UNIVERSITY OF THE WESTERN CAPE

CHALLENGES EXPERIENCED WITH ADHERENCE TO TB TREATMENT BY PATIENTS IN A FACILITY IN THE NORTHERN SUB-DISTRICT, CAPE TOWN

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A mini thesis submitted in fulfilment of the requirements for a degree of Masters in the School of Nursing, Faculty of Community and Health Sciences at the University of the Western Cape.

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KEYWORDS

Tuberculosis

Adherence

Loss to follow up

ABSTRACT

Tuberculosis (TB) is an infectious disease caused by Mycobacterium tuberculosis that has existed for millennia and is considered to be the top infectious disease killer in the world with 4 400 victims daily. Poor adherence to treatment results in increased transmission rates of the *tubercle bacilli*, a delay in positive sputum conversion to smear-negative, morbidity and mortality, and eventually escalates the cost of the TB control programmes. Multiple reasons for poor adherence have been reported and, in some cases, interventions were implemented to combat this problem; however, this phenomenon is not abating. This implies that the current strategies might not be applicable, feasible or relevant within specific contexts. Therefore, it is imperative to find new information that might contribute to new innovations in specific settings. Hence, this study aims to explore the challenges experienced with adherence to TB treatment by patients in a facility in the Northern Sub-district of Cape Town.

A qualitative, explorative and descriptive design was employed to collect data among GeneXpert positive patients until saturation was reached. Semi-structured interviews were conducted, audio - recorded and transcribed verbatim. Pre-testing was performed to eliminate any ambiguity during the interviewing process and ensure clarity of posed questions in the interview guide. Thematic analysis was employed during the data analysis process which involves analysis of the data by emerging themes. Trustworthiness of the study was ensured through application of the criterion of confirmability, dependability, credibility and transferability. All ethical principles including confidentiality and anonymity was adhered to throughout the study. The study revealed that distance, long waiting time, unemployment, inadequate household food supply, stigma, ignorance, side effects and residential mobility impacted negatively on patients and were significant challenges that TB patients experienced.

DECLARATION

I, **Christeline Booysen**, declare that the research entitled "**Challenges experienced with adherence to treatment by patients in a facility in the Northern sub-district, Cape Town"** is my own work, that it has not been submitted before for any degree or examination in any other university, and that all the sources used or quoted have been indicated and acknowledged as complete references.

Name: Christeline Booysen Date: March 2023

DEDICATION

I dedicate this work to the people who play a positive role in my life, my dear husband, Selvyn Booysen, my mother, Magdalena Nyman and in loving memory of my dear father, the late Appollis Nyman, as well as my siblings who believe in me.

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LIST OF ABBREVIATIONS

BANC:	Basic antenatal care
CCW:	Community care workers
DOTS:	Directly observed treatment short course
HIV:	Human immunodeficiency virus
IMCI:	Integrated management child illness
LTFU:	Loss to follow-up
NSP:	National Strategic Plan (South Africa)
PLHIV:	People Living with HIV
RNTCP:	Revised National Control Programme
SANA:	South African Nursery Association
SANAC:	South Africa National Strategic Plan
SANAC:	South African National Aids Council
SANDH:	South African National Department of Health
SRHC:	Sexually reproductive health care
STIs:	Sexually transmitted infections
TB:	Tuberculosis
WHO:	World Health Organization

1 CHAPTER ONE: STUDY OVERVIEW

1.1 Introduction

Tuberculosis (TB) is an epidemic that has existed for millennia and is the top infectious disease killer worldwide with a death rate of 4,400 victims per day (WHO, 2019). According to the World Health Organization's Global Tuberculosis Report 2019 (WHO, 2019), the disease causes ill-health in millions of people each year and consequently, plays a major role in economic devastation where a cycle of poverty and illness continues, entrapping families, communities, and countries. TB is an infectious disease caused by Mycobacterium tuberculosis. Singh, Benmamoun, Meir and Arikan (2021) define tuberculosis as a strange, infectious, but chronic disease caused not only by a bacillus but also by poverty, and that it is both exogenous and indigenous. Singh et al. (2021) state that the pathogen causing pulmonary tuberculosis was first isolated in 1882 by Robert Koch. Normally, TB affects the lungs, but it can also affect other fundamental organs in the body. According to the TB Alliance (2017), the World Health Organization (WHO) estimates that two billion people, or one-third of the world's population, are infected with Mycobacterium tuberculosis (MTB), the bacteria that causes TB. Eight countries account for two-thirds of the global total: India (27%), China (9%), Indonesia (8%), the Philippines (6%), Pakistan (5%), Nigeria (4%), Bangladesh (4%), and South Africa (3%) (Chakaya et al., 2021).

In 2020, an estimated 9.9 million people were infected with TB, equating to 127 cases per 100,000 people (Global Tuberculosis Report, 2021). The number of infected cases has slightly declined compared with 2019 (1.9%) (Global Tuberculosis Report, 2021). The World Health Organization (WHO) reported that TB affects people of all sexes, but the highest burden was found in men aged 15 years, who accounted for 57% of all TB cases in 2017, with women accounting for 32% and children aged 15 years for 11%. Among all TB cases in 2017, 8.6% were people living with HIV (PLHIV) (Chakaya et al., 2021). Despite more than 9 million people becoming ill with TB annually, more than 3 million are not diagnosed, treated, or officially registered by national TB programmes globally (Jeremiah et al., 2021), consequently, resulting in negative outcomes such as death.

Although TB is preventable and curable, it is one of the top ten causes of death worldwide (Global Tuberculosis Report, 2021). TB results in the death of more than 1 million people every year, most of them in low- and middle-income countries (Kyu et al., 2018). Globally, 1.2 million (range 1.1–1.3 million) TB deaths among HIV-negative people were estimated in 2018 (a 27% reduction from 1.7 million in 2000) and an additional 251 000 deaths (range 223 000–281 000) among HIV-positive people, a 60% reduction from 620 000 in 2000 (Global Tuberculosis Report, 2019). The Global Tuberculosis Report (2021) recorded that 95% of TB deaths occur in low- and middle-income countries. Therefore, there is a need for these countries to adopt strategies that will curb disease spread and mortality. The rapid expansion of the standard approach to TB, which recommended diagnosis and treatment as proposed by the WHO enabled more than 36 million people to be cured between 1995 and 2008, thus, averting approximately 6 million deaths. An estimated 66 million lives were saved through TB diagnosis and treatment between 2000 and 2020. In terms of treatment efficacy, an estimated 54 million lives were saved through TB diagnosis and treatment between 2000 and 2017, with a 33% drop in TB deaths between 2000 and 2017 (Jeremiah et al., 2021).

Nonetheless, given the infectious nature of the condition, attempts to control the level and spread of the disease as well as number of deaths are dependent on the achievement of high levels of adherence to TB treatment (Global Tuberculosis Report, 2021). Poor adherence to TB treatment and loss to follow-up (LTFU) continue to be major problems among TB patients for the last fifty years (Andargie, Molla, Tadese & Zewdie, 2021). This is despite the implementation of the Revised National Control Tuberculosis Programme (RNTCP) in 1962 together with the directly observed treatment short course (DOTS) launched by the World Health Organization (WHO) in 1995 (Osman et al., 2021). This implies that TB patients are not adhering to their treatment programmes. Hirasen et al. (2018) reported that by 12 months on treatment, (31.3%) of patients had either died or been LTFU.

1.2 Background

South Africa suffers from an extremely high burden of TB, as it is one of the seven countries that account for 64% of new TB cases (Chakaya et al., 2021). According to the District Health Barometer for 2016–2017 (Molapo, Sello & Massyn, 2017). The TB epidemic in South Africa is driven by transmission through the air (inhalation), and therefore, it is vital to treat TB-diagnosed patients immediately. In 2019, South Africa registered 209,500 new patients with TB, an estimated treatment coverage of 58%, with more than 150,000 people with TB left undiagnosed, or ILTFU (diagnosed but untreated and not registered in a TB treatment register) (Osman et al., 2021). The Department of Health estimates that South Africa is missing about 160 000 patients with TB, which is the country's contribution to over 4 million TB patients who are not on treatment (Nogueira, Kocks & Botha, 2018). An estimated 328, 000 South Africans became ill with TB in 2020, and an estimated 61 000 people died from TB in the same year (Fukunaga et al., 2021). Therefore, to achieve better outcomes and reduce mortality rates, effective TB treatment and control programmes that adopt innovative tools and modernised programme service delivery methods need to be put in place (Grace et al., 2021).

TB is one of the leading causes of deaths in South Africa and accounted for 8.4% of all natural deaths in 2015 (Kim, Tanser, Tomita, Vandormael and Cuadros (2021). Jeremiah et al. (2021) also confirmed that for the 2020 reporting period in South Africa, the top five leading underlying natural causes of death were TB, diabetes mellitus, cerebrovascular diseases, other forms of heart disease, and human immunodeficiency virus (HIV) disease. According to a study on mortality and causes of death in South Africa in 2018, a total of 776,176 TB deaths for the period 2005–2015 were reported (Osman et al., 2021). The study revealed that the highest number of deaths occurred in 2018 among those aged 65–69 years (8.4%), while the lowest number was observed among those aged 5–9 and 10–14 years (0.6% and 0.8%, respectively). TB was still the main leading cause of death from 2016–2018, although the proportion of TB-related deaths declined from 6.5% in 2016 to 6.0% in 2018 (Osman et al., 2021).

In contrast, the rate of TB is not declining fast enough and is additionally fuelled by high human immunodeficiency virus (HIV) co-infection rates and further compounded by drug-resistant forms of the disease (Das, Khajanchi & Kar, 2020.). HIV co-infection is the most important risk factor for developing active TB, which increases susceptibility to primary infection, re-infection, and/or reactivation for patients with latent TB (Matatiele, Stiegler & Bouchard, 2021). According to Osman et al. (2021), HIV infection drives TB incidence, and in most African countries, 80% of people with TB have HIV infection as well. The very high number of people with HIV in South Africa is increasing the number of people with active TB. According to Garrett et al. (2022), South Africa has an estimated 7.8 million people living with HIV (PLHIV), of which nearly 230,000 were new HIV infections and 83 000 AIDS-related deaths occurred in 2020. There is substantial variation in HIV prevalence by province, with KwaZulu-Natal having the highest prevalence (18%), followed by Mpumalanga (15%), with the Northern Cape and Western Cape having the lowest HIV prevalence, at 6.8% and 6.6%, respectively (World Health Organization, 2021). The co-infection exacerbates the multiple challenges that negatively impact TB outcomes and the inability of the country to achieve the "End TB Strategy" targets as well as the ambitious goal of ending TB by 2035 (World Health Organization, 2021).

According to Dreyer, Mbambo, Machaba, Oliphant and Claassens, (2017), the Western Cape which hosts the sub-district and research setting for this study, reported a TB incidence rate of 690.1 per 100 000 in the 2015/2016 reporting year, which was a decline from 710 per 100 000 in 2014. This is in line with the reported low decline in TB incidence rates observed nationally (Fukunaga et al., 2021). Nonetheless, according to the Western Cape Government Health Annual Report for 2020–2021 (published 01 April 2022), 92% of all patients were started on TB treatment, but 79% of those treatments were successful. This is a reduction from the 84% success rate in the 2015–2016 financial year. Sadly, the Western Cape Government Health Annual Report (2022) reported that the loss to follow-up rate doubled from 9% in the 2015/2016 financial year to 18 % in the 2020/2021 financial year. Therefore, the Western Cape continues to be a high-burden TB province, with HIV/AIDS and TB remain the leading causes of death in women and overall (Western Cape Burden of Disease Report, 2019). Hence, this study aims to explore the challenges

experienced with adherence to TB treatment by patients in a facility in the Northern Sub-district, Cape Town.

In their study, Sannathimmappa, Parameshwara, Aravindakshan, and Nambiar (2021) found that the key challenges to meeting set TB targets included delays in diagnosis and non-compliance with treatment by TB patients. TB treatment is long and involves taking several medications; side effects are common, and patients usually feel better before treatment has been completed. Consequently, some patients disrupt or completely stop taking their treatment until completion (Taylor et al., 2022).

Although TB is curable, poor adherence to treatment is highly problematic as it can result in complications associated with drug-resistant strains. The emergence of drug-resistant strains in the early 1990s is a global threat to the control of TB and could put at risk the gains made in the efforts to end TB (Kontsevaya et al., 2021). In 2018, approximately half a million new cases of rifampicin-resistant TB, of which 78% were multidrug-resistant (Global TB Report, 2020). Globally, 3.4% of new TB cases and 18% of previously treated cases had multidrug-resistant TB or rifampicin-resistant TB (MDR/RR-TB) (Global TB Report, 2020). A study by Andargie et al. (2021) reported that one-third of global antimicrobial resistance deaths are attributed to drug-resistant tuberculosis. According to the Western Cape Government Health Annual Report (2021), the total number of TB cases diagnosed between 1 September 2020 and 31 August 2021 was 38 846, with 1578 (4.1%) of these being drug resistant.

The key challenges to overcome continuing high incidence rates of TB in South Africa are early disease detection, treatment before transmission can occur and adherence to treatment until completion (Andargie et al., 2021). Mohiuddin, Parkes and Gardam (2019) in addition to Thaller, Maxwell and Moor (2019) found that poor and/or non-adherence is considered to be one of the most serious challenges, which is reflected by the decrease in treatment success and the emergence of MDR-TB, which prolongs the infectiousness of the disease and increases the relapse and death of patients. Hence, messages that drive early detection, TB preventive treatment, and retention in care are the main health care interventions available to reduce the risk of a latent TB infection

progressing to active TB disease as well as the likelihood of a positive disease outcome (Global TB Report, 2020). Home visits and community outreach programmes are often employed as methods to optimise treatment adherence among patients (MacNeil, Glaziou, Sismanidis, Date, Maloney and Floyd, 2020). Nonetheless, non-adherence to TB treatment is still a serious barrier to TB prevention and control (Osman et al., 2021). According to Chakaya et al. (2021), treatment adherence has long been recognised as being crucial to successful TB treatment, although the achievement of good adherence has been the subject of controversy.

Khan et al. (2021) defined adherence as the process by which patients take their medications as prescribed. Furthermore, Chakaya et al. (2021) considered adherence to have three components: namely; initiation, implementation, and discontinuation. The moment a patient takes the first dose of a prescribed medication is defined as "initiation." Implementation of the dosing regimen refers to the extent to which a patient's actual dosing corresponds to the prescribed dosing regimen from initiation until the last dose is taken, and discontinuation (being the end of therapy) occurs when the next dose to be taken is omitted and no more doses are taken thereafter. Thus, for TB treatment to be successful, patients need to complete their TB treatment for six or nine months, depending on the regimen (Bea et al., 2021).

There are key factors that have been associated with poor treatment adherence in patients diagnosed with TB. Simbayi et al. (2019) highlighted social and economic factors, health system factors, therapy-related factors, condition-related factors, and patient-related factors as contributors to this phenomenon, individually or simultaneously. Bea et al. (2021) added fear and stigmatization to the list of contributory factors to poor adherence. It has been documented that the TB burden is driven by poor living conditions and late presentation to health facilities (Simbayi et al., 2019). Migliori and Garcia-Basteiro (2018) describe socio-economic deprivation as lacking social and economic basic necessities. Not only does the poorest 40% of the population bear 65% of the TB burden, but people with lower socio-economic status also experience barriers to accessing health care (Bea et al., 2021).

Although basic TB services are available and free of charge in almost all countries and particularly in South Africa, the process required for people with TB to reach facilities that provide those services is often time-consuming, cumbersome and costly (Kapwata, Breetzke, Wright, Marcus & Eales, 2022). For instance, most TB patients reported that daily visits to the TB clinic, especially the initial two months of treatment, were very difficult and physically demanding, and thus, some patients regarded them as unnecessary (Nidoi et al., 2021). As a result, poor adherence becomes an outcome.

In many communities, which include the Western Cape, stigma related to TB diagnosis is another important factor that significantly affects treatment adherence (Khan et al., 2021). The perceived stigma manifested itself in a variety of ways, but most commonly, participants expressed feelings of embarrassment about having an illness that is highly contagious, fearing that people will want to distance themselves from them (Thomas & Stephen, 2021). Key and vulnerable populations are often highly marginalised, which diminishes their access to health information and deters them from seeking healthcare services (Khan et al., 2021). During the implementation of the NSP 2012–2016, a survey to better understand stigma and discrimination was conducted (the PHLIV Index, a national survey of more than 10,000 people living with HIV and/or TB). The survey found that 35.5% of PLWHIV and 36.3% of TB patients reported experiencing externalised stigma, and 43% and 27%, respectively, experienced internalised stigma (Thomas & Stephen, 2021). This often resulted in patients not adhering to their treatment, resulting in a lack of follow-up.

1.3 Problem statement

A patient's ability to adhere to TB treatment is a complex, dynamic phenomenon with a wide range of factors impacting treatment-taking behaviour (Khan et al., 2021). Consequently, retaining patients on TB treatment is a major challenge in many countries including South Africa (Kiwanuka et al., 2020). Despite the high efficacy of TB drug regiments, one of the barriers in the TB control programme is non-compliance to treatment (Nidoi et al., 2021). It appears to be difficult to convince patients to take treatment for the required durations (Kapwata et al., 2022). As a result, the South African government developed different interventions such as the National Strategic

Plan (South Africa NSP for HIV, STIs and TB 2017-2022) which follows three previous NSPs (2000–2005, 2006–2011 and 2012-2016), and adopted international strategies such as the Global Plan to End TB (WHO, 2015a) to control the spread of TB by early detection, prevention, and treatment. Despite the significant efforts done by the South African government to end the TB burden by 2032, there are still challenges that need attention, one of which is ensuring the retention of TB patients in care until they complete their treatment.

Poor adherence to treatment by patients is a major challenge because it increases the rate of treatment failure, the continuous existence of infections, risk of drug resistance, and death (Kapwata *et al*., 2022). Rumende, (2018) supported the stated risks and added that poor adherence to treatment inadvertently decreases the effectiveness of the TB control programme. According to Kchouk *et al*. (2021), poor adherence to treatment leads to an increased transmission rate of Tubercle bacilli, delay in positive sputum conversion to smear-negative, morbidity, mortality and an escalation of the cost to the TB control programmes. The reasons for poor adherence have been reported in many research reports (Mekonnen & Azagew, 2018; Kapwata et al., 2021), however, the challenge persists. This implies that the strategies used to manage poor adherence may not be acceptable, feasible or relevant to certain geographical areas due to contextually specific factors. Additionally, it signals the possibility of a gap in understanding these challenges which then hinders the implementation of misaligned proposed strategies.

In the Western Cape, there is insufficient documented evidence of initial "loss to follow up" amongst newly diagnosed smear-positive TB patients. As such, it is a key concern for the programme management of TB in highly burdened areas (Skinner & Claassens, 2016b) such as the study setting where loss to follow-up (LTFU) rate of 11.1% in quarter one, 2019 was reported. Children account for 30% of new TB diagnoses which is an indication that there are still high levels of TB transmission in the Western Cape communities (Western Cape Government Health Annual Report, 2021). According to Williams (2018), TB persists because people have developed a degree of immunity which enables TB to remain in a latent state in otherwise healthy people for decades before it is passed on. The author further reported that there are populations in the Western Cape where close to everyone aged 20 years or more has a latent TB infection thus making the

eradication of TB difficult. Understanding the contextual socio-economic, cultural, and health system barriers that drive the TB epidemic, including the loss to follow-up which results in poor adherence to treatment is important in achieving favourable outcomes, particularly in HIV-co-infected patients. Hence, the need to explore the patients' challenges regarding adherence to treatment in their context, that is, the Northern sub-district of Cape Town.

1.4 Research Question

The main research question for the study is as follows:
What are the challenges with adherence to treatment experienced by TB patients in a facility in the Northern sub-district of Cape Town?

1.5 Aim

The study aims to explore and describe the challenges with adherence to TB treatment experienced by patients in a facility in the Northern sub-district in Cape Town (South Africa).

1.6 Research Objectives

The objectives of the study are as follows;

1. To explore and describe the personal challenges experienced by TB patients regarding their adherence to their treatment; and
2. To explore and describe the health system challenges experienced by TB patients regarding their adherence to their treatment.

1.7 Significance of the study

The National TB programme of South Africa has made efforts in reducing loss to follow-up in an attempt to ensure that TB patients adhere to their treatment. However, this goal has not been achieved which suggests that there are related impediments. Patients are key in unlocking the challenges from their own experiences thereby facilitating relevant and feasible future planning and problem-solving. Thus, the findings from this study will generate a body of knowledge that

could contribute information from patients' perspectives regarding their challenges and consequently, assisting policy-makers to contextualise the planned interventions. Findings from this study will also contribute to nursing where the components of TB management in the curriculum will include recommended and approved outcome measures as identified. Furthermore, these findings can also be used as the baseline for future research in the Western Cape and the research field.

1.8 Paradigmatic perspective

Polit and Beck (2020, p: 13) define a paradigm as "a way of looking at the natural phenomenon that encompasses a set of philosophical assumptions and that guides one's approach to enquiry." According to Laudan (2004), a paradigm is a set of assumptions about the basic kinds of entities in the world, about how these entities interact, and about the proper methods to use for constructing and testing theories of these entities. According to De Vos, Delport, Fouch and Strydom (2011).), the paradigmatic perspective describes how the researcher views and explains the research material. For this to be understood, the following meta-theoretical, theoretical statements and methodological statements define the paradigmatic perspective within which the researcher conducted this research.

