with the right pills?

Participant: Yes, after two weeks I went to Ohalushu and I was assisted by the nurse there. She gave me the pills for two weeks and said I should come back after two weeks again.

Researcher: At Ohalushu, did the nurse also not give you some health education on what TB is and all the information regarding TB treatment?

Participant: No, not at all, you know the nurses are very busy the clinics are always very full. I don't think they have time for these education sessions, and I really do not blame them as long as they give us our pills to get healed

Researcher: Sir, in the hospital records it shows that you stopped going to get your pills and you were lost to follow-up on your TB treatment, how did that happen?

Participant: No, I was not lost to follow-up to my treatment per se, it's just that the last time I went to collect my pills, the HCW did not say I should go back to the clinic and by that time I felt very well and cured so I thought the reason she did not tell me to go back again it is because I am cured and did not need to go back again, so when I saw that I was healed I quickly went to my cattle post for some time, after I came back from the cattle post I went to the hospital to collect my ARVs and that is when I was told that apparently I am lost to follow-up on TB treatment but I was so shocked because I drank my pills so well and I was healed.

Researcher: Sir, I remember in the beginning you said you were treated with TB before, how long did you take your treatment that time?

Participant: No, that time I was admitted to the hospital for a very long time and I cannot really remember how long I took the treatment.

Researcher: I see you have now restarted your treatment again, this time around what did the nurses tell you how should you apparently take your treatment?

Participant: Mmh!, my dear this health system nowadays is very different I just came to collect my ARVs and I was even in a rush because I needed to buy food for the people at the cattle post. When I arrived at the ARV ARV Clinic the HCWs are telling me I am lost to follow-up on my TB treatment and that I should go to the TB clinic. When I arrived at the TB clinic they are telling me that I will have to be admitted because they have to inject me for some time and I did not come prepared for admission, I was even asking the nurses there that if I had not come for my ARVs how were they going to get me back on treatment?

Researcher: That was unfortunate so what did you do?

Participant: I am a person that is very serious with adhering to the instructions from HCWs I just told my wife to bring me some toiletries and told her to buy the food for the people at the cattle post so that she could send it with transport going there, and it is very difficult to get transport going there because the cattle post is far in Angola, but we managed and I stayed for some time in the hospital getting the injection until I was discharged to continue getting pills from Ohalushu. This time around they explained everything to me nicely that I will take my pills for 8 months even when I feel better I should just still continue drinking until I am done.

Researcher: You talked about your wife, is she the one that takes care of you and reminds you to take your pills?

Participant: Aaah, I am a big man what taking care? I just put an alarm on my phone to remind me but yes, she is the one who cooks for us and makes sure I do not take my pills on an empty stomach.

Researcher: Sir, how is your relationship with the nurses and the way they provide the services to you?

Participant: No, the nurses are good, they do their job very well but maybe because of the overload of work and too many patients they sometimes forget to give us clear instructions because, to be honest, I can never miss my follow-ups or maybe to abscond from treatment, how can an old man like me do something like that, it is because of this pills that we are still strong like this they really help us.

Researcher: Do you have any questions or maybe a comment or even a recommendation you would like to give when it comes to TB treatment?

Participant: No, I do not have a question at all.

Researcher: If you have no questions, thank you very much sir for taking part in this study.

Participant: But, wait I think I have a question or maybe an addition, you see with my ARV they give me pills for 3 months why do they not do this with TB because with TB you really have to go to the hospital or clinic a lot of times to collect the pills and it is very costly, that is all I wanted to say.

Researcher: Thank you, sir, I will include your suggestion in the recommendations.

Participant 7

Sex: Male

Age: 35

Education: Secondary

Occupation: Unemployed

Marital Status: Single

Researcher: Tell me about your whole TB treatment experience from being diagnosed until the time when you defaulted on your treatment.

Participant: To be honest with you up until today I really do not believe that I have or had TB, and I do have reasons why I am saying so.

Researcher: Would you please enlighten me more on the reasons why you believe that you do not have TB?

Participant: The illness I have is spiritual, my illness appeared to me in a dream, that later became a reality. In that dream, I saw people stabbing me and thereafter I started to experience some sharp pain in my chest, when the chest pain became unbearable I went to Eenhana Hospital. I told the doctor about my dream and he referred me to have an X-ray and the X-ray revealed that I am okay. The doctor then told me that my condition is difficult to treat because it is a spiritual one.