1.9 Meta-theoretical statements

In research, assumptions are embedded in the philosophical base of the framework, design and interpretation of findings, and they influence the logic of the study (Burns & Grove, 2011). The metaparadigm constitutes the global perspective of a discipline and serves as an encapsulating unit or framework within which the more defined models, paradigms or theories develop (Van den Brink & Bruns, 2014).

The researcher's meta-theoretical assumptions are based on Watson's (1979) theory and the four metaparadigm concepts of nursing, which are the most general basis of nursing practice, the elements of nursing, which is human being, health, environment and nursing. The researcher's assumptions are as follows.

1.9.1 Human being

Human being refers to "a valued person in and of him-or herself to be cared for, respected, nurtured, understood, and assisted; in general, a philosophical view of a person as a fully functional integrated self". The human is viewed as greater than, and different from, the sum of his or her parts (Watson, 1979). Human beings are social bio-psychosocial beings, worthwhile, and should make decisions about their medical care and be part of the healthcare planning. It is from this meta-theoretical view that TB patients in this research should be respected and treated with dignity, provided with knowledge through health education and health promotion and should be treated equally and comprehensively such that their physical, mental and spiritual health is addressed to create harmony. This could be achieved by understanding the challenges and recommending corrective measures.

1.9.2 Health

Health refers to "unity and harmony within the mind, body, and soul and is also associated with the degree of congruence between the self as perceived and the self as experienced" (Watson, 1979). The researcher shares the same point of view with the WHO-UNICEF (1978) definition of health, which refers to it as a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity. Health is the continuum of health/wellness to illness and access to care. The effect of the interaction of TB patients with their internal environment, that is their body, mind and spirit, plays an important role in determining their continuum of health. Health is dynamic, a state of complete wellbeing and should not be taken for granted. In this study, health refers to the ability to access quality health care, and the availability of human resources and equipment to provide health care for TB patients to achieve a state of well-being.

1.9.3 Environment

Caring (and nursing) has existed in every society. Every society has had some people who have cared for others. A caring attitude is not transmitted from generation to generation by genes. It is transmitted by the culture of the profession as a unique way of coping with its environment" (Watson, 1979). In this study, the environment is internal, external and social factors that influence TB patients and their health status. According to Watson (1979), the social environment affects society which provides the values that determine how one should behave and what goals one should strive toward. Furthermore, Watson (1979) states that patients need to belong and be part of society, and each patient needs affection, a need to love and be loved, therefore, it is within the practice of caring that nursing can assist in meeting these needs. Thus, the researcher believes that the environment can be modified to improve health status, that interactions with family and friends are good for personal health and that the nurse-patient relationship creates a trusting environment.

1.9.4 Nursing

Nursing refers to "a human science of persons and human health-illness experiences that are mediated by professional, personal, scientific, esthetic, and ethical human care transactions" (Watson, 1979: p. 301). According to Watson (1979), nursing's goal, through the caring process, is to help patients gain a high degree of harmony within the self to promote self-knowledge, and self-healing, or to gain insight into the meaning of the happenings in life. The researcher believes that the nurse's main functions in undertaking nursing duties are to promote health, prevent illness, care for the sick and restore health. Therefore, in this study, nursing means the provision of care given by nurses concerning the well-being of TB patients, treating patients in the manner they want to be treated as human beings, and undertaking nursing duties with conscience, dignity and respect for human life.

1.9.5 Theoretical statement

The theoretical statements of this study will be explained by the central theoretical statement and operational definitions that grounds this study.

1.9.5.1 Central theoretical statement

Exploring and describing the challenges experienced by TB patients regarding adherence to their treatment in a facility in the Northern Sub-district in Cape Town would enable a clear understanding of the contextual challenges and consequently contribute to the formulation of recommendations that will guide in the development of measures intended to improve TB treatment adherence.

1.9.5.2 Operational definitions

The following operational definitions are central to this study and are as follows:

a) **Tuberculosis (TB)** is a highly contagious disease caused by a bacterium known as Mycobacterium tuberculosis. The disease usually affects the lungs, although in up to one-third of cases other organs are also involved (Jetan *et al*., 2010). This concept will be used as is in this study.

b) **"Loss to follow-up" (previously known as "default", "treatment interrupted" or LTFU)** refers to a TB patient who did not start treatment or whose treatment was interrupted for two consecutive months or more (WHO, 2020). In this study, "loss to follow-up" refers to patients who were previously treated for TB and were declared as "loss to follow-up" at the end of their most recent course of treatment.

c) **Directly observed treatment short course (DOTS)** is a process whereby a trained healthcare worker or other designated individual (treatment supporter) provides the prescribed TB drugs and watches the patient swallow every dose (South African National Department of Health, 2010).

d) **Adherence** refers to "the extent to which a person's behaviour-taking medication, following a diet, and or executing lifestyle changes, corresponds with agreed recommendations from a health care provider" (WHO, 2020). In this context, adherence will be implied when a patient is following the recommended course of treatment by taking all the prescribed medication without interruption for the entire length of his/her treatment period.

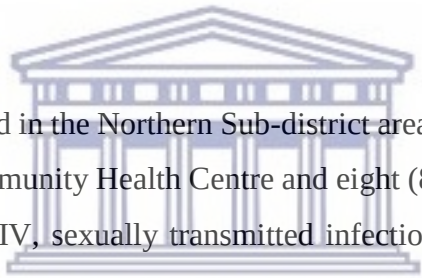
1.10 Methodological statement

A summary of the methodology will be discussed in this section with a detailed description to be provided in Chapter Two.

1.10.1 Research design

In this study, a qualitative, explorative and descriptive design was applied to explore and describe the challenges experienced by TB patients regarding their adherence to TB treatment in a facility in the Northern sub-district of Cape Town (South Africa). Burns and Grove (2011) define qualitative research as a systematic, subjective approach used to describe life experiences and give them meaning.

1.10.2 Research setting



The research study was conducted in the Northern Sub-district area of Cape Town in South Africa which consists of a 24-hour Community Health Centre and eight (8) Primary Health Care Centres that provide treatment for TB/HIV, sexually transmitted infections (STIs), basic antenatal care (BANC), integrated management child illness (IMCI) and sexually reproductive health care (SRHC). One facility was chosen because it is one of the two larger facilities in the sub-district and this facility's "loss to follow-up" rate has increased in 2016 from 2.5% to 6.8% in Quarter two and Quarter three, respectively.

1.10.3 Sampling and sample size

Sampling refers to the process of selecting a group of people, events, behaviours, or other elements with which to conduct a study (Grove et al., 2015). In this study, the purposive sampling method was employed. Purposive sampling, also known as selective, judgmental or subjective sampling relies on the judgment of the researcher on choosing the members of the population to participate in the survey. Therefore, the researcher selected only newly-diagnosed GeneXpert and smear positive patients with a history of "loss to follow- up" on their treatment who were willing to participate. This specific group formed the sample that data was collected from and comprised

patients of various ethnicities and gender, aged from 18 years and older. The researcher aimed to sample twenty (20) patients; however, data collection ceased when data saturation of sixteen (16) was achieved. This is because enough information to replicate the study was obtained from sixteen (16) participants and no additional new information was attained. Therefore, the researcher decided that further coding was not feasible.

1.10.4 Data collection

Permission to conduct the study was obtained from the facility manager who assigned a designated TB person to recruit participants for the study so as to prevent the researcher from perusing through the patients' files. This person acted as a recruiter to introduce and explain briefly the researcher's role and the study purpose and those who agreed were referred to the researcher. The Information Sheet (**Appendix A, Appendix B**) was given and explained to the participants prior to signing the Consent Form (**Appendix C, Appendix D)** after they agreed to participate in the study. The interview was conducted in a private room selected by the facility managers for the day. In terms of privacy during the interviewing process, a "Do not disturb" sign to indicate an interview was in progress, was attached to the door to facilitate privacy. This was the procedure followed for all interviews conducted at the facility. As for the interview (1) that was conducted at the home of the participant, the researcher allowed the participant to select a convenient day and time for him/her to be interviewed. During the at-home interview process, only the researcher and participant were present at the home of the participant. After the procedures were followed, semi-structured interviews (**Appendix I, Appendix J)** were then used to collect data. The questions were posed to the participants and probes were used to gain the necessary depth of the discussion.

1.10.5 Pre-testing

A convenient time and location were chosen for the trial run to ensure that the questions posed will explore and describe what is intended to eliminate problems that could not be foreseen when designing the interview schedule. The activity was also done to test the interview skills of the researcher and improve them as necessary. Pre-testing was done at the facility with two (2) LTFU TB patients who attended the facility. The process of pre-testing was expanded over two separate

days. Information with regard to the purpose of the study was provided to two (2) participants who were interviewed over a two-day period and upon agreement, consent was taken. The purpose of pre-testing was done with the aim to obtain information for improving the study, by discovering the strengths and weaknesses of the study and effect corrections where necessary. The pre- testing revealed no pitfalls and no changes were made to the original interview guide.

1.10.6 Data analysis

Apart from the researcher, an experienced, independent co-coder in qualitative research was assigned. All the concepts were coded by both researchers, transcribed and analysed using a thematic approach. This process of coding was followed using ATLAS, Ti 7 package.

1.10.7 Trustworthiness

Trustworthiness of the data collected was measured in terms of confirmability, dependability, credibility, and transferability (Krefting, 1991). To ensure trustworthiness in qualitative research, the researcher must establish that the research findings are confirmable, dependable, credible, and transferable. A discussion is provided below.

Confirmability refers to the degree to which the findings are a function solely of the informants and conditions of the research and not of other biases, motivations, and perspectives (Lincoln & Guba, 1985). In this study, the researcher ensured that the raw data, field notes and the interview schedule were available for the co-coder (Krefting, 1991). Themes generated by the independent coder were discussed with that of the researcher to ensure that they were true reflections of the responses of participants. Discrepancies in themes generated were also discussed to reach a consensus.

Dependability emphasises whether the findings would be consistent if the inquiry were replicated with the same subjects or in a similar context (Krefting, 1991). To ensure dependability in this study, the enquiry audit approach was used (Polit & Hungler, 1993). This implies scrutiny of the data and related supported documents by an external auditor as well as a research expert. Thus,

my supervisor was made aware of every stage of the study, and updates were given accordingly. **Therefore an audit trail should be kept to ensure consistency and reliability of research findings.**

Credibility determines whether the researcher has established confidence in the truth of the findings for the subjects or informants and the context in which the study was conducted (Guba & Lincoln, 1985). In this study, it was obtained from the discovery of the participants' experiences. Moreover, due processes in conducting interviews were followed, by recruiting the participants who were in the position to provide responses required in answering the research questions of the study, including building the necessary rapport to ensure that they freely volunteer information that is essential to the study. As part of the member checking process, the summary of the results and the analysis of the data were presented to the study participants again for confirmation and validation.

Transferability refers to the degree to which the findings can be applied to other contexts and settings (Krefting, 1991). The ability to generalise was not relevant in this study as the study was conducted in a natural setting and the focus was on the participants' experiences regarding their challenges with treatment adherence.

1.11 Ethical considerations

Approval to conduct the proposed study was obtained from the Biomedical Research Ethics Committee at the University of Western Cape (**BM 18/3/22**) as well as from the Western Cape Provincial Research Health Committee and the facility under study. An Information Sheet (**Appendix A, Appendix B**) explaining what the study is about, the purpose, procedure and the expectations of both the researcher and the participants was given to the participants. A written voluntary Consent Form (**Appendix C, Appendix D)** was then obtained from participants, and they were also informed regarding their rights and if they encountered any problems, they could notify the researchers' supervisor. A Consent Form (**Appendix C, Appendix D)**) was also

obtained from those who preferred to be interviewed in their homes. The researcher adhered to the following principles:

1.11.1 Informed consent

Information such as the aims of the study, duration of the interviews and the right to withdraw from the study at any time without fear that it will have an impact on their access to health care in future were explained to the participants in a language that they understood (**Appendix D).** The participants were also informed that there were no benefits for participating in the study but that the outcome will assist the Department of Health to develop a strategy that would benefit the community.

1.11.2 Privacy and Confidentiality

The interviews were conducted in a designated area provided by the facility manager to ensure privacy and to prevent any interference from others. The participants were informed that the data was only available to the researcher and the supervisor and that their judgement and opinions remained strictly confidential. Furthermore, their names and any other information that could trace responses to participants were not obtained. In respect of the adherence to the fundamental rights principle of the participants, the study was paying serious attention to the following respect for persons, beneficence and justice which will be discussed in detail in Chapter Two.

1.12 Thesis overview

Chapter One provides the overview of the study including the background, aims, objectives and methodology.

Chapter Two provides the research methodology employed in the study.

Chapter Three presents the findings generated from the study and includes the demographic information of participants as well as the emergent themes and subthemes.

Chapter Four provides a discussion of the findings in relation to current literature and similar studies.

Chapter Five is the concluding chapter for the study and discusses limitations of the study as well as the reflections of the study.

1.13 Summary

This chapter provided the introduction, background and overview of the study. The chapter also presents the problem statement, significance, research questions as well as aims and objectives of the study. All operational definitions of concepts are presented as well as the paradigmatic perspective underpinning the study. Lastly, the chapter provides a basic discussion of the methodology and ethical principles adhered to in the study. Chapter Two will provide a full description of the research methodology adopted in this study.

2 CHAPTER TWO: RESEARCH DESIGN AND METHODOLOGY

2.1 Introduction

"The goal of qualitative research is the development of concepts which help us to understand social phenomena in natural (rather than experimental) settings, giving due emphasis to the meanings, experiences, and views of all participants" (Kyngäs, 2020). According to Fuster Guillen (2019), qualitative research is a rigorous, interactive, holistic, subjective research approach used to describe life experiences and give them meaning. Therefore, the goal of this chapter is to provide an overview and rationale for the research methodology in this study to explore the challenges experienced with adherence to TB treatment by patients. This chapter includes the research design, the population and sampling process, the data collection method, data analysis, ethics and study rigour.

2.2 Research design

According to Sileyew (2019), a research design is an overall plan that gives the exact instructions or guidelines on how to address the research problem or answers to the research question. The research process for qualitative research is emergent, as the key behind qualitative research is to learn about the problem or issues from participants and to explore the research to obtain the information (Creswell & Hirose, 2019). According to Mello (2021), this type of research is conducted to explore, describe and promote an understanding of human experiences, events and cultures over time. Exploratory-descriptive qualitative research is conducted to address an issue or problem in need of a solution and/or understanding (Sileyew, 2019). In this study, a qualitative approach which is explorative, descriptive and contextual, was used to explore the challenges experienced with adherence to TB treatment by patients. The purpose of the design was to maximise the possibility of obtaining a valid answer to the research question (Mello, 2021).

The researcher adopted a qualitative explorative, descriptive and contextual design for this study to help investigate the full nature of a phenomenon, how it manifests and other related factors (Jain, 2021).

2.3 Exploratory design

Exploratory designs are useful when there is limited information available and there are wishes to have flexibility for future exploration of research areas (Dawadi, Shrestha & Giri, 2021). For this study, an exploratory design was relevant since the phenomenon under study was the challenges experienced by the participants on their TB treatment since an exploratory design is conducted to acquire an understanding of a situation, phenomenon and persons (Polonsky & Waller, 2018). This allows the participants to respond in their own words which are rich and explanatory (Creswell & Hirose, 2019).

2.4 Descriptive design

Descriptive research is designed to provide a complete and truthful description of a particular situation, social setting or relationship in everyday life (Siedlecki, 2020). Also, according to Dawadi et al. (2021), a descriptive design is used to determine current problems in practice and to identify what others, in similar situations, are doing and when more information is required. The descriptive design has as its main objective the comprehensive accurate portrayal of the characteristics of persons, situations, groups or the frequency within which the phenomenon occurs (Ellis, 2021). In this study, a descriptive design was used as it allowed the researcher to describe and give meaning to the challenges experienced by TB patients as they provided detailed information from their lived experiences.

2.5 Contextual design

Contextual research design examines behaviours, organisational culture and perception of the phenomenon under investigation (Lestari, Supardi, & Widodo, 2019). Research findings need to be contextualised within the parameters of the phenomenon studied. According to Schneider, Vis and Koivu (2019), qualitative research aims to describe and understand events within the concrete and natural contexts in which they occur. In this study, the context refers to circumstances and conditions as put forth by Ellis (2021). Lestari et al. (2019) further explained that research can be

described as contextual as the study is made of phenomena in the participants' immediate environment or context.

2.6 Qualitative research

The goal of qualitative research is understanding rather than explanation and prediction (Lestari *et al*., 2019). Hennink and Kaiser (2021) explained that qualitative research as a type of scientific research which sets out to answer questions using predefined systems or procedures. Also, according to these authors, this approach is more aligned with describing and explaining relationships and experiences as they occur in particular research settings which is flexible, iterative, text-rich and semi-structured.

Due to the flexibility of this research approach, semi- structured data collection tools were used which enabled the researcher to modify the questions and the flow of the data collection tools according to the research participants' responses. This approach allowed for interaction with the participants and subsequently granted the researcher the opportunity to have a deep understanding and detailed description of the challenges the TB patients' experience. Therefore, this approach gave the participants the possibility to express their experiences in their own words as the researcher was able to gain rich, detailed information.

2.7 Research methods

The research methods include the study setting, sampling, data collection, data analysis and ethics.

2.7.1 Study setting

In qualitative research, the setting is based on the purpose of the study, the accessibility of the setting or site, and the number and type of participants available in the setting (Hennink & Kaiser, 2021). This study was conducted in a natural setting, which according to Schneider et al. (2019) is an uncontrolled, real-life situation or environment. The research study was conducted in the Northern sub-district area of Cape Town that comprises of a 24-hour Community Health Centre

and eight (8) Primary Health Care Centres that provide treatment for TB/HIV, sexually transmitted infections (STIs), basic antenatal care (BANC), integrated management child illness (IMCI) and sexually reproductive health care (SRHC). One facility was selected for this study as it is one of the two larger facilities in the sub-district and this facility's 'lost to follow up' rate has increased in 2016 from 2.5% to 6.8% in quarter 2 and quarter 3, respectively. The selected facility is located in the Kraaifontein area in Cape Town, Western Cape (South Africa), and was identified as a high-risk settlement by the City of Cape Town Disaster Management officials (Van der Berg, Patel & Bridgman, 2022). According to Stats SA (2019), this area has a population of more than 36 583 people, comprising over 10 000 households with an average household size of 3.5 people.

2.7.2 Sampling technique and sample size

Sampling refers to the researcher's process of selecting a sample from a population to obtain information regarding a phenomenon in a way that represents the population of interest (Mello, 2021). A purposive sampling method was employed as it is widely used for the identification and selection of information-rich cases for the most effective use of limited resources (Campbell *et al*., 2020).

In this study, a purposeful sampling method was applied, and the participants were recruited according to the identified population that was relevant to the research question. Only TB patients who complied with the criteria below were purposively chosen to participate in this study.

- Inclusion criteria for patients to be selected for the study:
  - A positive diagnosis of TB.
  - Negative HIV status or co-infected.
  - Be Loss to follow-up (LTFU); and
  - Age of 18 years and older.

Additional requirements for participation in the study were the participant's consent to share their experiences; willingness to sign a consent form and permission to be audio-recorded. However, these will be discussed under ethical consideration and data collection. In this study, there was no

determined sample size as the sampling to redundancy technique was implemented. Data saturation means "sampling to redundancy", when no new information is forthcoming or when the information becomes repetitive (Mello, 2021). As previously mentioned, the researcher had an estimated sample size of twenty (20) participants and data saturation was reached after sixteen (16) participants were interviewed.

2.7.3 Data collection

Data collection is the process of gathering data from the selected participants (Mkandawire, 2019). Data are collected directly from the identified and selected sample populations which can be "direct data" or "indirect data" (Andrade, 2021). In this study, the data collected was direct as it included recordable spoken words and also observable body language, actions and interactions.

2.7.3.1 The role of the researcher

According to Archibald, Ambagtsheer, Casey and Lawless (2019), the researcher is typically involved in a sustained and intensive experience with participants as well as gaining entry to the research site and the ethical issues that might arise. Similarly, Andrade (2021) maintains that the researcher attempts to access the thoughts and feelings of study participants. They also believe that the primary responsibility of the researcher is to safeguard participants and their data (Andrade, 2021). Before data collection, the researcher obtained permission from the respective authorities to conduct the study.

The researcher submitted a research proposal, an Information Sheet (**Appendix A, Appendix B**), Consent Form (**Appendix C, Appendix D**) to the Biomedical Science Research Ethics Committee of the University of the Western Cape for the Study's approval (**Appendix E**). After obtaining approval from the Ethics Committee, the researcher also submitted the research proposal and the Study's Approval to the City of Cape Town/City Health Department to get permission to conduct the study. After receiving the Approval Letter from the City of Cape Town/City Health (**Appendix F**), the researcher submitted the research proposal, Appendix A and C to the Facility manager for approval (**Appendix G, Appendix H)** to obtain permission to conduct the study. The researcher

then arranged an appointment with the selected facility manager (see research setting) to discuss a period for data collection.