Researcher: So, when the doctor said your condition is difficult to treat what happened did you just go home without treatment?

Participant: Yes, I went without medication but I use to buy myself pills from the private pharmacy and they really use to help me a lot the pills are called REFPAIN. After on I

also went to church for the pastors to pray for me, but the pain was not getting better so I went to Engela Hospital and there the doctor referred me to the TB clinic at the TB clinic they gave me sputum bottles to put in sputum I was struggling to produce but I finally managed to produce some sputum. At Engela, the doctor also referred me to an X-ray so the results from the sputum said I was TB negative but the doctor said the X-ray showed that I had TB which I did not believe.

Researcher: You are saying even when the doctor said your X-ray showed that you had TB you did not believe it, but I learn in the hospital records that you did start with the TB treatment and eventually ended up being lost to follow-up on your treatment. How did that happen?

Participant: Yes I did start with the TB treatment. I took the TB pills for 3 months consecutively at Ongha Clinic and even at Ongha Clinic one nurse was doubting if I really had TB, so when I realised that my pain was not going away even with the TB treatment, I decided to quit the treatment and continue taking REPAIN because it really use to help me a lot. I did not see the importance of continuing taking the TB pills if they were not helping me at all.

Researcher: Since you did not complete your TB treatment because you had doubts, did you ever get help to resolve your pain?

Participant: Yes, I recovered from the sharp pain after I visited a traditional healer, and I also recovered because my sister got a prophecy about my condition at the church because with my condition there were also other stories connecting to my father's. I really became much better when I visited the traditional healer.

Researcher: Did you tell your parents or maybe a family member about your TB diagnosis?

Participant: Yes, both my mother and sister were aware of my condition.

Researcher: Before you started with TB treatment, did the HCWs give you health education on the TB disease?

Participant: No, the HCWs did not give me any health education at all, but I am very much informed about TB because back in those years there were a lot of campaigns on TB they use to go on the radio and TV even house to house, but I do not see these programs happening anymore.

Researcher: How was your relationship with health care workers in general?

Participant: My relationship with the nurses was very great and they also understood my problem that is why they did not even force me to continue taking the pills when I decided to quit.

Researcher: Just to sum up our interview, is there perhaps something you would like to comment on or recommend regarding the TB treatment?

Participant: All I would like to add is that the nurses and doctors should take patients complaints seriously and not just put them on treatment that is not working because some problems are spiritual.

Researcher: I would like to find out from you, you mentioned that you were treated by a traditional healer and you also added that some patients are suffering from spiritual problems, would you advise that the hospitals should be referring patients to traditional healers?

Participant: I am currently a born again and I do not believe in traditional doctors or medicine anymore, what I advise is that people should adhere to their treatment from the doctors and they should not mix it with traditional medicines, but these are personal decisions and sometimes people just seek such help

Researcher: Okay, thank you so much for your time and for agreeing to take part in this study. I really appreciate your participation, your time and your consideration for our invitation to this discussion. Do you perhaps have a question?

Participant: No, I really do not have a question at all.

Researcher: Okay, thank you so much.

Participant 8

Sex: Male

Age: 37

Education: Secondary

Occupation: Unemployed

Marital Status: Single

Researcher: Tell me about your whole TB treatment experience from being diagnosed until the time when you defaulted on your treatment?

Participant: This is the third time I am being diagnosed with TB, the first diagnosis was made when I was still in Otjiwarongo, the second and current one was diagnosed in Engela Hospital.

Researcher: Okay, let's talk about your last diagnosis and how it happened and what led to you being lost to follow-up on your TB treatment?

Participant: I was not feeling well and then I went to our local clinic, Onekwaya. The nurses at the clinic gave me sputum bottles to put in sputum and after some days I received a phone call that I should report myself to the clinic because my results came and it was TB positive.

Researcher: So, when you arrived at the clinic what exactly happened?

Participant: The nurses told me that since it is not my first time suffering from TB, they will have to send me to Engela to get admitted because I will be receiving an injection for 3 months.

Researcher: So, upon arriving at Engela what happened there?

Participant: The nurses just told me that I will be admitted for 3 months for them to inject me every day and they also advised me to take my medications well and that I should not drink alcohol while I am on treatment, I then stayed in the hospital until I was discharged.

Researcher: After being discharged, did you continue taking your medication?