2.7.3.2 Data collection tool: Semi-structured interview

Jain (2021) refers to an interview as a method of data collection in which one person (an interviewer) asks questions of another person (a respondent) which are conducted face-to-face. Data were collected using semi-structured interviews. Semi-structured interviews consist of several key questions that help to define the areas to be explored, but also allow the interviewer or interviewee to diverge to pursue an idea or response in more detail (Andrade, 2021).

Semi-structured interviews are usually scheduled in advance at a designated time in a location normally outside everyday events (Dawadi et al., 2021). They comprise a set of predetermined questions and usually contain probes which may lead to other questions emerging from the dialogue. In terms of duration, semi-structured interviews range from 30 minutes to several hours.

2.7.3.3 Interview guide

The guiding question for the study was, "What are the challenges with adherence to treatment experienced by TB patients in a facility in the Northern sub-district of Cape Town? The literature search was conducted using academic databases: Google, Google Scholar, PubMed, Google Books, Science Open, Research Gates and Semantic Scholar. The keywords were combined using the Boolean search words "OR" and "AND". The search was limited to all studies published in English only and included the search words Tuberculosis, challenges, experience, adherence, stigma, side effects, lived experience, knowledge, determinants, barriers, lost to follow up, treatment and non –adherence. The researcher consulted a literature on TB treatment, challenges faced by TB Patients and barriers to TB Treatment in preparation for the interview guide. This literature review provided the researcher with an opportunity to identify any gaps that may exist in the body of literature and to provide a rationale for how the proposed study may contribute to the existing body of knowledge.

The researcher started with the process of developing the interview guide by writing down the larger research questions of the study and outlined the broader areas of knowledge that were relevant to the subject. The researcher then developed questions within each of these major areas, and shaped them to suit the respondents. On selection of the questions they were aligned to match the objectives of the study research questions. Thereafter, the language of the interview was adjusted according to the respondent, in this case TB patients. Special attention was paid to the wording of questions that enabled respondents to answer as honestly and completely as possible. The researcher asked a range of "how" questions to get the stories of the process and developed probes to elicit more elaborate responses. The interview guide commenced with a simple question for rapport-building and tried as best to arrange the questions in a manner that would flow naturally.

The interview guide comprised Section A and Section B. The questions in Section A were close-ended and sought to establish and determine the demographic information of the participants such as age, gender, language, employment status, educational background, marital status as well as living arrangements.

The questions in Section B were open-ended and allowed participants to answer freely, without pre-determined responses. Section B was designed to address the objectives of the study which are a) to explore the personal challenges experienced by TB patients regarding their adherence to their treatment; and b) explore the health system challenges experienced by TB patients regarding their adherence to their treatment. This section was further categorised into challenges relating to experience with TB, challenges relating to experiences after TB diagnosis; and challenges relating to the family after disclosure of TB.

The next category of questions related to objective two, which highlighted health system challenges experienced by TB patients regarding treatment adherence. This section also comprised a category highlighting access to facilities and including probes such as challenges relating to the distance of the facility. The purpose of this probe was to establish if the distance from health

facilities contributed to non-adherence to TB treatment. This category also included questions that determine the availability of emotional or financial support provided to the participant.

In terms of access to information, participants were probed as to how they accessed information regarding TB and treatment. Participants were also asked about their satisfaction with the care received at the health facility. Additional probes included how well the needs of participants were met and their views about the TB treatment. The purpose of these probes was to assess if dissatisfaction/satisfaction with service provision at healthcare facilities were a challenge to adherence to TB treatment.

In terms of treatment periods, participants were asked if the duration of the treatment period was too long. The purpose of this question was to establish if long treatment periods played a role in participants' non-adherence to TB treatment and if it posed a challenge to adherence. Further probes sought to establish participants' knowledge concerning the consequences of incomplete treatment. The purpose of this probe was to establish if a lack of knowledge about the consequences of incomplete treatment caused participants not to complete TB treatment.

Additional probes asked participants of they believed that TB treatment could cure them as well as their opinions regarding the possibility of re-infection after treatment. The purpose of these probes was to establish participants' knowledge concerning the efficacy of TB treatment.

In terms of knowledge relating to side-effects, participants were asked about their experiences relating to side effects whilst on treatment, to whom they reported the side effects and if the information given to them by health professionals helped them to tolerate the medication.

To establish treatment adherence, participants were asked if they had stopped treatment and were asked to provide the reason for doing so. Lastly, participants were asked to relate their experiences regarding the role of the healthcare staff at the health and the attitude of the staff at the health facilities towards them. The purpose of this question was to establish if mistreatment from staff or

lack of support to TB patients may be a contributing factor to non-adherence to treatment, and consequently a challenge to adherence.

Lastly, participants were asked if there was room for improvement at the health facility. The purpose of this question was to extract possible recommendations for health facilities, which may assist with improved adherence and treatment.

2.7.3.4 Data collection process

Before the data collection process, informed consent (**Appendix C, Appendix D**) was obtained from eligible participants to participate in the study. The recruiter who was working in the TB room identified the patients from the register as well as the LTFU (loss to follow-up) patients who visited the clinic for treatment on that particular day. The recruiter identified the participants and contacted them telephonically to obtain permission to conduct the study. The options presented to the participants were either to interview at home or at the facility. In instances where the participants could not be reached telephonically, the recruiter did home visits to recruit participants. Only one (1) participant preferred to be interviewed in their home. The rest of the participants (19) agreed to be interviewed at the clinic. The data collection period was extended from February 2019 to June 2019.

After contacting the participants, the recruiter introduced the researcher and interviewer to the participants. The researcher identified an independent interviewer who had conducted multiple qualitative interviews previously. The role of the interviewer was to assist in the interviewing process and to facilitate isiXhosa-speaking participants. The researcher personally conducted two (2) interviews, as the participants were Afrikaans-speaking. The remainder of the eighteen interviews (18) was conducted by the interviewer in isiXhosa; however, the researcher was present at every interview and made all field notes and observations.

The communication techniques employed during the interviewing process were guided by De Vos, Strydom, Fouche and Delport (2011) and used clarifying, probing, minimal verbal responses and

listening skills. **Clarifying** was employed to clarify ambiguous statements using clarity-setting questions such as "What did you mean exactly when you said…", and **probing** through the use of open-ended questions was used to allow participants to speak freely and elicit more information from them, such as, "How do you feel about that?" **Minimal verbal responses** were used to denote acknowledgement, comprehension and assurance to the participants (Hmmm, yeah, yes, I see), and lastly, **listening skills** were used to absorb information.

2.7.3.5 Data management process

Data management describes the organisation, storage, preservation, and sharing of data collected and used in a research project. The researcher used an audio-recorder to record all interviews. The recorder was fully charged and prepared before the commencement of the interview. Permission to audio-record was sought before the commencement of the interview. In addition, participants were asked to sign a consent form before commencement and were assured of anonymity and their right to withdraw at any time. The interview was conducted in a private room at the facility, which was arranged by the operational managers of the facility for the day. On the day of the interview, tables and chairs were arranged in a face-to-face manner to facilitate the interviewing process. The duration of the interviews ranged from 15-30 minutes, depending on the willingness of the participants to talk.

Before the commencement of the interview, the researcher provided each participant with an Information Sheet (**Appendix A, Appendix B)** and Consent Form (**Appendix C, Appendix** D), after the researcher ensured that the participant fully understood what was expected of them. The original interview guide was English (**Appendix I, Appendix J**) and was translated by a qualified translator to isiXhosa, as most (18/20) of the participants were isiXhosa speaking. The researcher also provided the participants with the opportunity to ask questions if they were unsure regarding the information given to them.

During the interviewing process, the researcher used field notes, which were the researcher's description of participants' body language, gestures and intonation or inflection of voice. They are

a record of the research experience, personal reflections and physical description of the setting. To ensure accuracy, the field notes corresponded to the interview and were labelled accordingly, i.e., Field notes (A) to Interview Participant (A). The interviews lasted between 15-30 minutes, wherein the researcher made field notes and in conclusion, thanked each participant for their participation in the study. The field notes and transcriptions were only accessible to the researcher and were stored in a file on a password-locked personal computer.

At the end of each day after the completion of interviews, the researcher sent the audio recordings (via email) to an independent professional transcriber/translator for transcription and translation. The transcriber/translator was informed that the confidentiality of the study was of utmost importance. The transcriber/translator informed the researcher of absolute confidentiality and that no external parties will have access to the audio files. Thereafter, each transcription was individually checked by the supervisor for accuracy.

2.7.3.6 Field notes

According to Phillippi and Lauderdale (2018), field notes refer to the documentation of the unstructured observations made in the field and the interpretation of those observations. During the interview process, the researcher had the opportunity to observe the participants' non-verbal communication such as their body language, facial expressions, and tone of voice while they were narrating their stories. Field notes were used together with the transcribed interviews in the data analysis process. The process of making field notes was guided by Hirose and Creswell (2022) and included descriptive, demographic and field notes. Descriptive notes refer to reports on the descriptions of the participants, such as context, and the activities that occurred during the interviewing process. Demographic notes refer to the described information about the time, place and date of the physical setting where the interviews took place and reflective notes provide a personal account and thoughts of the researcher such as speculation of incidents, feelings, ideas generated during the process, hunches, impressions and prejudices.

2.8 Data analysis

The purpose of data analysis is to organise, provide structure to, and elicit meaning from data which is an active and interactive process (Hirose & Creswell, 2022)). Lochmiller (2021) noted that *"*qualitative data analysis tends to be an ongoing and interactive process, implying that data collection, processing, analysis and reporting are intertwined, and /or not necessarily a successive process*"*. The researcher was guided by Braun and Clark (2006) steps to data analysis to validate the accuracy of the information.

Firstly, data was organised and prepared for analysis, using transcription and preparation of field notes (see above). Thereafter, the coding process commenced which refers to coding as the process of organising the data by bracketing chunks (or text or image segments) and writing a word representing a category in the margins. The researcher used the following six (6) phases by Braun and Clark (2006) to form codes:

a) Phase 1: Familiarising oneself with the data to be familiar with the depth and breadth of the content such as taking notes, grouping ideas for coding and transcription of verbal data (interviews).
b) Phase 2: Generating initial codes which involved the production of initial codes of the data.
c) Phase 3: Searching for themes means that different codes are grouped into potential themes and collating all the relevant coded data extracts within the identified themes.
d) Phase 4: Reviewing themes refers to the refinement of themes which involved reviewing and refining the themes. The reviewing process was to consider whether the collated extracts appeared to form a coherent pattern. The refining process involved the entire data set and considering the validity of the individual themes.
e) Phase 5: Defining and naming themes by identifying the essence of what each theme was all about and determining what aspect of the data each theme captures.
f) Phase 6: Producing the report involved the final analysis and write- up of the report.

Lastly, an independent co-coder was appointed to analyse the data. All the transcripts were sent to the co-coder immediately after transcription, translation and confirmation of translated data. The co-coder and the researcher independently analysed the data which was followed by a discussion. Thereafter, a consensus was reached on the categories that emerged from the analysed data.

The data analysis procedure in the current study was guided by Braun and Clark (2006) steps to data analysis. The data analysis was guided by the following steps:

- All the transcriptions were read carefully to get a general impression by writing notes as thoughts and ideas that came to mind.
- The most interesting interview was selected and read to try to get meaning from the information.
- Similar topics were arranged in groups by forming columns, labelled major topics, unique topics and leftovers.
- The topics were abbreviated as codes and the codes were written next to the appropriate segment of the text. Data organisation was also observed to check whether new categories or codes emerged.
- The total list of categories was reduced by clustering topics that relate to each other to form a list of categories.
- A final decision was made on the abbreviation of each category and the codes were arranged alphabetically.
- All the data material belonging to each category was put together in one place and a preliminary analysis was performed.

2.8.1 Transcription

The transcripts were translated from isiXhosa to English which was checked and verified by the seasonal interviewer. Transcription is the action of providing a written account of spoken words and assists the researcher in organising data (Garvey & Jones, 2021). In qualitative research, individual interviews are transcribed verbatim from audio-recorded files (Oluwafemi *et al*., 2021). In this study, an independent verified translator in the isiXhosa language and the researcher's

supervisor had access to the audio recordings and listened to them. In addition, the supervisor also checked the recordings against the transcripts for accuracy. Each transcript was assigned a code so as not to reveal the identity of the participant and maintain anonymity and ensure confidentiality. As soon as the transcripts were transcribed, they were translated by a translator. Thereafter, the researcher with the aid of a coder was able to commence the coding process. The researcher trusted the accuracy of the translated transcripts as they were done by a verified legal translator.

2.8.2 Rigour

Rigour in qualitative research refers to openness, relevance, epistemological and methodological congruence, thoroughness in data collection and the data-analysis process, and the researcher's self-understanding (Nyathi et al., 2019). Self-understanding in qualitative research is an interactive process between the researcher's personal history, values, gender, social class, race and ethnicity and those of the participants (Johnson, Adkins & Chauvin, 2020). On the other hand, Cloutier and Ravasi (2021) suggested that the key principle of good qualitative research is located in the notion of trustworthiness: the neutrality of its findings and decisions.

2.8.3 Credibility/

Credibility, in agreement with, Lincoln and Guba(1985) and Cloutier and Ravasi (2021), determines whether the researcher has established confidence in the truth of the findings for the participants or informants and the context in which the study was conducted. In addition, Daniel (2019) reported that to reach the ultimate goal of credibility, the researcher has to indicate that the investigation was conducted in such a manner as to ensure that the subject was correctly identified and described. The findings of this study were based on the experiences of the participants. As part of the interview process, participants who could respond to the research questions and built the rapport necessary to ensure that they freely provided information that was essential to the study, in accordance with due processes were recruited. The following strategies were used to ensure the credibility of collected data and correct data interpretation:

2.8.3.1 Member checking

Raskind et al. (2019) refer to member checking as feeding back data, analytical categories, interpretation and conclusions to the participants from whom the data was obtained. In this study, member checking was done after each interview to ensure that the participants understood the questions and agreed to the accuracy of the collected data. These interviews were conducted until data saturation was reached. The analysis of the data and a summary of the results were given to some of the participants as part of the member-checking process by the researcher in order to confirm and validate the study's findings. The researcher double-checked participants' data throughout the study and questioned the participants if the interpretation accurately represented their viewpoints.

2.8.4 Transferability

Krefting (1991) and Raskind et al. (2019), refer to transferability, a type of external validity, the degree to which the phenomenon or findings described in one study are applicable or useful to theory, practice, and future research, that is, the transferability of the research findings to other contexts. Similarly, Munthe-Kaas, Nøkleby, Lewin and Glenton (2020) refer to transferability as a process of demonstrating the applicability of one set of findings to another context. Transferability thus requires a clear and comprehensive description of the project participants, setting, and the process associated with data collection and analysis (Munthe et al., 2020; Schloemer & Schröder-Bäck, 2018). In this study, the researcher enhanced transferability by providing a clear and detailed description of the participants, setting, target population, data collection and data analysis.

2.8.5 Confirmability

Confirmability is established when the data accurately reflects the information provided by the participants and the findings are not imagined by the inquirer (Byram, 2022). Haven and Van Grootel (2019) suggest that confirmability may be achieved through the triangulation of different sources and perspectives. Confirmability guarantees that the findings, conclusion and

recommendation are supported by the data and that there is an internal agreement between the researcher's interpretation and the actual evidence (Byram, 2022). To achieve confirmability, the researcher must demonstrate that the results are linked to the conclusions in a way that can be followed and, as a process, replicated (Baumgart, Craig & Tong 2021). In order to verify the research process for this study, the researcher consulted another researcher with experience. The audio recordings were manually and verbatim transcribed, and independent coding was used to compare it to the researcher's transcription and coding in order to reach an understanding of the themes, codes, and sub-themes that had been identified. An audit trail was made accessible to make sure that conclusions and interpretations could be tracked back to their sources and that the findings were supported by those sources. (Babbie & Mouton, 2011).

2.8.6 Dependability

Dependability refers to the consistency and reliability of the research findings and the degree to which research procedures are documented, allowing someone outside the research to follow, audit, and critique the research process (Daniel, 2019; Stenfors, Kajamaa & Bennett, 2020). For a study to be accurate, Korstjens and Moser (2018) suggest that an audit trail be kept. An inquiry must also provide its audiences with evidence that if it were to be repeated with the same or similar respondents (subjects), in the same (or a similar) context, its findings would be similar (Poerwandari, 2021). In this study, to minimise bias during the data analysis process, the coding was done by the researcher and the co-coder. In this study, all participants were interviewed using the interview guide (Appendix I and Appendix J), the researcher made use of field notes during the interview process, and specifically recorded entries, based on the interviews in the researcher's reflexivity journal, as soon as possible after the interview was conducted.

2.9 Ethics

Ethics refer to the study of moral standards and the rights of the humans participating in the study which the researcher should consider in all stages of the research process (Nichol, Mwaka & Luyckx, 2021), According to Steenkamp and Tekelas (2021), ethical measures include providing the participants with adequate information regarding the research and giving them assurances of

privacy, anonymity, confidentiality, informed consent, dignity, and feedback. When conducting research, the researcher must ensure the protection of the rights of respondents and the facility in which research is done, while maintaining the scientific integrity of the study. In this study, the following procedures and principles were adhered to.

In respect of the adherence to the fundamental rights principle of the participants, the study was paying serious attention to the following:

- Respect for person: All participants were treated as autonomous agents as they were informed that their participation in the study is voluntary and that they had the right to withdraw f////rom the study at any time without penalty.
- Beneficence: While the risks of participating in the study were not obvious, the researcher availed the services of experts who would deal with unintended emotional trauma the participants might suffer. The researchers' phone number and clinic addresses were provided on the cover letter to enable easy contact in case any respondent need more information.
- Justice was ensured through fair selection and treatment, the right to privacy and anonymity and confidentiality. The researcher ensured that only the participants directly related to the study problem were selected, the participant had the right to know that all information would be kept private, only code names were used when discussing data and that no data would be made available to unauthorised persons.

2.9.1 Confidentiality

Confidentiality refers to the non-disclosure of any information provided by an individual to others and, in the context of research, presenting the findings of the study in a manner that safeguards the identity of the individuals (Hoft, 2021). To protect the rights and privacy of the participants, appropriate ethical approval for this study was obtained from the Biomedical Science Research Ethics Committee of the University of the Western Cape (**BM18/3/22).** The researcher implemented safeguards to protect the confidentiality of the participants throughout the following stage.

As previously mentioned, the researcher strictly protected the privacy of participants by conducting the interviews in a private room, which was pre-selected by the facility managers. A "Do not disturb" sign to show that an interview was in progress, was attached to the door of the private room. This was the procedure followed for all interviews conducted at the facility. Similarly, the one interview which was conducted in the home of the participant also ensured privacy. The participant was asked to select a convenient time and day for the interview. On the day of the interview, only the researcher and participant were present at the home of the participant. Hence, there was no external interference and disturbances during the interviewing process. Only the researcher, interviewer and participant were allowed in the room during the interviewing process. Permission was sought to record the interviews before data collection commenced.

To ensure anonymity and confidentiality, the participants were informed that their names will not be attached to the interviews and that only the researcher will have access to the data. Therefore, codes were assigned to recordings and transcripts of the participants to the extent that no links could be made between the participant and the information reported. The researcher assured the participants that all information given to them would only be used for the stated purpose of the research. The researcher also emphasised to the participants that any personal information regarding their cultural beliefs, feelings or practices will be protected and not be held against them. The privacy of all participants was protected throughout the process.

2.10 Informed consent

According to Babbie and Mouton (2001), the ethical principles of voluntary participation and protecting the participants from harm are formalised in the concept of "informed consent" which has three major elements: a) The type of information needed from the research participant; b) the degree of understanding that the participant must have to give consent; and c) the fact that the participant has the choice of whether or not to give consent. According to Millum and Bromwich (2021), informed consent means that the participants have adequate information about the research, comprehend the provided information, and have the ability to consent to or decline

participation voluntarily. Written consent (**Appendix C, Appendix D)** was obtained from the participants before the commencement of the interview, during which their anonymity was maintained using coded identities.

2.11 Summary

This chapter provided a broad overview of the research methods adopted and included the research philosophy, research approach, research strategy, data collection techniques and data analysis method used for the study. For this study, the sample consisted of twenty (20) Gene Expert TB patients from a healthcare facility in the Northern sub-district of Cape Town (Western Cape). Before the data collection process, permission was obtained from the management at the facility and the participants to conduct the study. The interviews were mostly conducted at the premises of the facility; however, one (1) was conducted at the home of the participant. Data were collected via interviews using a semi-structured style. In addition, field notes were compiled to produce richer data. Data collection was done via audio recording, whereafter the interviews were transcribed, and then analysed using a coding process. The researcher used a thematic analysis which was captured in the form of words. Data was then summarised, organised, and categorised to provide the researcher with a better understanding of the data and the development of themes.

The chapter concluded with a discussion on ethics, being considered from the beginning to the end of the research process. The researcher ensured all participants of their anonymity in the study and that their responses were confidential. They were also assured of their right to withdraw from the study at any point.

The following chapter provides the analysis of the interviews conducted during the research process and presents the resultant findings and themes based on the analysis of the interviews.

3 CHAPTER THREE: PRESENTATION OF RESULTS

3.1 Introduction

In Chapter Two, a detailed description of the research design and methods were discussed. This chapter presents the research findings in alignment with the study's research objectives. A discussion of the demographic information of the participants, the emergent themes, subthemes and categories from the qualitative data and the presentation, interpretation and discussion of the study findings are provided.