Participant: Yes, I continued collecting my pills from the Onekwaya Clinic for some time until I stopped going to collect the pills.

Researcher: Why did you stop going to collect your pills

Participant: Things are very hard for me. I am on ARVs and also on antipsychotic medications but I do not work and the people at home do not really support me at all, sometimes I have to take my pills on an empty stomach which is very difficult because I end up being dizzy and vomiting so I thought it is better I just stop taking the pills.

Researcher: Who are you living with?

Participant: I live with my aunt and we are always arguing she recently even threatened that I should leave her house, even when she cooks, she does not give me food to eat.

Researcher: So, you are saying you stopped going to the clinic to get your pills because you did not have food.

Participant: Yes, I really did not continue taking the TB and the other pills because they leave me very weak when I drink them on an empty stomach and no one supports me at all.

Researcher: Apart from that, was there any other reason and how was your relationship with the nurses?

Participant: Yes, that is the main reason why I stopped. My relationship with the nurses was very good and they treated me so well.

Researcher: How do you plan on making sure you complete your TB treatment?

Participant: It is very for me really for example this one eye of mine does not even see at all and no one has ever offered to assist me to at least have me registered on the social grant. On top of that, my aunt likes lying to people that I gamble the money people assist me with so many family members have stopped assisting me because of that reason, which is not even true.

Researcher: I understand your predicament but I would encourage you to really complete your TB treatment.

Participant: Yes, madam I will try to complete my treatment and this brother of mine that brought me today to the clinic I am sure he will help me from now on.

Researcher: That is good to hear, I think we are almost at the end of our interview do you have any questions or maybe addition?

Participant: No, I have no question but just to maybe add that the MoHSS should also come up with a program that visits the patients' houses just to assess their situation and see if really they are able to take their pills in a good condition and if they are well taken care of because really it is very difficult out here.

Researcher: Thank you so much for that recommendation I will add it to my report and thank you so much for coming to participate in this study

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Participant 9

Sex: Female

Age: 33

Education: Junior Secondary

Occupation: Unemployed

Marital Status: Single

Researcher: Tell me about your whole TB treatment experience from being diagnosed until the time when you defaulted on your treatment and would you please raise your voice for me a bit.

Participant: I started feeling cold and I had a sharp pain on the left side of my chest and back, when I realised that the pain was not getting better, I came here to Okatope Clinic. The nurses referred me for a TB test and I collected sputum, in the sputum bottles they

gave me the results came and it said I had TB. They also send me to have an HIV test and it came out negative.

Researcher: You said you were referred to get the TB test, was it not done here at the clinic?

Participant: I think the test is done in Engela but I submitted my sputum here at the clinic what I meant when I said referred is because I was being treated in the nurses' room but there is a certain gentleman that works with TB and he is not a nurse but he is responsible for giving us our TB pills and he is also the one who gives out the sputum bottles.

Researcher: Okay, I now understand what you mean, so after you were told that you tested positive for TB what happened thereafter?

Participant: No, from there they just said I will start drinking TB pills.

Researcher: After you were told that you would start taking the pills, did the HCWs not give you some health education on TB and the treatment?

Participant: The HCW did tell me some information like to refrain from sharing cups and plates with my housemates and anybody else. I was also told about how TB spreads. The HCW also told me that the TB I have is not resistant it can be cured, I was then given pills for a month and told to come back after a month after taking the pills for a month I was really feeling better

Researcher: The clinic records shows that you became lost to follow-up on your TB treatment, what caused that?

Participant: I use to take my pills very well for three consecutive months. I never missed any follow-up, the problem only came because I had to go plough at one of our fields that side of Okongo and while I was there I never knew that I could collect my pills at any

nearest clinic even if it is not where I started my treatment and also I was really feeling well so I also thought I was cured.

Researcher: You are saying you did not know that you could get pills at any nearest clinic but did you inform the HCWs here at Okatope that you will be away for some time so they could make arrangements for you?

Participant: No, I did not inform them.

Researcher: Who do you stay with?

Participant: I stay with my mother.

Researcher: Was she aware of your TB diagnosis and did she support you during your treatment?

Participant: Yes, my mother is supportive and caring. She cooked and reminded me to take my medication all the time.

Researcher: How was your relationship with healthcare workers?