3.2 Demographic profile of the participants

Seventeen (17) participants volunteered of which one (1) person was excluded as s/he did not meet the study criteria. Sixteen (16) participants completed the interview, of which the majority (13) were male, and three (3) were females. In terms of age, eleven (11) participants were between the ages of 21- 40 years, three (3) were between the ages of 44-45 and two (2) were 50 and 61 years old, respectively. At the time of the study, six (6) were employed and ten (10) were unemployed. With regards to educational background, four (4) did not complete primary school, eight (8) did not complete secondary school, two (2) had matriculated and two (2) did not indicate completion of primary or secondary school. Regarding marital status, three (3) were married, one (1) was divorced and twelve (12) indicated single status. The majority (13) were isiXhosa speaking, and three (3) were Afrikaans speaking but understood English. Table 3.1 shows the demographic information of the participants.

Table 3.1 Demographic information of participants

Participants	Age	Gender	Race	Education	Employment status
A	23	M	C	Gr 10	Yes
B	49	M	C	Gr 10	Yes
C	22	F	B	Gr 12	Yes
D	35	M	B	Gr 9	No
E	42	M	B	Sub B	No
F	38	M	C	No school	No
G	17	F	C	Gr 10	No
H	31	F	B	Gr 10	No
I	21	F	B	Gr 12	No
J	38	M	B	Gr 4	Yes
K	25	M	B	Gr 8	No
L	61	M	B	Gr 6	No
M	23	M	B	Gr 8	No
N	45	M	B	Gr 2	Yes
O	44	M	B	Gr 4	No
P	39	M	B	Unknown	Yes

Participant G did not qualify to participate in the study due to age.

3.3 Themes that emerged from the qualitative data

DeSantis and Ugarrizan (2000) define a theme as, “an abstract entity that brings meaning and identity to a recurrent experience and its variant manifestations. As such, a theme captures and unifies the nature or basis of the experience into a meaningful whole.” They further state that themes, once identified, appear to be significant concepts that link substantial portions of the data together. Seven (7) themes with subthemes were extracted from the study and presented under each objective as captured in Table 3.2.

Table 3.2 Themes, subthemes and categories

Themes	Sub-themes	Categories
Objective One: Personal challenges		
Theme 1: Socio-economic conditions	↓ Financial challenges	▪ *Work vs health as priority* ▪ *Unemployment*
	↓ Inadequate household food supply	▪ *Food as a precursor for treatment ingestion.*
Theme 2: Timeous access of TB treatment	↓ Residential mobility	▪ Disimprisonment ▪ *Household relocation/ Prolonged cross-province visits*
	↓ Apathy	▪ *Ignorance*
Theme 3: Patients' comprehension of TB disease	↓ Inadequate knowledge related to side effects	▪ *Side effects experiences*
Theme 4: Self-Stigma	↓ Perceptions of stigma	▪ *Thoughts about stigma* ▪ *Experiences of stigma*
Objective Two: Systematic challenges		
Theme 5: Access to **comprehensive and quality** care	↓ Difficulty to access the health facility	▪ *Distance*
	↓ Support services	▪ *nutrition supplement programme*
Theme 6: Perception regarding the appropriateness of Care	↓ Health facility processes	▪ *Long waiting time* ▪ *Information sharing* ▪ *Staff attitudes*
Theme 7: TB patients' voices towards adherence support	↓ Family inclusion in care plan	▪ *Encouragement*

3.4 Objective One: Personal challenges experienced by TB patients regarding their adherence to their treatment

Four (4) themes highlight the personal challenges experienced by participants regarding adherence to TB treatment, namely; a) socio-economic conditions; b) timeous access of TB treatment; c) patients' comprehension of TB disease; and d) self-stigmatization.

3.4.1 Socio-economic conditions

Many participants lamented that the socio-economic conditions they found themselves in posed grave challenges to their ability to adhere to TB treatment. Financial challenges driven by the participants' responsibilities and access to employment opportunities informed the decisions they made. All the employed participants were breadwinners and, in most cases, worked as unskilled labourers where if they did not work, would not get paid. Thus, many were forced to prioritise earning an income over maintaining their health. Thus, they were forced to choose between waiting in long queues at the clinic which interfered their work time and going to work. The assertion made by Participant A indicated that he had no choice but to work.

> *"It's like now I'm sitting at home and my boss is fighting me, he is not paying me and last year it was the end of the year and the work staff was stressing, so he was like shouting at me because of every time I'm going to the day hospital, so according to me I didn't have any other way, I'm the only breadwinner in the house and I didn't have other choice than go to work.*" (Participant A, Male: 25 years)

According to this participant, visiting the clinic for treatment interfered with his work and created issues with his employer at the workplace. As the only breadwinner of his family, he was forced to put the financial responsibility of providing for his family above his health.

Another socio-economic condition that participants reported as a challenge was insufficient household food supply. Most participants were unemployed and relied on their families for support, more specifically the provision of food. Participants reported that they could not take medication on an empty stomach as they felt sick when doing so. Hence, health facilities were seen as a means to access food through the supplement programme which in some cases, was the only source of food for the TB patient and the entire household.

"I must eat this pap they provide here at the clinic then I can be healthy, so I would get the pap here sometimes I will not get it for two month and they would give me all these dates and not get it." (Participant K, Male: 25 years)

3.4.2 Timeous access of TB treatment

Participants also indicated personal factors that impacted their ability to access TB treatment on time which in turn affected their treatment adherence. These personal factors were residential mobility and apathy.

With regards to residential mobility, participants reported that this phenomenon occurs despite their satisfaction with the service they received in a health facility. In this cohort, residential mobility was due to either the participants being incarcerated and on parole, visiting for a prolonged time in another province or relocating back to their birth province due to lack of work opportunities or illness. Participant E reported that he did not adhere to his treatment due to disimprisonment and being on parole and said;

"You know, I don't want to be like someone who doesn't want to get help, because at the same time there is no other place I can get help than here. However, I am still busy with this sentence (Correctional service)." (Participant E, Male: 42 years)

Another participant (Participant B) reported that his obligation to his parole officer was a problem as that it interfered with his ability to adhere to treatment. The participant further indicated that the duration of treatment was not a contributor to his non-adherence, but that the activities expected from a parolee were. He said,

"Taking treatment is not that long from what they told me but the problem is I am very busy all the time. I have to go and sign on that side for this case I'm busy with." (Participant B, Male: 50 years)

Apathy from the participants was also reported as a contributor to non-adherence to TB treatment. Apathy happened despite patients receiving good healthcare services from healthcare facilities and was associated with the danger of non-adherence. Some participants confirmed that they received the necessary encouragement and information regarding the importance of taking their TB medication but still decided to stop taking their treatment. One participant asserted that;

> *"Nurses are very encouraging to me as this is the fourth time, I have TB because I would stop taking my treatment even though they explain to me the importance of the treatment, but I was ignorant and stop taking my treatment."* (Participant N, Male: 45 years)

Participant G mentioned that the process of collecting medication daily contributed to her non-adherence. She said,

> *"Sometimes it is boring, because I don't like to wake up all the time and come here just to wait."* (Participant G, Female: 18 years)

Participant G's response reflects a sense of indifference to TB as a disease and the impacts of neglecting one's health, despite the fact that that she was provided with the necessary information and possible repercussions of non-adherence.

3.4.3 Patients' comprehension of TB disease

The third theme is related to the participants' overall comprehension of the disease as lack thereof may contribute to non-adherence to TB treatment. Comprehension in this context includes knowledge about the side effects which was one of the key drivers for participants to stop taking their medication.

Some participants reported that they experienced side effects while drinking their medication. The participants indicated a lack of knowledge regarding the causes and had not anticipated the

possibility of their occurrence. This was perceived to be a challenge as most patients mentioned that they took TB medication to become cured and not feel worse. Hence, for these participants, adherence to treatment was perceived as challenging. Participant I particularly mentioned that sleepiness and changes in their body were side effects and said,

> *"The change that took place was my body, they would make me feel sleepy sometimes, like I would feel like sitting down and sleep."* (Participant L, Male: 61 years)

3.4.4 Self-stigmatisation

Perceptions of stigma were reported as a personal challenge experience by the participants and a contributor to non-adherence. Although the participants reported some level of stigma directed towards them by others, self-stigmatisation was detected as the first response they have when diagnosed with TB. For example, Participant C reported that on being informed about her TB diagnosis, her initial reactions and thoughts were the possibility of discrimination and stigma from her siblings and friends.

> *"The first thing that came to my mind, was that I won't be able to spend some time with other people and maybe my friends will gossip about me, maybe some will laugh at me and also my siblings will not eat the same food with me."* (Participant C, Female: 22 years)

3.5 Objective Two: Systematic challenges experienced by TB patients regarding their adherence to treatment

Two themes emerged from this objective, namely, a) access to holistic care and; b) perceptions regarding the appropriateness of care as contributors to TB patients' non-adherence to treatment.

3.5.1 Access to comprehensive care

One of the main systemic factors that participants viewed as a challenge to non-adherence to TB treatment was the inability of TB patients to access what they perceived as holistic care. These difficulties patients experienced included getting to the healthcare facility as well as the irregularity of support services such as the nutrition supplement programme. Participants indicated that if these were in order (easy access to the clinic and consistent nutrition supplement supply), they would be motivated to adhere to TB treatment. Participants reported that they had to travel long distances to reach the clinics which demotivated them, moreso when they could not afford transport costs. Some participants reported having to wake early to travel long distances in order to access the healthcare facility timeously. Most participants travelled long distances to access their nearest clinic. Participants E, P and L confirmed this and responded,

> *"…it is very long to get here…"* (Participants E (Male: 42 years); Participant O (Male: 39 years); and Participant L (Male, 61 years)

Their responses indicated that long distances to travel to the clinic was a challenge that discouraged compliance and resulted in non-adherence.

Inconsistency of the nutrition supplement programme meant that food supply was not regularly available and was reported as a challenge that impacted "holistic" care. Participants felt that their socio-economic conditions should be considered by the healthcare system, which should comprehensively support and motivate them to adhere to TB treatment. Some participants who met the criteria for additional food supplements were dependent on them as they were their only source of food for the patient and the family. These food supplements were provided to them for the duration of their TB treatment and sadly, in some cases, and were the only reason some participants visited the clinic for TB treatment.

> *"My only complaint is that I don't get that porridge here and they said I would get it at a certain time and I don't know whether it is limited for us*

or what. Maybe they don't know how many people who are taking this porridge at the clinic because we have folders there. They should know who has TB at the clinic. We will end up not getting it when you come here and be disappointed every time because it is finished and you don't end up coming here." (Participant K, Male: 25 years)

Based on this response, it appears that nutrition supplements are the main motivation for some patients to visit the clinic for treatment. The disappointment expressed by participants when they do not receive the nutrition supplements indicated that it was their lifeline to taking their TB treatment.

3.5.2 Perceptions of the health facilities' processes

The first factor that was reported as a challenge within the system due to health facilities' processes was the long waiting time. A number of participants reported wasted time whilst waiting to receive treatment. Participant H disclosed that although she visited the clinic in the mornings, she would wait up to two hours before she was attended to. She complained that she spent hours at the clinic and this coupled with her being a single parent, unemployed and taking care of her grandmother and other dependants was quite challenging. This influenced her decision to return for treatment collection, consequently, impacting treatment adherence.

"Sometimes maybe two hours or sometimes I sit here from the morning until 12h00 to 13h00." (Participant H, Female: 31 years)

However, one participant indicated that the amount of time spent waiting at the clinic was dependent on the number of patients visiting the clinic at that particular time. If patients were few, they were attended to speedily. This participant also indicated a ten-minute waiting period when patients were few:

"It's not even 10 minutes if it is not full, I will wait for some time, but I don't know how long." (Participant M, Male: 23 years)

The second factor perceived as a challenge to the health facility processes was how information was shared with the TB patients. Most participants confirmed that they received information regarding TB and the consequences of incompletion of TB treatment. However, Participant D, mentioned that the information he received was too much and therefore, he could not remember all of it. The information overload was considered a negative aspect as it desensitised the patients, affecting their ability to fully comprehend the impacts of non-adherence.

''I don't remember.'' (Participant D, Male: 35 years)

The last factor regarding facility processes as a challenge is the nurses' perceived treatment of TB patients. Some participants reported dissatisfaction as a result of the nurses' attitude. Participant H reported that she had a bad experience with a staff member after missing her appointment date. According to her, she had been absent for a week, which infuriated a nurse. The participant felt she deserved better treatment and should have been asked about her reasons for not visiting the clinic for treatment that particular week. She said:

"For a week I was not here. I didn't use my pills, then I came, and she just shouted at me and not ask me nicely what was happening or something you se. So, I just told her back that you must respect me also then I can respect you also you must not be hardegat (pig-headed). Then I said, no it's wrong what you are doing then if you don't want to help me its fine. Then I left and went home but I came back the next day." (Participant H, Female: 31 years)

Another participant (Participant B) reported that he did not receive any support from the community care workers (CCW) who were assigned to him to assist with his TB journey. This is despite the implementation of the Directly Observed Treatment (DOT) strategy aimed at ensuring

that TB patients adhere to treatment. The participant expressed disappointment in the health system and said,

> *"Actually nobody, there once came people at my home and said they are my supporters, they said they will come once or twice a week, but they never came, I only saw these people once during the time I did my medication."* (Participant B, Male: 50 years)

3.5.3 TB patients' voices towards adherence support

Although the participants were asked about the challenges that contributed to and exacerbated their non-adherence to TB treatment, they also proposed possible solutions for their support to change the status quo.

> *''Sometimes they don't even ask me question or something sometimes, really because they don't ask, they only give my pills and the weight and so you see.''* (Participant H, Female: 31 years)

The first proposal focused on a need for the family to be included in the care plan of the TB patient. This could be done through encouragement to support the TB patient so that they can adhere to treatment. Family support was discovered to be critical to patients' TB treatment. The majority of the participants in this study confirmed that help from loved ones assisted them with adherence to TB treatment. This help was considered essential in their treatment adherence experience. Participant I mentioned that her mother afforded her a chance to sleep longer on some days, whilst she waited in her stead at the queue at the clinic, and said,

> *"My mother would come here every day to wait in a queue for me here at the clinic while I'm still sleeping at home then at the right time I would come."* (Participant I, Female: 21 years)

3.6. Summary

This chapter focused on the presentation of the study findings which included, the demographic profile of the participants, themes, subthemes and categories from the analysed data analysed.

4 CHAPTER FOUR: DISCUSSION

4.1 Introduction

Chapter Three reported the findings of the study, and this chapter provides a discussion of the main themes presented in the previous chapter. TB is a disease prevalent among poor communities and upon diagnosis requires continuous treatment for a period of at least six months (Moyo et al., 2020). This implies that patients should consistently visit the clinic daily for the initial two weeks of their TB treatment. The main research question for this study was, "What are the challenges with adherence to treatment experienced by TB patients in a facility in the Northern sub-district of Cape Town?''

To answer the research question for the study, the conclusions were derived from the findings yielded from the interviews that were conducted to explore and describe the challenges experienced by TB patients regarding adherence to their treatment in a facility in the Northern Sub-district in Cape Town. The findings were supported by direct quotations of the participants presented in italics, and confirmation was also made through reference to relevant literature.

4.2 Demographic profile of participants

The lack of gender parity in the findings of this study was driven by the fact that more males than females were infected with TB. This was not due to exclusion, as all patients who consented to participate in the study were included. Tola et al. (2017) found in their study that the number of males infected with TB was slightly higher than females. However, Dogah, Aviisah, Kpene, Lokpo and Edziah (2021) observed gender to be significantly associated with treatment adherence whereas male respondents were about three times more likely to adhere to TB treatment.

4.3 Objective One: Personal challenges experienced by TB patients regarding their adherence to their treatment

Socio-economic conditions, timeous access to TB treatment, patients' comprehension of TB disease and self-stigma are the four themes that highlight the personal challenges the participants had in adhering to their TB treatment regimens.

4.3.1 Theme 1: Socio-economic conditions

The theme outlined two key issues, namely, a) financial challenges and b) inadequate household food supply that patients had experienced while on TB treatment.

4.3.1.1 Financial challenges

The findings of this study indicated that many patients who became very ill encountered financial challenges in getting to the clinic to get their TB treatment. Living conditions were frequently disrupted by TB as monetary income was reduced, particularly when breadwinners became ill. All the participants who were employed were primary wage earners who had unskilled jobs that required them to labour to get paid. As a result, they had to prioritise making a living over maintaining their health. This forced them to choose between reporting to work and waiting in a long queue at the clinic that would disrupt their schedule. According to one participant, seeking treatment at the clinic interfered with his ability to perform his duties at his job and caused problems with his employer. In contrast, a study Gyimah and Dako-Gyeke (2019) in Ghana, reported that patients experienced the same dilemma of work regarding their clinic attendance, and chose to quit their respective jobs when commencing TB treatment, leaving the financial burden on their spouse.

In this study, it was clear that the participants were breadwinners and thus, were unable to leave their work. This action predisposed the patients in this study to severe TB illness as they chose not to adhere to TB treatment. The financial challenges due to the patients' inability to work clouded their judgement with regard to the strategies used in the facilities. These strategies are designed to

help patients adhere to TB treatment and get cured. The first two weeks of initiating TB treatment requires TB patients to attend the clinic on a daily basis for DOT coverage and counselling. This is designed to monitor the patient for any complications that may develop. The expected daily visits placed significant financial demands on patients and their families. Furthermore, it became a challenge for some patients who were employed and could not get leave from work. This was especially true if the patient did not want to disclose their TB diagnosis.

Hence, financial challenges significantly contributed to non-adherence to TB treatment among the participants who were employed and could not leave their work. This is in contrast with Gyimah and Dako-Gyeke (2019), who reported that many of the patients expressed favourable perspectives on the purpose of DOTS. Their study further indicated that the participants described the mode of TB treatment as significant for enhancing adherence, monitoring progress and a form of support for clients (Gyimah & Dako-Gyeke, 2019).

4.3.1.2 Inadequate household food supply

Inadequate household food supplies were listed by the participants as another socio-economic circumstance that presented difficulties. Similarly, Nezenega, Perimal-Lewis and Maeder (2019) who conducted a study in Ethiopia, found that financial constraints to get adequate food were found to influence non-adherence to TB treatment.

Most participants were jobless and dependent on their families for food support. Participants acknowledged that they were unable to take their medications on an empty stomach since doing so made them feel sick. Accordingly, health facilities were considered to obtain food through the supplement programme, which in some cases, served as the only source of food for TB patients and their entire household. In cases where the food supplement programme was not available, patients had no need to adhere to treatment. This was due to the side effects associated with the lack of food. Additionally, unemployed participants relied completely on social grants for support, which was only received while undergoing treatment. The amount of money awarded by the social grant was deemed insufficient by some participants because they lacked any other sources of

support and thus could not buy food. Consequently, being undernourished affected their ability to adhere to the treatment plan. Thus, lack of food in the home makes it difficult for TB patients to follow their treatment regimen. Boru (2017) observed that a lack of food security prompted underprivileged TB patients to discontinue their medication. Also, according to Salifu and Eliason (2017), the feeling of uneasiness after taking medication on an empty stomach or with inadequate food has been documented in individuals who had defaulted on TB treatment. Similarly, a study conducted in Botswana reported that the most significant factor affecting the population was food insecurity, which includes not only hunger and under-nutrition but also uncertainty and stress related to food access (Wang et al., 2022).

4.3.2 Theme 2: Timeous access of TB treatment

The participants identified individual factors that had an impact on their capacity to receive TB treatment promptly, and consequently on their capacity to adhere to treatment. They were apathy and residential mobility. The participants reported that despite their satisfaction with the care they received at the facility, the phenomenon of residential mobility still exists. Residential mobility in this cohort was caused by participants who were either in prison and on parole, visited another province for an extended period, or moved back to their home province due to a lack of employment possibilities or illness. Ruru et al. (2018) reported similar findings, demonstrating that frequent travel or migration was linked to poor adherence to TB treatment.

The results of this study showed that two (2) participants found it challenging to fully comply with their TB treatment. This is because they had daily requirements to report to their parole officer, which occasionally clashed with their TB treatment. For example, the participants mentioned that their obligations to their parole officer interfered with their ability to adhere to therapy. The participants also explained that their non-adherence was caused by the tasks they were required to do as parolees, and not the actual duration of treatment. Allwood et al. (2021) conducted a study in Paraguay and revealed that the majority of parolees completed treatment in prison and on release, only adhered to treatment if they were admitted to socio-sanitary centres.

The study also reported that DOT throughout treatment in prison resulted in better adherence after release. In addition, the study showed that anti-tuberculosis treatment adherence in prisoners was high even after release with adequate coordination among extra-penitentiary and intra-penitentiary programmes (Allwood et al., 2021). However, most parolees did not adhere to treatment after release. Adane et al. (2017) also conducted a study in an Ethiopian prison and revealed that most prisoners did not understand the disease and did not understand the importance of adherence to treatment after release. Reasons for non-adherence include living in remote areas and a lack of knowledge, as well as interference with daily activities. The study recommended health education interventions in prison, especially for those living in remote areas after release (Adane et al., 2017).

Nonetheless, in this study, the need for parole officers to be trained on the importance of supporting parolees on TB treatment to timeously access TB care and thus adhere to treatment was identified.

Moving to new residences and traveling across provinces were cited as challenges that led to non-adherence to treatment. Furthermore, the situation worsened when patients changed contact details (cell phone numbers), making them inaccessible to health workers who tried to contact them, thus impeding access to available treatment in their area. As a result, these patients were unable to access treatment timeously, and became lost to follow-up and thus considered non-adherent.

Participants' demonstrated apathy and indifference to the need for TB treatment, which was a contributing factor to delayed access to treatment. This occurred despite the patient receiving care from the facility. Apathy expressed towards the need for TB treatment may be considered an indicator related to a lack of awareness of the risk posed by not accessing treatment routinely and timeously. The participants acknowledged getting the encouragement and information they needed to remember to take their TB medicine, but despite this chose to cease treatment. One participant indicated that the process of getting to the facility daily, contributed to his apathy, thus resulting in non-adherence. According to this participant's reaction, some patients seem to be unconcerned with TB as a disease and the consequences of not taking one's health seriously.

Apathy was also reported to be the result of information overload. The participants acknowledged receiving essential motivation and education regarding the value of taking their TB medicine; however, they chose to discontinue their treatment because they felt overwhelmed by the information. One participant complained that he received too much information and was having trouble recalling it. This was in contrast with a study done by Mwansa-Kambafwile, Jewett, Chasela, Ismail and Menezes (2020), who reported that counseling and communication with health workers were lacking and a contributing factor to a lack of knowledge. Similarly, Gebreweld et al. (2018) reported that patients were not provided with enough health education while taking their TB treatment resulting in a lack of knowledge regarding the period of TB treatment and the risks of non-adherence to TB treatment.

4.3.3 Theme 3: Patients' comprehension of TB disease

The third theme is concerned with the participants' general understanding of the illness, as a lack of it appeared to be a factor in treatment non-adherence. Included under this theme, is knowledge of the side effects, which was a major factor in individuals stopping their treatment. Whilst most participants experienced side effects, only a few reported they did not encounter any. Hassard, Ronald and Angella (2017) reported adverse effects as the primary reason most patients did not continue with DOTS treatment. A study conducted in Ethiopia concluded that TB patients who experienced side effects from antibiotics, stopped taking their prescription and sought alternative treatments believed to not yield adverse effects (Woimo et al., 2017; Zegeye, Dessie, Wagnew, Gebrie, Islam & Tesfaye, 2019). Gube, Debalkie, Seid, Mengesha, Zeynu and Gebremskel (2018) found that the side effects of drugs are also a significant reason for anti-TB drug non-adherence among TB patients. Similarly, Ahmed and Martin (2018) found that the majority (77%) of defaulted patients reported side effects of TB medication and mentioned the burden of TB drugs and their side effects being the major challenges to treatment adherence. However, this is an indication of a lack of understanding regarding the dangers of untreated TB and its side effects. Additionally, it may imply that patients do not understand that side effects are often not long-term, and that they can be mitigated in some instances

4.3.4 Theme 4: Self-stigmatization

Participants' emotional reactions to stigmatization had an impact on their perception of the healthcare system. However, their responses were either aimed at a specific person or the entire system, and their perception was influenced by a particular person or the healthcare system. The researcher recognised the necessity to focus on the issue of stigmatization. This is because it significantly impacted how patients used healthcare services, even though it was not initially intended to be a part of the research. These reactions impacted the willingness of TB patients to use the healthcare services offered at the facility.

The participants described stigmatization as a personal challenge and a factor in their non-adherence. Self-stigmatization was found to be the first reaction participants had when they were diagnosed with TB, even though individuals claimed to experience some sort of stigma from others. For instance, some participants expressed shock and surprise at the disclosure of a positive diagnosis, while others expressed concerns about "*what people would say*".

A study done by Bresenham, Kipp and Medina-Marino (2020), regarding Quantification and correlates of tuberculosis stigma along the tuberculosis testing and treatment cascades in South Africa, revealed that TB presumptive had the highest levels of TB stigma compared to both community members and TB patients. Also Koontalay, Suksatan and Prabsangob (2021) in Thailand discovered that the majority of participants who received a positive TB diagnosis were distressed due to the stigma attached to the disease within their community. Some participants mentioned that living with TB was "not nice" and expressed despondency, embarrassment, shame and were generally demoralised. In terms of the impact of stigma associated with adherence, Choowong, Maneechote and Sawatdee (2019) noted that the emotion of stigma could reduce one's capacity to carry out daily physical activities and adhere to treatment regimens.

In this study, although self-stigmatization was a key issue, some participants anticipated stigmatization was based on their community's reaction considering it to be a "norm" while others related personal experiences of stigma. Consequently, participants were scared and avoided

treatment. Similarly, a study done by Gyimah and Dako-Gyeke (2019) found that relocation to a different community was sometimes used to avoid stigma. Also, Matlala, Matlou and Skaal (2020), revealed in their study done in the Limpopo Province of South Africa, that some participants prefer not to disclose the type of illnesses that they were living with due to fear of discrimination and some of the other participants disconnected from the people in their communities. On the other hand, Ahmed and Martin (2018) stated in their study that participants did not notice significant changes in the behaviour of people towards them, and reported that they received social support from family and friends which further encouraged treatment adherence.

4.4 Objective Two: Systematic challenges experienced by TB patients regarding their adherence to treatment

Three themes, namely, a) access to holistic care; b) perceptions of the appropriateness of care and c) TB patients' voices towards adherence support as contributors to TB patients' non-adherence to treatment, arose from this objective.

4.4.1 Theme 5: Access to comprehensive and quality care

Two subthemes emerged from this theme which are; a) difficulty to access the health facility and; b) support services.

4.4.1.1 Difficulty to access the health facility

a) Distance

The inability of TB patients to get what they perceived as comprehensive care was one of the key systemic factors participants viewed as a challenge contributing to non-adherence to TB treatment. This included transportation challenges such as long travelling distances which patients had to undergo when visiting the healthcare facility. Participants reported that easier access to the healthcare facility would be a motivating factor to better treatment adherence. In addition, participants were also demotivated by the costs of transportation and inability to afford them. Some

participants reported waking early in order to reach the healthcare facility timeously. Others suggested that long distances from the clinic contributed to non-compliance, leading to non-adherence. This is in line with Gube et al. (2018) in Southern Ethiopia who found that travelling long distances to the healthcare facility significantly contributed to non-adherence. Similarly, another study done in Ethiopia indicated that there was a significant difference in the occurrence of non-adherence to anti-TB treatment amongst patients who travelled long distances to health institutions in comparison to those who did not (Zegeye et al., 2019).

4.4.1.2 Support services

b) Nutrition supplement programme

The demographic information of the participants in this study indicated that most were unemployed and were reliant on their families for financial support**.** The inconsistent operation of the nutrition supplement programmes, where these food supplies were not consistently available in sufficient amounts, has been identified as a problem that affects "holistic" care. In some instances, social grants were their only source of income and the household did not have sufficient enough food to provide for the family. Hence, participants believed that the healthcare system should fully support them due to their socio-economic circumstances so that they are motivated, to adhere to TB treatment. De Schacht, Mutaquiha, Faria, Castro, Manaca and Manhic (2019) found in their study that patients frequently reported a lack of food and requested food subsidies which also highlighted the degree of poverty and access to basic life necessities in the population of Mozambique.

One participant in this study complained that the clinic stopped supplying her with nutritional supplements without providing any reason. Some patients who met the criteria for receipt of food supplements were only entitled to receive them for the first six months of their treatment. Additionally, the clinic occasionally ran out of food supplements. This had serious ramifications for patients who were the family's primary providers and relied heavily on supplements to maintain themselves and their families. As patients receiving TB treatment typically feel an increased appetite, a shortage of food or the inaccessibility of it could probably be the cause of non-

adherence. Nutritional supplements appear to be the primary reason some patients seek treatment at the clinic. Participants' unhappiness and dissatisfaction about not receiving nutritional supplements was evidence that they depended on them to take their TB medication. Similarly, Akeju, Wright and Maja (2017) and Gebreweld et al. (2018) reported that lack of food due to unemployment was a significant barrier to treatment and contributed to non-adherence to TB treatment.

4.4.2 Theme 6: Perception regarding the appropriateness of care

The purpose of this theme is to describe the challenges patients encounter when receiving care at the facilities. One subtheme was identified as health facility processes with three categories namely, a) long waiting time; b) information sharing and c) staff attitude.

4.4.2.1 Long waiting time

Long waiting times are harmful to patients and have been reported as a challenge within the healthcare system because of the processes. Long waiting periods between entering and leaving the facility were also highlighted by participants. In addition, participants mentioned that they preferred being informed of the waiting times as it would allow them to be better prepared and make the necessary arrangements. Some participants lived in close proximity to the healthcare facility or clinic which facilitated regular attendance at the clinic to get TB treatment. Still, they were forced to "*wake up too early*" to avoid lengthy waiting periods at the clinic. Even though the participants arrived at the clinic timeously for treatment, they reported having to wait for two to four hours before they were attended to. However, one participant noted that long waiting periods were dependent on the number of patients present at the clinic on a particular day. If the patients were few, then they received prompt attention and did not have to wait long periods before getting treatment. Similarly, one participant mentioned a ten-minute waiting time if patients were few. In contrast, Sahile, Yared and Kaba (2018) conducted a study in Addis Ababa (Ethiopia) regarding patients 'experiences and perceptions associated with TB treatment adherence. The study confirmed that most patients reported that waiting times were longer due to different circumstances such as late arrival of staff, different schedules for staff and longer waiting time in the intensive

phase (Sahile et al., 2018). Similarly, Zegeye et al. (2019) reported that there was significant causality between long waiting time in healthcare institutions and non-adherence to anti-TB treatment.

4.4.2.2 Information sharing

How information is provided to TB patients is the second aspect that healthcare facility processes are perceived to be a challenge. Most participants acknowledged having received information on TB and the repercussions of not completing treatment. This study discovered that every participant recognised the value of finishing their TB treatment. For instance, they were aware that stopping TB treatment was risky, that it was crucial for their health, and that when they finished it, they would be healed. The challenges they experienced while undergoing TB treatment, however, did not prevent the study participants from not finishing their TB treatment. Similarly, findings from this study are supported by Koontalay *et al.* (2021) in Thailand where they found that TB patients perceived physical and mental health problems leading them to discontinue the DOTS treatment due to their insufficient knowledge of TB disease. However, Charyeval, Curtis, Mullen, Senik and Zalisnyak (2019) stated that TB patients reported that nurses continuously provided them and their family members with a lot of information such as facts about TB, side effects, the importance of staying on treatment to prevent drug resistance, healthy nutrition, recipes, exercise, walks, and personal hygiene.

4.4.2.3 Staff attitude

Many participants believed that their relationship with the nurse was a key element that promotes high-quality care. Based on their interactions with patients, many participants reported that nurses were supportive. However, some participants expressed displeasure with the nurses' demeanour. For example, one participant reported a negative interaction with a staff worker after missing her appointment date. The participant informed the nurse that she had been absent for almost a week, which subsequently enraged the nurse. The participant believed she deserved better care and that the staff member should have questioned her about her reasons for not attending instead of shouting at her. This suggests that nurses' attitudes are quite significant in patients' **adherence** with

TB treatment. Similarly, a study conducted in Ukraine found that the harsh, rigid style of TB healthcare providers compromised patient willingness to continue treatment and led to lost opportunities for providers to convey information about TB and the importance of TB treatment (Aibana et al., 2020).

To effectively treat TB, patients and healthcare professionals must communicate regularly and with respect. Some participants expressed dissatisfaction with the nursing staff as well as the operational administration of the clinic. For instance, they explained that they were not informed of how the clinic system operated and that patients who arrived late for their appointments frequently received assistance first. Additionally, they mentioned a shortage of healthcare professionals on duty. Maintaining efficient communication is crucial for healthcare professionals if they want their patients to comply with their treatment plans. It is obvious that patients require assistance; for instance, one participant claimed that healthcare staff administered medication to her without asking her any questions and that the counsellor was the only one to do so. This indicates that there is no interaction between the patients and the nursing staff, which may be the cause of the patients' non-adherence to TB treatment.

Similarly, a study by Nezenega et al. (2019) in Ethiopia found that poor relationships between providers and patients, communication gaps, disrespect for the patient, and a lack of professional commitment affected non-adherence to TB medication. This is supported by a study conducted in Ukraine which found that the qualities of the nurses and their excellent interpersonal communication skills appear to have been a critical component of the success of the TB program (Charyeval *et al*., 2019). They further found that caring attitudes of nurses played a significant role in treatment adherence as the patients felt that staff sincerely wanted to help them recover.

4.4.3 Theme 7: TB patients voices towards adherence support

The purpose of this theme shows how the absence of encouragement and the exclusion of family members from the care plan both contribute to non-adherence to TB treatment.

4.4.3.1 Family inclusion in care plan

a) Encouragement

People in high-burden regions tend to link TB and HIV (Wouters et al., 2022). In general, patients are reluctant to tell their loved ones or close acquaintances about their condition. Effective support from family and nursing staff is crucial for patients' adherence to treatment TB therapy. The participants offered potential solutions in addition to discussing the difficulties that increased and contributed to their non-adherence to TB treatment, showing their support for changing the *status quo.*

The first proposal emphasised the importance of including family members in the TB patient's care strategy. This could be accomplished by encouraging others to assist the TB patient so they would adhere to the prescribed course of action. It was observed that patients' TB treatment depended heavily on family support. Most study participants agreed that support from loved ones helped with adherence to their TB treatment regimen. This assistance and the support of a family member, neighbour or friend was seen as crucial to their experience of treatment adherence. However, Gube et al. (2018) found in their study that having a treatment supporter does not affect anti-TB drug non-adherence.

The second proposal underlines the significance of the operating system, for example, in a healthcare facility. Some of the participants asserted that they were unaware of the workings of the system. One participant mentioned that his appointment with the doctor at the facility was often cancelled and rescheduled despite the fact that he had waited the entire day to see the doctor. Additionally, he stated that the healthcare staff did not attend to him in the doctor's stead. Furthermore, one participants mentioned inconsistency in the numbering system at the clinic For example, he mentioned that even though he was assigned number 20 in the queue, the healthcare staff would call out number 36. He then enquired why patients who came to the clinic after him were attended to first. He also mentioned that the numbering system and procedure were not

explained to him and thus he was unaware of how the healthcare system operated. He also suggested that nurses should inform patients of the clinic system.

One participant mentioned that the nursing staff did not know how to approach him appropriately. These allegations generated the impression that family, friends, and community support, in addition to the nursing staff's views toward the patient, play a significant part in the patient's non-adherence to treatment.

4.5 Conclusions of the findings in relation to the meta-theoretical statement

As discussed in Chapter One, this study was based on Watson's (1979) theory and the four metaparadigm concepts of nursing, the elements of nursing, which include human being, health, environment, and nursing, formed the researcher's meta-theoretical assumptions.

Access to quality and comprehensive care is essential for the participant's as human beings and is of utmost importance to their overall wellbeing. The participants in this study faced various challenges to healthcare access, such as apathy (ignorance), residential mobility (disimprisonment, prolonged cross-province visits, household relocation), side effects experiences, distance to the health facility, long waiting time, lack of information sharing, and negative staff attitudes.

It is thus important for participants to feel that the care they receive is appropriate for their individual needs in order to enjoy good health and an overall wellbeing. From this metatheoretical point of view, the researcher believes that TB patients should be respected and treated with dignity, provided with necessary knowledge through health education and health promotion, and treated equitably and comprehensively, in order to attain physical, mental, and spiritual harmony.

Patient's perceptions of the efforts made by healthcare facilities that are aimed at helping them to adhere to treatment were influenced by financial challenges/difficulties, access the health facility, inadequate household food supply, and support services (nutritional supplement programme). Hence, the assumption of health, which in this study referred to the ability to access quality and

comprehensive health care and the availability of resources to provide it, did not entirely meet their needs.

The researcher supports the belief that the environment affects health and well-being, emphasising the importance of modifying it for improved health status. Also, relationships with family and friends are beneficial for health, as well as fostering trust between the nurse and patient. These approaches underscore the significance of considering the environment when promoting health outcomes. Therefore, health facility processes such as long waiting times, inadequate information sharing, staff attitudes, inclusion of family in care plan (encouragement) are some of the key issues that need to be addressed to improve the participants' perception of appropriateness of TB care. The researcher also believes that encouraging the loved ones of TB patients to be part of their support system and to work actively with them towards adherence to the treatment, may help provide quality and comprehensive care.

In this study, nursing refers to the provision of care by nurses for the well-being of TB patients, treating patients as they would like to be treated as human beings, and carrying out nursing responsibilities with conscience, dignity, and respect for human life. Therefore, a supportive and engaging attitude from nurses was seen to be highly motivating, whereas a dismissive attitude had a considerable dampening effect on patients' well-being engagement with TB treatment.

4.6 Summary

The findings of the research regarding the challenges experienced with adherence to TB treatment by patients in the Northern sub-district, Cape Town, were reviewed, interpreted and compared with existing literature. Chapter Four discussed the themes identified in Chapter Three and elaborated on how each theme was linked to the research questions of the study. The following chapter provides the conclusions, limitations, recommendations, and reflections of the study.

5 CHAPTER FIVE: CONCLUSIONS AND RECOMMENDATIONS

5.1 Introduction

In the previous chapter, the research findings were discussed. The findings were supported by direct quotations from the interview participants presented in italics, and confirmation was also made through reference to relevant literature. In this chapter, the conclusions and the study's limitations, recommendations and reflections of the researcher will be discussed. In 2002, the World Health Organization (WHO) listed tuberculosis (TB) as a global health emergency. There is no vaccine or cure for TB, and it is a leading cause of death, disability, and illness worldwide. Treatment adherence is often cited as one of the most important factors in successful TB treatment outcomes. In the Northern Sub-District of Cape Town, where this study was conducted, adherence to TB treatment is critical to managing the disease and ensuring a positive outcome for patients.

Seven themes emerged from this study, namely socio-economic conditions, timeous access to TB treatment, patients' comprehension of TB disease, self-stigma, access to holistic care, perception regarding the appropriateness of care and TB patients' voices towards adherence support. Therefore, the conclusion relating to these themes are consequently discussed below.

5.2 Socio-economic conditions

Adherence to TB treatment is a complex and multifaceted process, which requires not only effective TB treatment but also interventions that address a patient's socioeconomic circumstances.

Financial challenges - The study showed that employment status, specifically being the main breadwinner, and working in low-skilled or unskilled jobs significantly influenced adherence to TB treatment.

Financial difficulties – Due to the inability of many patients to find employment, they are forced to make choices between receiving healthcare treatment and earning an income. This results in a decrease in treatment adherence because patients cannot spare the time needed to follow their

treatment regimen. Furthermore, patients' perceptions of the healthcare facilities' efforts to help them adhere to treatment were found to be influenced by the financial difficulties they experienced. Therefore, among the patients who were employed, financial difficulties strongly led to non-adherence to TB therapy.

Inadequate household food supply – Lack of food in the home was a significant factor in determining adherence to treatment. Patients who did not have access to nutritious food were unable to take their TB medications as prescribed. Therefore, this study found that a dearth of food in the home was considered a challenge and barrier to treatment adherence.

5.3 Timeous access to TB treatment

Residential mobility – Patients often moved to new homes and made lengthy trips across provinces, which consequently, impeded continuity of treatment. Patients who could not maintain residency in one area were more susceptible to miss scheduled visits and appointments. As a result, the success rate of completing TB treatment was less favorable. Furthermore, their lack of commitment to TB treatment was evident from the fact that they lost track of follow-up appointments, and eventually ceased to adhere to therapy.

Apathy – Many patients cited apathy as the main reason for their non-compliance with TB treatment. Lack of knowledge regarding the risks of irregular treatment has been indicated by the patients' display of apathy and indifference towards the necessity of TB therapy. Even though patients received the motivation and knowledge they needed to take their TB medication, they decided to cease TB treatment.

Disimprisonment – Some patients were parolees and had commitments with their parole officer which interfered with their ability to follow through with treatment. Therefore, it is suggested that parole officers be informed of the importance of helping parolees undergoing TB treatment to promptly seek TB care and maintain treatment **adherence**.

5.4 Patients' comprehension of TB disease

Inadequate knowledge related to side effects – The absence of a general grasp of the condition by the participants seemed to be a contributing factor to treatment non-adherence. Knowledge of side effects plays a significant role in patients terminating their treatment. Whilst the majority of patients experienced side effects, only a few patients mentioned none. This demonstrates a lack of knowledge of the risks associated with untreated TB and its adverse effects. Furthermore, it suggests that patients are unaware of the fact that side effects are sometimes temporary and that they can be avoided in some circumstances.

5.5 Self- stigma

Perception of stigma – Patients' emotional reactions to stigmatization impacted on their perception of the healthcare system. The researcher recognised the necessity to focus on the issue of stigmatization as it significantly impacted on how patients used healthcare services, even though it was not initially intended to be a part of the research. These reactions impacted the willingness of TB patients to use the healthcare services offered at the facility. Self-stigmatization was found to be the first reaction patient experienced when they were diagnosed with TB, even though individuals claimed to experience some sort of stigma from others. Patients also expressed unhappiness, despondency, embarrassment, and shame and became demoralised. In this study, although self-stigmatisation was a key issue, patients anticipated stigmatization based on their community's reaction.