Participant: The HCWs are really good with me, even after I was lost to follow-up on my treatment, they just told me politely that I needed to restart my treatment again and they further educated me on the consequences of interrupting my treatment. There was a time I had to go to Oshakati and they gave me a paper to take along there so I could still continue with my treatment. I was involved in an accident and I contracted HIV because of the accident I also became a bit confused so I was put on antipsychotic medications. I also drank them well until I was cured.

Researcher: Okay, I understand. So to sum up the interview, could you please again tell the reason you became lost to follow-up on your TB treatment?

Participant: To be honest I am the one who was at fault because I just felt better and got too much into alcohol and I missed my follow-ups and the story also of going to Okongo and not knowing I could get assisted there also.

Researcher: Okay, so do you perhaps have any questions or recommendations you would like to make concerning TB treatment?

Participant: I think all is well. I am at fault for missing some of my follow-ups.

Researcher: Thank you so much for agreeing to take part in this study.

Participant 10

Sex: Male

Age: 42

Education: Primary

Occupation: Unemployed

Marital Status: Single

Researcher: Tell me about your whole TB treatment experience from being diagnosed until the time when you defaulted on your treatment.

Participant: I was having a very bad cough, I was coughing nonstop especially during the night after some time I realised my appetite was poor and I even lost weight by that time I was at the cattle post in Angola. My cousin then told me that maybe it could be TB and I should go back home here in Namibia so that I could go to the hospital and get treated because it was becoming worse. When I arrived home the following day, immediately I went to Engela Hospital and I was given two bottles to put in sputum one

I did right there at the hospital the other one I went with it home and they told me to put in sputum early in the morning before eating anything, that is what I did and I brought back the other bottle after a day the hospital called my mother that I should go back to the hospital so when I come there they said I have TB and I should start with the treatment.

Researcher: Before starting with the treatment, what did the HCWs tell you about TB?

Participant: Nothing, they just said I will start the pills and that I will drink the pills for six months and that I could always pick up my pills at the nearest clinic which is Odibo Clinic.

Researcher: So, there was no health education given to you on what TB is and how it is spread?

Participant: No, they just said I should stop drinking alcohol if I do and that my next follow-up I should go to Odibo Clinic

Researcher: You said the nurses told you that you will have to take your pills for six months but in the hospital records it shows that you stopped going to get your pills and you became lost to follow-up on your TB treatment.

Participant: Ooh, that issue no, that issue was resolved with the nurses and I restarted the treatment again I am even almost done.

Researcher: Yes sir, I know you have restarted the treatment again but I want to understand what happened during your initial treatment that made you become lost to follow-up on treatment.

Participant: You, these nurses are not the same they change a lot and as they change so does their manners, some explain things nicely to you but some don't. What happened

that other time it was just the misunderstanding the nurse did not tell me very well that even if I felt healthy and well I still needed to drink the pills.

Researcher: But the nurses told you that the TB treatment is to be taken for six months, am I correct?

Participant: Yes, that is what the nurses at Engela told me so I thought six months is for people who get admitted to the hospital because I know some people get admitted at the TB ward in Engela for a very long time and I thought those ones are the ones to drink for six months.

Researcher: How did you end up restarting your TB treatment again?

Participants: You know after I felt better and realised that I was healed now, I went back to the cattle post, while at the cattle post I got very sick again and the people at the cattle post had to rush me to Engela Hospital. While I was admitted there that is how the nurses picked it up that I was on TB treatment and I did not complete it.

Researcher: So, the nurses never came to look for you at your house after they realised you were lost to follow-up?

Participant: No, they didn't because if they had come to our house my mother was going to send a message to the cattle post that the hospital is looking for me but they never went to our house.

Researcher: So now that you restarted your treatment, did the nurses explain everything to you, how you should take your pills and for how long?

Participant: Yes, they did and this time around we even had a long discussion with one of the HCW who told me that TB can become resistant if I do not take my pills well and

that TB spread through the air and he taught me so many things, unlike the first time nothing was explained to me.

Researcher: How is your relationship with the HCWs and their treatment towards you?

Participant: Aah, the nurses are different some are very good but some are very rude and they like shouting at people like I am a small child, but that is how life is I am just happy I am almost done with my treatment now.

Researcher: Do you have any questions, comments or maybe recommendations towards the treatment of TB?

Participant: No, I do not have any questions just to maybe say the nurses should be polite with the patients because we are sick and they should explain the right things.

Researcher: Thank you so much for participating in this study.