5.6 Access to comprehensive and quality care

Difficulty in accessing healthcare facility/ies – Patients viewed access to the healthcare facility as a problem that contributed to non-adherence to TB treatment as they did receive what they perceived to be comprehensive care. Due to long distances from the facility, patients experienced difficulty with travelling and arranging transportation. Patients claimed that easier access to the health facility meant better adherence to TB treatment. Patients demotivation was directly linked

to the lengthy travel times to the clinics, to seek treatment. Others said that being far from the clinic increased the likelihood of non-compliance and non-adherence.

5.7 Support services

Nutrition supplement programme – The inconsistency of the nutrition supplement programme, where food supplies were not consistently available in sufficient amounts, has been identified as a problem that affects comprehensive and quality healthcare. Likewise, it is suggested that healthcare system should fully support TB patients and consider their socio-economic circumstances, so that they can adhere to TB treatment. A lack of food supplements has been directly linked to patients' non-adherence to TB treatment. Therefore, the absence of these nutritional supplements meant that patients had no reason to attend the clinic as patients relied heavily on them for their TB medication.

5.8 Perception regarding the appropriateness of care

Health facility processes – Due to healthcare facility systems, long waiting times have been noted as a systemic challenge that negatively affects patients' daily lives. Patients also concurred that it would be very helpful if nursing staff had provided information on what causes lengthy waits. With this information, patients might be informed and take the necessary precautions. One participant did point out that depending on how many individuals were in the clinic on any given day, the wait periods varied in length. Fewer patients would require quick care and less time waiting for treatment if there were fewer patients.

Information sharing – How information is presented to TB patients is challenging at healthcare facilities. Most patients reported receiving information about TB and the repercussions of incomplete treatment. This study found that patients understood the importance of completing their TB treatment and were generally aware of the risks involved in not finishing TB treatment. However, some patients still elected to not continue with treatment.

Staff attitude – Many patients expressed the importance of a good relationships with the healthcare staff and nurses in promoting high-quality care. Several patients confirmed that nurses' attitudes and general demeanour towards them were sometimes demotivating and that it played a major role in patients' attitudes towards compliance with treatment adherence.

It is imperative for patients and healthcare professionals to interact respectfully and often in order to achieve TB treatment adherence. Some patients voiced their displeasure with the clinic's operational management and nursing personnel. They noted that the operation of the clinic's system was not explained to them. In addition, patients who were tardy for their appointments routinely received assistance first. Therefore, healthcare practitioners need to maintain effective communication if they want their patients to adhere to their treatment programmes.

5.9 TB patients' voices towards adherence support

Family inclusion in care plan - Patients generally want to adhere to treatment, as they understand that it is in their self-interest to do so. Patients also rely heavily on their loved ones for support in helping them adhere to their treatment regimen. This is because TB treatment is a team effort and support from loved ones is essential for success. The key to ensuring adherence is to ensure patients understand their illness and the importance of their treatment.

5.10 Summary

In conclusion, financial difficulties among employed participants were one of the challenges to non-compliance with TB therapy. A lack of food was also a barrier to treatment adherence. Therefore, it has proven difficult for TB patients to stick to their treatment plan when there are food shortages at home. Lack of awareness of the risks of immediate and continual treatment were signaled by apathy towards the need for TB therapy. Home immobility also greatly contributed to patients' reluctance to adhere to treatment plans, as these patients found it challenging to stay in one place for long periods. Patients' commitment to their parole officer impaired their ability to continue therapy. For this reason, parole officers should be educated on the importance of helping parolees who are undergoing TB treatment to seek prompt TB treatment and maintain treatment

compliance. Addressing the challenges of adherence means ensuring that patients understand TB and the importance of getting treatment. Furthermore, the health system should provide participants with the necessary support, consider their socio-economic conditions, and ensure that they adhere to TB treatment on a natural basis.

Due to healthcare facility systems, long wait times have been noted as a systemic challenge that negatively affects patients' daily lives. Participants also concurred that it would be very helpful if nursing staff had provided information on what causes lengthy waiting times. This will allow them to be informed and take the necessary precautions. Concerning staff attitudes, many participants felt that their relationship with the nurse was essential to promoting high quality care. Some participants voiced their displeasure with the clinic's operational management as well as the nursing personnel. These accusations led to the conclusion that the patient's non-adherence to treatment is significantly influenced by support from family, friends, and the community as well as the attitudes of the nursing staff toward the patient.

5.11 Limitations

Due to the limited scope of this work (mini dissertation), only GeneXpert positive non-adherence TB patients were included in the study. Therefore, the viewpoints of all other TB patients and nursing staff were excluded. In terms of research setting, the study was conducted at a clinic which was situated in an area with a specific demographic, mainly an under-sourced area. The clinic thus only attracted a specific group of people, thereby limiting access to other categories of individuals which might have given different opinions or additional perspectives.

5.12 Recommendations

5.12.1 Recommendations for nursing education

Based on the findings where nurses are implicated as one of the barriers that results in LTFU, it is recommended that;

- The nursing institutions should broaden the scope of TB management in the curriculum and include social constructs and policy imperatives to ensure that students are aware of their impact on the patients and the success of the national TB programme.
- Clinical training of nurses should "adequately" expose the students to the TB programme and have competency assessments done specifically on TB.

5.12.1 Recommendations for research

- Further research is needed for nursing practice regarding the involvement of family members that needs to be explored.
- Further study is needed to understand patients' perspectives and understandings of their experiences of the side effects of TB treatment. Better strategies for patient education and support should be developed.
- The City of Cape Town district has major disparity in terms of its population composition particularly socio-economic status based on geographical placement. Hence, a broader study which includes the entire district is recommended to explore perspectives of patients from different socio-economic backgrounds regarding the challenges of adherence to TB treatment.
- A study on nurses' perspective about their role in facilitating accessible and quality care to TB patients in the City of Cape Town district is recommended.
- A study on nursing students' knowledge about TB management and their perspectives about the current status quo on TB management in their curriculum should be conducted.

5.13 Reflections

Dewey (1991) refers to reflection as an active and intentional process that can begin with some discomfort with an experience and end with learning and deeper insights. For many years I worked at a hospital where we administered TB medications to patients as per the doctors' prescription. Upon discharge, patients were given TB medications for two weeks and were informed that the remainder would be provided by their nearest clinic to continue TB treatment. In a controlled

environment like the hospital, we as nurses were not aware of the struggle the clinic staff faced to ensure that the patients are compliant with their TB treatment.

When I started at one of the two high-burden clinics in Kraaifontein, I was shocked at how little I knew about TB medications, duration, treatment, and the TB register (the importance of how and why to register patients). The clinic was situated in an informal settlement, which is a diverse community including a population of people who spoke isiXhosa (main language), Afrikaans, English and Sotho. Communication was thus a challenge for me as my native tongue is English. I am fortunate to be a fast learner, and I started to enjoy fighting the TB battle. After one month, I asked the question, “Why are patients not coming for follow-up?" I could not see the reason for not coming for their treatment. I decided to do home visits with the TB assistants, in order to have a better understanding of patients’ living conditions and what were the possible causes of non-adherence. I found some patients working and others leisurely sitting in the sun. Some patients promised to attend the clinic the following day but would not, and would attend haphazardly... Hence, I was inspired to conduct a study relating to the challenges experienced by TB patients in adhering to their TB treatment.

Recruiting the patients was not difficult as they were quite eager to participate in this study. After making home visits to recruit lost-to-follow-up patients, I realised how people in under-sourced areas have become accustomed to living in poverty-stricken environments. I noticed children playing in narrow roads with sewerage from the drain overflowing into the streets whilst adults sat in the streets talking idly and casually in a care-free manner.

Overall, it was a very enlightening journey, and I am still amazed at how people are living and how they are supporting each other despite their circumstances.

I encountered many obstacles during the interviewing process. Although my project was approved, access to a private room wherein the interviews could be conducted was challenging. I was forced to check daily which staff member not off duty was to occupy the room. Some days I had to share the room with counsellors, and we would alternate using the room. I gained new colleagues who

were very accommodating and always gave priority to my interviews. Looking back, I realise that this experience was priceless. I gained more insight as to which direction I would like to pursue identified areas where I could make a difference.

6 REFERENCES

Adane, K., Spigt, M., Johanna, L., Noortje, D., Abera, S.F. and Dinant, G.J., 2017. Tuberculosis knowledge, attitudes, and practices among northern Ethiopian prisoners: Implications for TB control efforts. PloS one, 12(3), p.e0174692.

Ahmed, A. O. A., Martin, H. P. (2018). Barriers leading to treatment default among Tuberculosis patients in Khartoum State, Sudan. A qualitative study. DOI:10.15761/CMI.1000152

Aibana, O., Dauria, E., Kiriazova, T., Makarenko, O., Bachmaha, M., Rybak, N., Flanigan, T.P., Petrenko, V., Becker, A.E. and Murray, M.B., 2020. Patients' perspectives of tuberculosis treatment challenges and barriers to treatment adherence in Ukraine: a qualitative study. BMJ open, 10(1), p.e032027.

Akeju, O. O., Wright, S. C., & Maja, T. M. (2017). Lived experience of patients on tuberculosis treatment in Tshwane, Gauteng Province. *Health SA Gesondheid, 22*(1), 259-267.

Allwood, B.W., Stolbrink, M., Baines, N., Louw, E., Wademan, D.T., Lupton-Smith, A., Nel, S., Maree, D., Mpagama, S., Osman, M. and Marx, F.M., 2021. Persistent chronic respiratory symptoms despite TB cure is poorly correlated with lung function. *The International Journal of Tuberculosis and Lung Disease*, *25*(4), pp.262-270.

Ames, H., Glenton, C. and Lewin, S., 2019. Purposive sampling in a qualitative evidence synthesis: A worked example from a synthesis on parental perceptions of vaccination communication. *BMC medical research methodology*, *19*(1), pp.1-9.

Andargie A, Molla A, Tadese F, Zewdie S (2021) Lost to follow-up and associated factors among patients with drug resistant tuberculosis in Ethiopia: A systematic review and meta-analysis. PLoS ONE 16(3): e0248687.

Andrade, C., 2021. The inconvenient truth about convenience and purposive samples. *Indian Journal of Psychological Medicine*, *43*(1), pp.86-88.

Andrade, C., 2021. The limitations of quasi-experimental studies, and methods for data analysis when a quasi-experimental research design is unavoidable. Indian Journal of Psychological Medicine, 43(5), pp.451-452.

Annual Report, 2021 to 2022. Department of Health and Wellness (Western Cape Government)

Archibald, M.M., Ambagtsheer, R.C., Casey, M.G. and Lawless, M., 2019. Using zoom videoconferencing for qualitative data collection: perceptions and experiences of researchers and participants. *International journal of qualitative methods*, *18*, p.1609406919874596.

Babbie, E. and Mouton, J., 2001. The practice of social research: South African edition. *Cape Town: Oxford University Press Southern Africa*.

Baumgart, A., Craig, J.C. and Tong, A., 2021. Qualitative research in CKD: how to appraise and interpret the evidence. *American journal of kidney diseases*, *77*(4), pp.538-541.

Bea, S., Lee, H., Kim, J.H., Jang, S.H., Son, H., Kwon, J.W. and Shin, J.Y., 2021. Adherence and associated factors of treatment regimen in drug-susceptible tuberculosis patients. *Frontiers in pharmacology*, *12*, p.625078.

Boru, C.G., Shimels, T. and Bilal, A.I., 2017. Factors contributing to non-adherence with treatment among TB patients in Sodo Woreda, Gurage Zone, Southern Ethiopia: A qualitative study. *Journal of infection and public health*, *10*(5), pp.527-533.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. Qualitative Research in Psychology, 3, 77–101. doi:10.1191/1478088706qp063oa

Bresenham, D., Kipp, A. M., & Medina-Marino, A. (2020, 2020/10/22). Quantification and correlates of tuberculosis stigma along the tuberculosis testing and treatment cascades in South Africa: a cross-sectional study. *Infectious Diseases of Poverty*, *9*(1), 145. https://doi.org/10.1186/s40249-020-00762-8

Burns, N., & Grove, S. K. (2011). Understanding nursing research: Building an evidence-based practice (5th Ed.). St. Louis: Saunders Elsevier.

Byram, J., 2022. Do you trust me? Rigor and Information Power in Qualitative Research. *The FASEB Journal*, *36*.

Campbell, S., Greenwood, M., Prior, S., Shearer, T., Walkem, K., Young, S., Bywaters, D. and Walker, K., 2020. Purposive sampling: complex or simple? Research case examples. *Journal of research in Nursing*, *25*(8), pp.652-661.

Chakaya, J., Khan, M., Ntoumi, F., Aklillu, E., Fatima, R., Mwaba, P., Kapata, N., Mfinanga, S., Hasnain, S.E., Katoto, P.D. and Bulabula, A.N., 2021. Global Tuberculosis Report 2020–Reflections on the Global TB burden, treatment and prevention efforts. *International Journal of Infectious Diseases*, *113*, pp. S7-S12.

Choowong, J., Maneechote, P. and Sawatdee, D., 2019. People with tuberculosis in Thailand impacts of stigma and directly observed treatment practice guidelines. *Southern College Network Journal of Nursing and Public Health*, *6*(1), pp.237-245.

Cloutier, C. and Ravasi, D., 2021. Using tables to enhance trustworthiness in qualitative research. *Strategic Organization*, *19*(1), pp.113-133.

Creswell, J.W. and Hirose, M., 2019. Mixed methods and survey research in family medicine and community health. *Family Medicine and Community Health*, *7*(2).

Daniel, B.K., 2019. Using the TACT framework to learn the principles of rigour in qualitative research. *Electronic Journal of Business Research Methods*, *17*(3), pp. pp118-129.

Das, D.K., Khajanchi, S. and Kar, T.K., 2020. The impact of the media awareness and optimal strategy on the prevalence of tuberculosis. *Applied Mathematics and Computation*, *366*, p.124732.

Davies M, Morden E, Mosidi T, Zinyakatira N, Vallabhjee K…Western Cape Burden of Disease Rapid Review Update 2019. Vol 1. Cape Town. Western Cape Department of Health, 2019. https://www.westerncape.gov.za/assets/departments/health/bod_a5_booklet_0.pdf (Accessed 21 November 2022)

Dawadi, S., Shrestha, S. and Giri, R.A., 2021. Mixed-methods research: A discussion on its types, challenges, and criticisms. *Online Submission*, *2*(2), pp.25-36.

De Schacht, C., Mutaquiha, C., Faria, F., Castro, G., Manaca, N., Manhica, I. and Cowan, J., 2019. Barriers to access and adherence to tuberculosis services, as perceived by patients: A qualitative study in Mozambique. PloS one, 14(7), p.e0219470.

De Vos, A. S., Delport, C., Fouch, C. B., & Strydom, H. (2011). *Research at grass roots*. (4th edition). Pretoria: Van Schaik.

DeSantis, L. and Ugarriza, D.N., 2000. The concept of theme as used in qualitative nursing research. *Western journal of nursing research*, *22*(3), pp.351-372.

Dogah, E., Aviisah, M., Kuatewo, D.A.M., Kpene, G.E., Lokpo, S.Y. and Edziah, F.S., 2021. Factors Influencing Adherence to Tuberculosis Treatment in the Ketu North District of the Volta Region, Ghana. *Tuberculosis research and treatment*, *2021*.

Dreyer, A.W., Mbambo, D., Machaba, M., Oliphant, C.E.M. and Claassens, M.M., 2017. Tuberculosis cure rates and the ETR. Net: investigating the quality of reporting treatment outcomes from primary healthcare facilities in Mpumalanga province, South Africa. BMC health services research, 17(1), pp.1-6.

Ellis, P., 2021. Sampling in qualitative research (3). *Wounds UK*, *17*(1).

Fukunaga, R., Glaziou, P., Harris, J.B., Date, A., Floyd, K. and Kasaeva, T., 2021. Epidemiology of tuberculosis and progress toward meeting global targets—worldwide, 2019. Morbidity and Mortality Weekly Report, 70(12), p.427.

Fuster Guillen, D.E., 2019. Qualitative Research: Hermeneutical Phenomenological Method. *Journal of Educational Psychology-Propositos y Representaciones*, *7*(1), pp.217-229.

Garrett, N., Tapley, A., Andriesen, J., Seocharan, I., Fisher, L.H., Bunts, L., Espy, N., Wallis, C.L., Randhawa, A.K., Ketter, N. and Yacovone, M., 2022. High rate of asymptomatic carriage associated with variant strain omicron. MedRxiv.

Garvey, C.M. and Jones, R., 2021. Is there a place for theoretical frameworks in qualitative research? *International Journal of Qualitative Methods*, *20*, p.1609406920987959.

Gebreweld, F.H., Kifle, M.M., Gebremicheal, F.E., Simel, L.L., Gezae, M.M., Ghebreyesus, S.S., Mengsteab, Y.T. and Wahd, N.G., 2018. Factors influencing adherence to tuberculosis treatment in Asmara, Eritrea: a qualitative study. *Journal of Health, Population and Nutrition*, *37*(1), pp.1-9.

Gill, S.L., 2020. Qualitative sampling methods. Journal of Human Lactation, 36(4), pp.579-581.

Global tuberculosis report 2020. Geneva: World Health Organization; 2020. L

Grace, P.S., Dolatshahi, S., Lu, L.L., Cain, A., Palmieri, F., Petrone, L., Fortune, S.M., Ottenhoff, T.H., Lauffenburger, D.A., Goletti, D. and Joosten, S.A., 2021. Antibody subclass and glycosylation shift following effective TB treatment. Frontiers in immunology, 12.

Gube, A.A., Debalkie, M., Seid, K., Bisete, K., Mengesha, A., Zeynu, A., Shimelis, F. and Gebremeskel, F., 2018. Assessment of anti-TB drug nonadherence and associated factors among TB patients attending TB clinics in Arba Minch Governmental Health Institutions, Southern Ethiopia. *Tuberculosis research and treatment*, *2018*.

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

Hassard, S., Ronald, A. and Angella, K., 2017. Patient attitudes towards community-based tuberculosis DOT and adherence to treatment in an urban setting; Kampala, Uganda. *Pan African Medical Journal*, *27*(1).

Hennink, M. and Kaiser, B.N., 2021. Sample sizes for saturation in qualitative research: A systematic review of empirical tests. Social Science & Medicine, p.114523.

Hirose, M. and Creswell, J.W., 2022. Applying Core Quality Criteria of Mixed Methods Research to an Empirical Study. *Journal of Mixed Methods Research*, p.15586898221086346.

Hoft, J., 2021. Anonymity and Confidentiality. *The Encyclopedia of Research Methods in Criminology and Criminal Justice*, *1*, pp.223-227.

Hopkins, K.L., Doherty, T. and Gray, G.E., 2018. Will the current National Strategic Plan enable South Africa to end AIDS, tuberculosis and sexually transmitted infections by 2022? Southern African journal of HIV medicine, 19(1).

Jain, N., 2021. Survey versus interviews: Comparing data collection tools for exploratory research. *The Qualitative Report*, *26*(2), pp.541-554.

Jeremiah, C., Petersen, E., Nantanda, R., Mungai, B.N., Migliori, G.B., Amanullah, F., Lungu, P., Ntoumi, F., Kumarasamy, N., Maeurer, M. and Zumla, A., 2022. The WHO Global Tuberculosis 2021 Report–not so good news and turning the tide back to End TB. International Journal of Infectious Diseases.

Jones, R., 2021. Data collection and transcription in discourse analysis: A technological history. *The Bloomsbury Handbook of Discourse Analysis*, p.9.

Kapwata, T., Breetzke, G., Wright, C.Y., Marcus, T.S. and Eales, O., 2022. Demographic and socio-economic risk factors associated with self-reported TB. *The International Journal of Tuberculosis and Lung Disease*, *26*(1), pp.33-37.

Kchouk, H., Mansour, A.B., Saad, S.B., Daghfous, H. and Tritar, F., 2021. Predictor factors to poor adherence to anti-tuberculosis treatment.

Khan, F.U., Asghar, Z., Tipu, M.K., Ur Rehman, A., Khan, A. and Ur-Rehman, T., 2021. Effect of displacement on Adherence to TB Treatment: An observational study in TB patients from Internally Displaced Persons of Pakistan. *Pakistan Journal of Medical Sciences*, *37*(3), p.675.

Kim, H., Tanser, F., Tomita, A., Vandormael, A. and Cuadros, D.F., 2021. Beyond HIV prevalence: identifying people living with HIV within underserved areas in South Africa. BMJ global health, 6(4), p.e004089.

Kiwanuka, J., Mukulu Waila, J., Muhindo Kahungu, M., Kitonsa, J. and Kiwanuka, N., 2020. Determinants of loss to follow-up among HIV positive patients receiving antiretroviral therapy in a test and treat setting: A retrospective cohort study in Masaka, Uganda. *PLoS One*, *15*(4), p.e0217606.

Kontsevaya, I., Lange, C., Comella-del-Barrio, P., Coarfa, C., DiNardo, A.R., Gillespie, S.H., Hauptmann, M., Leschczyk, C., Mandalakas, A.M., Martinecz, A. and Merker, M., 2021. Perspectives for systems biology in the management of tuberculosis. *European Respiratory Review*, *30*(160).

Koontalay, A., Suksatan, W., & Prabsangob, K. (2021)." I am afraid that others will feed scared and disgusted with me. So, I will keep it a secret till I die". A qualitative study among patients with tuberculosis receiving DOTS regimen in Thailand. *Belitung Nursing Journal, 7(6), 516-521. https://doi.org/10.33564/bnj.1678*

Korstjens, I. and Moser, A., 2018. Series: Practical guidance to qualitative research. Part 4: Trustworthiness and publishing. *European Journal of General Practice*, *24*(1), pp.120-124.

Kyngäs, H., 2020. Inductive content analysis. In *The application of content analysis in nursing science research* (pp. 13-21). Springer, Cham.

Kyu, H.H., Maddison, E.R., Henry, N.J., Mumford, J.E., Barber, R., Shields, C., Brown, J.C., Nguyen, G., Carter, A., Wolock, T.M. and Wang, H., 2018. The global burden of tuberculosis: results from the Global Burden of Disease Study 2015. The Lancet Infectious Diseases, 18(3), pp.261-284.

L. Haven, T. and Van Grootel, D.L., 2019. Preregistering qualitative research. *Accountability in research*, *26*(3), pp.229-244.

Langer, A.J., Navin, T.R., Winston, C.A. and LoBue, P., 2019. Epidemiology of tuberculosis in the United States. *Clinics in chest medicine*, *40*(4), pp.693-702.

Laudan, L. (2004). The epistemic, the cognitive, and the social. In P. Machamer, & G. Wolters (Eds.), Science, values, and objectivity (pp. 14–23). Pittsburgh, PA: University of Pittsburgh Press.

Lestari, E., Supardi, Z.A.I. and Widodo, W., 2019. Research Design prototype of Teacher Book and Student Book based on Contextual Teaching and Learning (CTL) to Practice Critical Thinking Skills of Grade VII. International Journal of Scientific and Research Publications (IJSRP), 9(10), p.p9436.

Lincoln, Y.S. and Guba, E.G., 1985. Naturalistic inquiry. Sage.

Lochmiller, C.R., 2021. Conducting Thematic Analysis with Qualitative Data. *Qualitative Report*, *26*(6).

MacNeil, A., Glaziou, P., Sismanidis, C., Date, A., Maloney, S. and Floyd, K., 2020. Global epidemiology of tuberculosis and progress toward meeting global targets—worldwide, 2018. *Morbidity and Mortality Weekly Report*, *69*(11), p.281.

Matatiele, M., Stiegler, N. and Bouchard, J.P., 2021. Tri-infection: tuberculosis, HIV, COVID-19 and the already strained South African health system. *Brain, Behavior, and Immunity*, *96*, p.5.

Matlala, S. F., Matlou, M. B., & Skaal, L. (2020). Lived experiences of men and women diagnosed with tuberculosis at a rural community of South Africa http://hdl.handle.net/10386/3285.

Mekonnen, H.S. and Azagew, A.W., 2018. Non-adherence to anti-tuberculosis treatment, reasons and associated factors among TB patients attending at Gondar town health centers, Northwest Ethiopia. *BMC research notes*, *11*(1), pp.1-8.

Mello, P.A., 2021. *Qualitative comparative analysis: An introduction to research design and application*. Georgetown University Press.

Migliori, G.B., Tiberi, S., Zumla, A., Petersen, E., Chakaya, J.M., Wejse, C., Torrico, M.M., Duarte, R., Alffenaar, J.W., Schaaf, H.S. and Marais, B.J., 2020. MDR/XDR-TB management of patients and contacts: Challenges facing the new decade. The 2020 clinical update by the Global Tuberculosis Network. *International Journal of Infectious Diseases*, *92*, pp. S15-S25.

Millum, J. and Bromwich, D., 2021. Informed consent: What must be disclosed and what must be understood? *The American Journal of Bioethics*, *21*(5), pp.46-58.

Mkandawire, S.B., 2019. Selected Common Methods and Tools for Data Collection in Research. Marvel Publishers.

Mohiuddin, Q.A., Parkes, L. and Gardam, M., 2019. Switching from expectorated to induced sputum cultures for tuberculosis diagnosis reduces cost without increasing risk. *American Journal of Infection Control*, *47*(8), pp.1022-1024.

Molopo, T., Sello, R. and Massyn, N., 2017. 11. HIV and AIDS. District Health Barometer, 18.

Moyo, S., Boffa, J., Mhlaba, T., Sulis, G., Sifumba, Z., Pai, M. and Daftary, A., 2020. COVID-19 and tuberculosis in South Africa: A dangerous combination. South African Medical Journal, 110(5), pp.341-342.

Mulogo, E. M., Nahabwe, C., Bagenda, F., & Batwala, V. (2017). Determinants of treatment completion among rural smear positive pulmonary tuberculosis patients: A cross-sectional survey conducted in south-western Uganda. *Infectious Diseases of Poverty*, *6*(1), 104.

Munthe-Kaas, H., Nøkleby, H., Lewin, S. and Glenton, C., 2020. The TRANSFER Approach for assessing the transferability of systematic review findings. *BMC medical research methodology*, *20*(1), pp.1-22.

Mwansa-Kambafwile, J.R., Jewett, S., Chasela, C., Ismail, N. and Menezes, C., 2020. Initial loss to follow up of tuberculosis patients in South Africa: perspectives of program managers. *BMC Public Health*, *20*(1), pp.1-8.

Nezenega, Z.S., Perimal-Lewis, L. and Maeder, A.J., 2020. Factors influencing patient adherence to tuberculosis treatment in Ethiopia: A literature review. *International Journal of Environmental Research and Public Health*, *17*(15), p.5626.

Nichol, A.A., Mwaka, E.S. and Luyckx, V.A., 2021, May. Ethics in Research: Relevance for Nephrology. In *Seminars in Nephrology* (Vol. 41, No. 3, pp. 272-281). WB Saunders.

Nidoi, J., Muttamba, W., Walusimbi, S., Imoko, J.F., Lochoro, P., Ictho, J., Mugenyi, L., Sekibira, R., Turyahabwe, S., Byaruhanga, R. and Putoto, G., 2021. Impact of socio-economic factors on Tuberculosis treatment outcomes in north-eastern Uganda: a mixed methods study. *BMC public health*, *21*(1), pp.1-16.

Nogueira, C., Kocks, D. and Botha, J., 2018. SASOM Annual Congress 2018. Occupational Health Southern Africa, 24(5), pp.164-168.

Nyathi, S., Dlodlo, R.A., Satyanarayana, S., Takarinda, K.C., Tweya, H., Hove, S., Matambo, R., Mandewo, W., Nyathi, K., Sibanda, E. and Harries, A.D., 2019. Isoniazid preventive therapy: Uptake, incidence of tuberculosis and survival among people living with HIV in Bulawayo, Zimbabwe. *PloS one*, *14*(10), p.e0223076.

Oluwafemi, A., Xulu, S., Dlamini, N., Luthuli, M., Mhlongo, T., Herbst, C., Shahmanesh, M. and Seeley, J., 2021. Transcription as a key phase of data analysis in qualitative research: Experience from KwaZulu-Natal, South Africa. *Field Methods*, *33*(4), pp.417-423.

Osman, M., du Preez, K., Seddon, J.A., Claassens, M.M., Dunbar, R., Dlamini, S.S., Welte, A., Naidoo, P. and Hesseling, A.C., 2021. Mortality in South African children and adolescents routinely treated for tuberculosis. *Pediatrics*, *147*(4).

Osman, M., Meehan, S.A., von Delft, A., Du Preez, K., Dunbar, R., Marx, F.M., Boulle, A., Welte, A., Naidoo, P. and Hesseling, A.C., 2021. Early mortality in tuberculosis patients initially lost to follow up following diagnosis in provincial hospitals and primary health care facilities in Western Cape, South Africa. *PLoS One*, *16*(6), p.e0252084.

Phillippi, J. and Lauderdale, J., 2018. A guide to field notes for qualitative research: Context and conversation. *Qualitative health research*, *28*(3), pp.381-388.

Poerwandari, E.K., 2021. Minimizing bias and maximizing the potential strengths of autoethnography as narrative research. *Japanese Psychological Research*, *63*(4), pp.310-323.

Polit, D. and Beck, C., 2020. *Essentials of nursing research: Appraising evidence for nursing practice*. Lippincott Williams & Wilkins.

Polit, D.F. and Hungler, B.P., 1993. Essentials of nursing research.

Polonsky, M.J. and Waller, D.S., 2018. *Designing and managing a research project: A business student's guide*. Sage publications.

Rahi, S., Alnaser, F.M. and Abd Ghani, M., 2019. Designing survey research: recommendation for questionnaire development, calculating sample size and selecting research paradigms. Economic and Social Development: Book of Proceedings, pp.1157-1169.

Rahman, M.M., Tabash, M.I., Salamzadeh, A., Abduli, S. and Rahaman, M.S., 2022. Sampling Techniques (Probability) for Quantitative Social Science Researchers: A Conceptual Guidelines with Examples. Seeu Review, 17(1), pp.42-51.

Raskind, I.G., Shelton, R.C., Comeau, D.L., Cooper, H.L., Griffith, D.M. and Kegler, M.C., 2019. A review of qualitative data analysis practices in health education and health behavior research. *Health Education & Behavior*, *46*(1), pp.32-39.

Rumende, C.M., 2018. Risk factors for multidrug-resistant tuberculosis. *Acta Medica Indonesiana*, *50*(1), p.1.

Ruru, Y., Matasik, M., Oktavian, A., Senyorita, R., Mirino, Y., Tarigan, L.H., van der Werf, M.J., Tiemersma, E. and Alisjahbana, B., 2018. Factors associated with non-adherence during tuberculosis treatment among patients treated with DOTS strategy in Jayapura, Papua Province, Indonesia. *Global health action*, *11*(1), p.1510592.

Sahile, Z., Yared, A., & Kaba, M. (2018). Patients' experiences and perceptions on associates of TB treatment adherence: A qualitative study on DOTS service in public health centres in Addis Ababa, Ethiopia. *BMC Public Health*, *18*(1), 462.

Salifu, Y. and Eliason, C., 2017. Tuberculosis treatment adherence in Ghana: patients' perspectives of barriers and enablers to treatment. *NUMID HORIZON: An International Journal of Nursing and Midwifery*, *7*, pp.6-23.

Sannathimmappa, M., Parameshwara, P.G., Aravindakshan, R. and Nambiar, V., 2021. Global scenario and recent advances in molecular diagnosis and management of drug-resistant tuberculosis. Biomedicine, 41(3), pp.522-530.

Schloemer, T. and Schröder-Bäck, P., 2018. Criteria for evaluating transferability of health interventions: a systematic review and thematic synthesis. *Implementation Science*, *13*(1), pp.1-17.

Schneider, C., Vis, B. and Koivu, K., 2019. Set-Analytic Approaches, Especially Qualitative Comparative Analysis (QCA). *American Political Science Association Organized Section for Qualitative and Multi-Method Research, Qualitative Transparency Deliberations, Working Group Final Reports, Report III*, *4*.

Siedlecki, S.L., 2020. Understanding descriptive research designs and methods. *Clinical Nurse Specialist*, *34*(1), pp.8-12.

Sileyew, K.J., 2019. *Research design and methodology* (pp. 1-12). Rijeka: IntechOpen.

Simbayi, L.C.Z.K., Zuma, K., Zungu, N., Moyo, S., Marinda, E., Jooste, S., Mabaso, M., Ramlagan, S., North, A., Van Zyl, J. and Mohlabane, N., 2019. South African national HIV prevalence, incidence, behaviour and communication survey, 2017: towards achieving the UNAIDS 90-90-90 targets.

Singh, N., Benmamoun, M., Meyr, E. and Arikan, R.H., 2021. Verifying rigor: analyzing qualitative research in international marketing. *International Marketing Review*.

Skinner, D., & Claassens, M. (2016). It's complicated: why do tuberculosis patients not initiate or stay adherent to treatment? A qualitative study from South Africa. BMC infectious diseases, 16(1), 1-9. https://doi.org/10.1186/s12879-016-2054-5

South Africa National Department of Health. Clinical Guidelines: PMTCT (Prevention of Mother-to-Child Transmission) 2010. [Accessed October 27, 2010

Stats, S.A., 2019. Mid-year population estimates 2018. *Pretoria, South Africa2019*.

Steenkamp, I. and Tekelas, F., 2021. Confirming" Ethical" Approach to Research.

Stenfors, T., Kajamaa, A. and Bennett, D., 2020. How to… assess the quality of qualitative research. *The clinical teacher*, *17*(6), pp.596-599.

Taylor, C.E., 2022. *Nutritional Abnormalities in Infectious Diseases: Effects on Tuberculosis and AIDS*. Routledge.

Taylor, H.A., Dowdy, D.W., Searle, A.R., Stennett, A.L., Dukhanin, V., Zwerling, A.A. and Merritt, M.W., 2022. Disadvantage and the experience of treatment for multidrug-resistant tuberculosis (MDR-TB). *SSM-Qualitative Research in Health*, *2*, p.100042.

Thaller, M., Maxwell, M. and Moor, C.C., 2019. 090 Anti-epileptic medications: causes of adherence failure. *Journal of Neurology, Neurosurgery and Psychiatry*, *90*(12), p.A28.

Thomas, B.E. and Stephen, A., 2021. Tuberculosis related stigma in India: roadblocks and the way forward. *Expert Review of Respiratory Medicine*, *15*(7), pp.859-861.

Tola, H.H., Garmaroudi, G., Shojaeizadeh, D., Tol, A., Yekaninejad, M.S., Ejeta, L.T., Kebede, A. and Kassa, D., 2017. The effect of psychosocial factors and patients' perception of tuberculosis treatment non-adherence in Addis Ababa, Ethiopia. *Ethiopian journal of health sciences*, *27*(5), pp.447-448.

Van den Brink, A. and Bruns, D., 2014. Strategies for enhancing landscape architecture research. *Landscape Research*, *39*(1), pp.7-20.

Van der Berg, S., Patel, L. and Bridgman, G., 2022. Food insecurity in South Africa: Evidence from NIDS-CRAM wave 5. Development Southern Africa, pp.1-16.

Wang, Q., Dima, M., Ho-Foster, A., Molebatsi, K., Modongo, C., Zetola, N.M. and Shin, S.S., 2022. The association of household food insecurity and HIV infection with common mental disorders among newly diagnosed tuberculosis patients in Botswana. *Public Health Nutrition*, *25*(4), pp.913-921.

Watson, J. (1979). Nursing: The philosophy and science of caring. Boston: Little, Brown.

Watson, J., 1999. *Nursing: Human science and human care: A theory of nursing* (Vol. 15, No. 2236). Jones & Bartlett Learning.

Watson, J., 2013. Nursing: The Philosophy and Science of Caring, Revised Edition. *Caring in nursing classics: An essential resource*, pp.243-264.

Western Cape Government Annual Report 2020/2021. Annual Report 2020 2021 01 Apr 2022 — _ 14 ... Employee Health and Wellness Programme Reporting System.

WHO, G., 2020. Global tuberculosis report 2020. *Glob. Tuberc. Rep*.

Who-UNICEF, A.A., 1978. Primary Health Care, ". Health for all" Series, 1.

Woimo, T.T., Yimer, W.K., Bati, T. and Gesesew, H.A., 2017. The prevalence and factors associated for anti-tuberculosis treatment non-adherence among pulmonary tuberculosis patients in public health care facilities in South Ethiopia: a cross-sectional study. BMC public health, 17(1), pp.1-10.

World Health Organization, 2019. *WHO guidelines on tuberculosis infection prevention and control: 2019 update* (No. WHO/CDS/TB/2019.1). World Health Organization.

World Health Organization, 2021. WHO global lists of high burden countries for tuberculosis (TB), TB/HIV and multidrug/rifampicin-resistant TB (MDR/RR-TB), 2021–2025: background document?

World Health Organization. Global tuberculosis report 2020. Geneva, Switzerland: World Health Organization; 2020. https://www.who.int/teams/global-tuberculosis-programme/tb-reports

Wouters, E., van Rensburg, A.J., Engelbrecht, M., Buffel, V., Campbell, L., Sommerland, N., Rau, A., Kigozi, G., van Olmen, J. and Masquillier, C., 2022. How the 'HIV/TB co-epidemic–HIV stigma–TB stigma'syndemic impacts on the use of occupational health services for TB in South African hospitals: a structural equation modelling analysis of the baseline data from the HaTSaH Study (cluster RCT). *BMJ open*, *12*(4), p.e045477.

Zegeye, A., Dessie, G., Wagnew, F., Gebrie, A., Islam, S.M.S., Tesfaye, B. and Kiross, D., 2019. Prevalence and determinants of anti-tuberculosis treatment non-adherence in Ethiopia: A systematic review and meta-analysis. *PloS one*, *14*(1), p.e0210422.

7. LIST OF APPENDICES

APPENDIX A: INFORMATION SHEET (ENGLISH)

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INFORMATION SHEET

Project Title: Challenges experienced with adherence to TB treatment by patients in a facility in the Northern sub- district, Cape Town.

What is this study about?

This research project is being conducted by Christeline Booysen at the University of the Western Cape. You are invited to participate in this research project as a suitable candidate. The purpose of this study is to explore the challenges experienced by patients regarding their adherence to TB treatment

What will I be asked to do if I agree to participate?

You will be asked to inform us if you have new information, As well as your address, if you are employed, if you staying alone and if not, how many people are staying with you, how many dependents you have, how many rooms in your house. Only your records will be used.

Would my participation in this study be kept confidential?

To ensure your confidentiality, the researcher undertakes to protect your identity. Furthermore, to ensure your anonymity, (1) your name will not be included on the study and other collected data; (2) a code will be placed on the study and other collected data; (3) an identification key will be use and only the researcher will have access to the identification key.

Any subsequent report or article written about the research project will not include your name. All the personal information and responses in the audio tapes will be kept in a secure place for five years after the results of the research have been published. The audio tapes will remain anonymously labelled to prevent linking the responses with any personal identification. In

order to maintain anonymity, the researcher will not mention your name or the name of the institution in the publication of the research findings.

What are the risks of this research?

All human interactions and talking about yourself or others carry some amount of risk. However, such risks will be minimised and we will act promptly to assist you if you experience any physical or emotional discomfort during the process of your participation in this study. When necessary, an appropriate referral will be made to a suitable professional for further assistance or intervention.

What are the benefits of this research?

This research is not designed to help you personally, but the results may help the investigator learn more about the reasons why the patients do not complete their TB treatment and what we, as health professionals, can do to help. We hope that in the future other people might benefit from this study through improved understanding of the patients need to complete their treatment.

Do I have to be in this research and may I stop participating at any time?

Your participation in this research is completely voluntary. You may choose not to take part at all. Further, if you decide to participate in this study, you may stop participating at any time and, you will not be penalized or lose any benefits to which you otherwise qualify.

What if I have questions?

This research will be conducted by C. Booysen at the University of the Western Cape. If you have any questions about the research study itself, then feel free to contact C. Booysen at 021 4445976

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Private Bag X 17, Bellville 7535, South Africa

Tel: +27 21-959 2274, Fax: 27 21-959 2679

E-mail 3616495@myuwc.ac.za

Prof J. Chipps
Head of Department: School of Nursing
University of the Western Cape
Private Bag X17
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jchipps@uwc.ac.za

Prof Anthea Rhoda
Dean of the Faculty of Community and Health Sciences
University of the Western Cape
Private Bag X17
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chs-deansoffice@uwc.ac.za

University of the Western Cape's Biomedical Research Ethics Committee
Private Bag X17
Bellville
Tel: 021 95942211
Email: research.ethics@uwc.ac.za

This research has been approved by the University of the Western Cape's Biomedical Researc
Ethics Committee
(REFERENCE

APPENDIX B: INFORMATION SHEET (ISIXHOSA)

IPHEPHA LOLWAZI

Isihloko ngoluphando: Imingeni kunye namava ekufumaneni unyango kwizigulane ze TB eziklinikini zase Northern sub-ofisi yesithili saseKapa.

Ingaba oluphando lungantoni?

Oluphando luqhutya ngu Christeline Booysen kwi Dyunivesiti yase Ntshona Koloni. Uyamenywa ukuba uthabathe inxaxheba koluphando njengomgqatswa ofanelekileyo. Isizathu soluphando kukujonga imingeni eye ijongane nezigulane ngukuphathelene ngokuhlala kwabo kunyango lwe TB.

Yintoni ezakucelwa ukuba ndiyenze ukuba ndiye ndavuma ukuthatha inxaxheba

Uzakucelwa ukuba usazise ukuba unolwazi olutsha. Kwaye nedilesi, ukuba uyasebenza, ukuba uhlala wedwa okanye hayi, bangaphi abantu abahlala nawe, bangaphi abaxhomekeke kuwe onabo, mangaphi amagumbi onawo endliniyakho.Zinkcukacha zakho kuphela ezizokusetyenziswa

Ingaba ukuthatha inxaxheba kwam koluphando kuyakugcinwa kuyimfihlelo

Ukuqiniseka ngemfihlelo yakho, umphandi uzakuqiniseka ngokhuseleko lokuveza ukuba ungubani. Siphinde, ukuqinisekisa ukuba awuzukwaziwa= (1) igama lakho alizukuba yinxalenye yoluphando kwananjalo nezinye inkcukacha eziqokelelweyo. (2) Kuzakusetyenziswa ikhowudi koluphando kwananjalo nakwezinye inkcukacha eziqokelelweyo. (3) Iqhosha lokwazisa lizakusetyenziswa kwaye ngumphandi kuphela ozokwazi ukufikelela kwesisitixi sekhabhinethi enenkcukacha.

Ombiko olandelayo okanye amanqaku ephepha othi abhalwe ngoluphando awasoze abandakanye igama lakho. Zonke inkcukacha zakho okanye impendulo zeteyiphi eshicilelweyo zakugcinwa kwindawo ekhuselekileyo iminyaka emihlanu emva kokuba iziphumo zophando zishicilelwe. Iteyiphi ezishicilelweyo zakuhlala zibhalwe ngokwemfihlelo ukunqanda ukuhlanganisa impendulo yakho nawe. Ukuze uhlale uyimfihlelo, umphandi akazulikhankanya igama lakho okanye igama leziko lezempilo ekushiceleleni Omnye iziphumo zophando.

Yintoni ingozi enobakho koluphando

Kuyo yonke intsebenziswano nabantu nokuthetha ngawe okanye ngabanye abantu bukhona ubungozi obuthile. Kunjalonje, obu'bungozi buyakunchitshiswa kwaye kuyakusetyenzwa ngokukhawuleza ukuncedisana nawe ukuba awuziva kakuhle ngokomzimba okanye awuziva ukhululekile ngokwasemoyeni ngelixa uthatha inxaxheba koluphando, kwananjalo uyakuthi udluliselwe kubantu abanothi bancedane nawe ngokufaneleyo okanye ukungenela

Yintoni imbuyekezo koluphando

Oluphando alwenzelwanga ukunceda wena buqu, kodwa iziphumo zinganceda umphandi afunde ngokuphangeleleyo izizathu zokuba kutheni izigulane zingalugqibi unyango lwazo lwe TB, kwaye yintoni thina njengonompilo esinokuyeza ukuzama ukunceda. Sinethemba loukuba abantu bangafumana inzuzo koluphando lokuqonda gcono imfuno zezigulane ukwenzela zigqibe unyango lwabo

Ingaba kunyanzelekile ukuba ndibe koluphando kwaye ndingayeka ukuthatha inxaxheba nanini na

Ukuthatha kwakho inxaxheba koluphando awunyanzelekanga. Ungakhetha ukungathathi inxaxheba kwaphela. Kodwa. Ukuba ugqhibe ukuba uthathe inxaxheba, ungayeka ukuthabatha ixaxheba nanini na, kwaye awusokuze wohlwaywe okanye ulahlekelwe yinzuzo obuzakuyifumana.

Ukuba ndinemibuzo

Oluphando luzakuqhutywa ngu C Booysen ose University of the Western Cape.Ukuba unemibuzo ngolu phando nkcakasane, khululeka ukutsalela umnxeba C Booysen ku 0214445976

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Private Bag X 17, Bellville 7535, South Africa

Tel: +27 21-959 2274, Fax: 27 21-959 2679

E-mail 3616495@myuwc.ac.za

Prof J. Chipps

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Dean of the Faculty of Community and Health Sciences

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Private Bag X17

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chs-deansoffice@uwc.ac.za

University of the Western Cape's Biomedical Research Ethics Committee

Private Bag X17

Bellville

Tel: 021 959 4111

Email: research.ethics@uwc.ac.za

APPENDIX C: CONSENT FORM (ENGLISH)

CONSENT FORM

Title of Research Project: Challenges experienced with adherence to TB treatment by patients in a facility in the Northern sub-district of Cape Town.

The study has been described to me in a language that I understand. My questions about the study have been answered. I understand what my participation will involve and I agree to participate of my own choice and free will. I understand that my identity will not be disclosed to anyone. I understand that I may withdraw from the study at any time without giving a reason and without fear of negative consequences or loss of benefits. I understand that I will be audio recorded by the researcher. These tapes will be kept by the researcher in a locked filing cabinet. I understand that only the researcher and co-coder will have access to these tapes and that they will be destroyed as soon as the results will be finalised and verified.

Participant's name……..

Participant's signature…….

Date……

APPENDIX D: CONSENT FORM (ISIXHOSA)

UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

Tel: +27 21-959 2274***Fax: 27 21-959 2679***

E-mail: 3616495@myuwc.ac.za

IPHEPHA LESIVUMELWANO

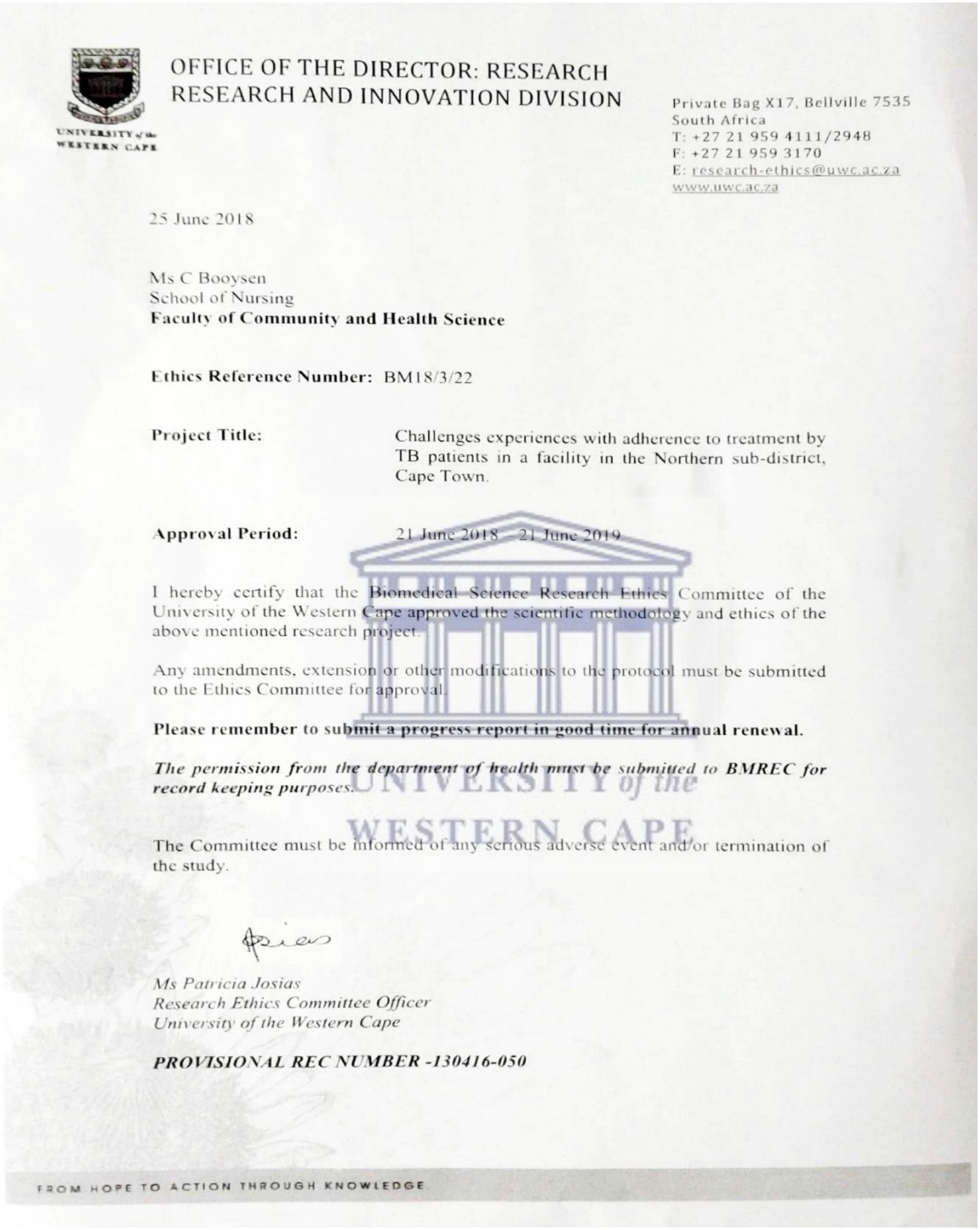
Isihloko ngoluphando: Imingeni namava ekufumaneni unyango kwizigulane ze TB eziklinikini zase Northen sub-ofisi yesithili saseKapa.

Uphando luye lwacaciswa kum ngolwimi endilwaziyo kwaye endiliqondayo. Imibuzo yam endinayo ngolu phando iye yaphenduleka .Ndiyakuqonda ukuba ukuthatha kwam inxaxheba kuzakubandakanyeka kwaye ndiyavuma ukuba ndithathe inxaxheba koluphando ngokuzithandela kwam kwaye ndinganyazelwanga. Ndiyaqonda ukuba igama lam alizukuchazwa okanye lichazelwe noba ngubani. Ndiyaqonda ukuba ndingayeka kwoluphando nakweliphi na ithuba ndifuna ngaphandle kokunika isizathu kunye nokoyikisela imiphumela emibi okanye ukungafumani inzuzo. Ndiyaqonda ukuba oludliwanondlebe luzakushicelelwa ngumphandi. Zonke ezi rekhoda zizakugcinwa ngumpandi kwikhabhinethi etshixiweyo. Ndiyaqonda ukuba ngumphandi kuphela kunye nomphathi wakhe ozakubanemvume yokufumana imvume kwezirekhoda kwaye zizakutshatyalaliswa ukufunyanwa kweziphumo kwaye zagqitywa.

Igama nefani lomthathi nxaxheba……..

Umtyikityo womthathi nxaxheba…….

APPENDIX E: STUDY'S APPROVAL ETHICS COMMITTEE (UWC)



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25 June 2018

Ms C Booysen
School of Nursing
Faculty of Community and Health Science

Ethics Reference Number: BM18/3/22

Project Title: Challenges experiences with adherence to treatment by TB patients in a facility in the Northern sub-district, Cape Town.

Approval Period: 21 June 2018 – 21 June 2019

I hereby certify that the Biomedical Science Research Ethics Committee of the University of the Western Cape approved the scientific methodology and ethics of the above mentioned research project.

Any amendments, extension or other modifications to the protocol must be submitted to the Ethics Committee for approval.

Please remember to submit a progress report in good time for annual renewal.

The permission from the department of health must be submitted to BMREC for record keeping purposes.

The Committee must be informed of any serious adverse event and/or termination of the study.

Ms Patricia Josias
Research Ethics Committee Officer
University of the Western Cape

PROVISIONAL REC NUMBER -130416-050

FROM HOPE TO ACTION THROUGH KNOWLEDGE

APPENDIX F: CITY OF CAPE TOWN/CITY HEALTH APPROVAL LETTER

CITY OF CAPE TOWN
ISIXEKO SASEKAPA
STAD KAAPSTAD

CITY HEALTH

Dr Natacha Berkowitz Epidemiologist: City Health

I hereby certify that the Biomedical Science Research Ethics Committee of the University of the Western Cape approved the scientific methodology and ethics of the above mentioned research project

T: 021 400 6864 F: 021 421 4894
E: Natacha.Berkowitz@capetown.gov.za

FROM HOPE TO ACTION THROUGH KNOWLEDGE.

APPENDIX G: PERMISSION TO CONDUCT THE STUDY FROM THE FACILITY MANAGER FOR APPROVAL

CITY OF CAPE TOWN
ISIXEKO SASEKAPA
STAD KAAPSTAD

CITY HEALTH: NORTHERN SUB DISTRICT

Mr. F.P. Daniels
Facility Manager: Health Northern Sub District
Wallacedene Clinic
T: +27 21 444 1299 **F**: 0865762679
E: Flip.Daniels@capetown.gov.za

22 October 2018

Research approval : Project ID 8019 on Challengers experience with adhere to TB treatment by clients

To Whom It May Concern

I hereby give Ms. Christeline Booysen approval to use Wallacedene to recruitment site for the above mention research.

Thanks

Regards'

APPENDIX H: COCT APPROVAL LETTER

T: 021 400 6864 F: 021 421 4894
E: Natacha.Berkowitz@capetown.gov.za

Ref: 24057 2018-09-21

RE: Challenges experienced with adherence to TB treatment by patients in a facility in the Northern sub- district, Cape Town.

Dear Christeline Booysen

Your research request has been approved as per your protocol. Please refer to the subsequent pages for the approval of any facilities or focus areas requested. Approval comments on any proposed impact on City Health resources are also provided.

Northern & Western:

Contact Person: Dr Andile Zimba (Area North Manager)

Tel/Cell: 021 980 1230/084 627 2425

Please note the following:

1. All individual patient information obtained must be kept confidential.
2. Access to the clinic and its patients must be arranged with the relevant Manager such that normal activities are not disrupted.
3. A copy of the final report must be uploaded to http://web1.capetown.gov.za/web1/mars/ProjectClosure/UploadReport/0/8019, within 6 months of its completion and feedback must also be given to the clinics involved.
4. Your project has been given an ID Number (8019). Please use this in any future correspondence with us.
5. No monetary incentives to be paid to clients on the City Health premises
6. If this research gives rise to a publication , please submit a draft before publication for City Health comment and include a disclaimer in the publication that "the research findings and recommendations do not represent an official view of the City of Cape Town "

The Committee must be informed of any serious adverse event and/or termination of

Thank you for your co-operation and please contact me if you require any further information or assistance.

Kind Regards
Dr Natacha Berkowitz Epidemiologist: City Health

CIVIC CENTRE IZIKI LOLUNTU BURGERSENTRUM
HERTZOG BOULEVARD CAPE TOWN 8001 PO BOX 2815 CAPETOWN
8000 www.capetown.gov.za

Making progress possible. Together.

Facilities

Area	Subdistrict	Facilities		
Area North	Northern	Facility name	Interaction Start date	Interaction end date
		Wallacedene Clinic	2018-07-15	2018-08-15

Please note

- If a requested facility does not appear in the list above, its interation request has been rejected and the reason for the rejection can be viewed in the link below
- Approval comments for facilities may exist. These comments can be viewed in the link below.

http://web 1.capetown.gov.za/web 1 /mars/ProjectFacility/Read/0/8019

APPENDIX I: QUESTIONNAIRE (ENGLISH)

INTERVIEW SCHEDULE

Section A: Demographical data

- Gender

- Home language

Male Female

English Afrikaans Xhosa Other

- Marital status

Married Single Divorced Widow Widower

- Formal educational level

Illiterate Primary school Secondary school Tertiary school

- Employment status

Unemployed Social grant Pensioner Casual labourer Permanent labourer

- With who do you stay

Alone Partner Family Friend

- How many people stay with you

  …….

- How many dependents do you have?

  ……

Section B Questions

Experiences of TB

- What does TB mean to you?
- **Probe**: the researcher will let the interviewee explain what they understand regarding TB

……

……

Define TB to the interviewee

- Tell me about your experience of TB
- **Probe**: the researcher will ask the interviewee to relate to experiences since diagnosis with TB
- **Prompt**:
  - how do they feel of having TB

……

……

  - what were their family respond when hearing that they have TB

……

……

- **Probe**: the researcher will ask the interviewee to relate to experiences they have with their families
- **Prompt**:
  - how did they feel when their families void their feelings

- how easy is it to get access to the facility

- **Probe:**

  - distance of facility

…….

……

  - What sort of support do you get?

- **Probe:** the researcher will ask the interviewee to relate to emotional or financial support

……

……

  - Where will you go if you have any questions regarding your TB?

- **Probe:** what are your concerns

- **Prompt:**

  - why would they go to where they have stated for information

  - Are you satisfied with the care you are receiving at the facility?

- **Probe**: how well are their needs met?

……

……

  - What do you think about the TB treatment?

- **Probe:** do they think that the duration is too long?

……

……

  - What do you think will happen if you do not complete your treatment?

- **Probe:**

  - Will you be cured?

- **Prompt:** do they think that they will get TB again

……

……

- Did you experience any side effects while on treatment?

- **Probe:** who did they report to when experience any side effects
- **Prompt:** did the information they received help them to tolerate the medication

……

……..

- Why did you stop your treatment?

- **Probe:** the researcher will ask them to relate to experiences regarding role of the staff/ lack of food, etc
- **Prompt:** what were their thoughts when stopping the treatment
- **Prompt:** How was the staff attitude towards you
- **Prompt:** did you have any family or financial support
- **Prompt:** how do you think the services at the facility can be improved

……

APPENDIX J: QUESTIONNAIRE (ISIXHOSA)

Isihlomelo 1 (Imibuzo)

Isheduli yompandi

Icandelo A: Inkcukacha eziphangaleleyo

- Iminyaka…….
- Isini sakho

  Indonda Umfazi

- Ulwimi lwasekhaya

  English Afrikaans isiXhosa Olunye

- Isimo somtshato

  Utshatile Awutshatanga Niqhawule Umhlolokazi uMhlolo umtshato

- Izinga lezemnfundo

  Awufundanga kwphela Amabanga aphantsi Amabanga aphakathi Amabanga aphakamileyo

- Isimo ngokomsebenzi

  Andiphangeli Isibonelelo sikarhulumente Umhlala phantsi Phangela amaxhesha athile Uphangela isigxina

- Uhlala nabani

Ndodwa Nomlingani wam Ilungu losapho Isihlobo

- Bangaphi abantu abahlala nawe

  …….

- Bangaphi abantu obaxhomekeke kuwe ngokwezimali?

  ……

6.1.1 Icandelo B Imibuzo

Amava nge TB

- Ingaba uTB uthetha ukuthni kuwe?
- **Ngena nzulu**: umphandi uyakunikezela kumthathi nxaxheba ukuba acacise ukuba yintoni ayiqondayo ngokuphathelene ne TB

……

……

Cacisa nge TB kumphandi

- Khawundixelele ngamava akho ngeTB
- **Ngena nzulu**: umphandi uzakubuza umthathi nxaxheba ukuba aqondisise ngamava akhe ukususela oko waphatwa yi TB
- **Qhubeka**:
  - Uziva njani ngokuba une TB

……

……

  - Ingaba akuphatha njani amalungu osapho lwakho akuva ukuba une TB

……
……

Ngena nzulu: Umphandi uzakucela umthati nxaxheba ukuba aqondise ngamava akhe athe wanawo ngosapho lwakhe

- **Qhubeka**:
    - Baziva njani xana amalungu osapho lwabo ephepha imivakalelo yabo
    - kulula kangakanani ukufumana ekuncedwa kwezempilo
- **Ngena nzulu:**
    - ubude ukuya kwezempilo

……
……

Ingaba yeyiphi inxaso oyifumanayo?

- **Ngena nzulu**: umpandi uzakucela umthathi nxaxheba ukuba aqondisise kwinxaso yezemali okanye ngokweemvakalelo

……
……

Ungaya aphi ukuba unemibuzo ngokuphathelene nge TB?

- **Ngena nzulu**:Yintoni inkxalabo yakho
- **Qhubeka:**
    - Kutheni bezakuya kulendawo bayichazileyo ukuze bayofuna ulwazi
    - Ingaba uyoneliseka luncedo olufumana kule kliniki?

Ngena nzulu: Ingaba imfuno zenu zikhawulelwa kangakanani?

……
……

- Ucinga ntoni ngonyango lwe TB?

- **Ngena nzulu:** Ingaba bacinga ukuba ithuba obathatha ngalo unyango lide kakhulu?

……
……

- Ucinga ukuba kuzokwenzeka ntoni ukuba awuligqibanga unyango lwakho lwe TB?

- **Ngena nzulu:**
  - Ingaba uzonyangeka?

    Qhubeka: Ingaba bacinga ukuba bangayifumana kwakhona iTB?

    ……

    ……

  - Ukhe wanawo amava yemiphumela ngelixa uthatha unyango lwakho lwe TB?
  - **Ngena nzulu**: Ingaba bachazela bani ukuba bafumana imiphumela ngenxa yonyango lwe TB
- **Qhubeka**: ingaba ulwazi abalifumanayo lwabanceda ukuba bakwazi ukumelana namayeza

……
……

  - Kutheni wayeka ukuthatha unyango lwakho lwe TB?

- **Ngena nzulu:** Umphandi uzakucela ukuba umthathi nxaxheba aqondisise amava akhe ngokuphathelene nendima yabasebenzi/ukungabikho kokutya njalo'njalo
- **Qhubeka :** Yayizintoni ingcinga zabo ekuyekeni kwabo unyango
- **Qhubeka :** Yayinjani impatho yabasebenzi kuwe
- **Qhubeka:** Ingaba wawunayo inxaso yezemali okanye kusapho lwakho
- **Qhubeka :** Ucinga ukuba kungenziwa ntoni ukuze uncedo lubengcono kwindawo yezempilo

……

APPENDIX K: EDITING CERTIFICATE

I & L Editing Services

Exactly what you need

Professional editing
(37205 certified)

CERTIFICATE OF ENGLISH EDITING

This is to certify that the paper with the provisional title "**Challenges experienced with adherence to TB treatment by patients in a facility in the Northern Sub-district, Cape Town**" to be submitted by **Christeline Booysen** of the University of the Western Cape (South Africa) has been edited for language by a professional copy-editor. Neither the research content nor the author's intentions were altered in any way during the editing process.

I & L Editing Services guarantees the quality of English language in the abovementioned paper, provided our editor's changes are accepted and further changes made to the paper are checked by our editor.

W. Martin
Copy-editor

Date: 8 November 2022

Cape Town, South Africa

ileditingservices@gmail.com wmartin.trans@gmail.com +27 82 074 7306