Treatment adherence in TB/HIV co-infected patients in Mount Frere, Eastern Cape.

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KEYWORDS

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Epidemic

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DECLARATION

I declare that this thesis entitled "Treatment adherence in TB/HIV co-infected patients in Mount Frere, Eastern Cape" is my own work. It has not been submitted for any degree or examination in any other university and that all the references I have used or quoted have been acknowledged.

Full name: Lungelwa Mbunyuza

Date: November 2020

Signed:

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GLOSSARY OF ACRONYMS AND ABBREVIATIONS

ART	Antiretroviral therapy
HIV	Human immunodeficiency virus
DR-TB	Drug resistant tuberculosis
TB	Tuberculosis
PLWH	People living with HIV
MDR-TB	Multi-drug resistant tuberculosis
XDR-TB	Extensively drug resistant tuberculosis
WHO	World Health Organisation
ECDoF	Eastern Cape Department of Health
StatsSA	Statistics South Africa

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DEFINITIONS

Adherence: Following the recommended course of treatment by taking all the medication as prescribed, for the entire length of time necessary (National Department of Health, 2011).

Experience: events or knowledge shared by all the members of a particular group in society that influences the way they think and behave (Oxford Advanced Learner's Dictionary, 2010)

Extensively drug-resistant (XDR-TB): Refers to a situation which there is resistance, *in vitro*, to: Isoniazid and rifampicin and any of the fluoroquinolones and one or more of the second-line injectable drugs (capreomycin, kanamycin, amikacin) (National Department of Health, 2009).

Multidrug-resistant (MDR-TB): Is defined as tuberculosis disease caused by strains of Mycobacterium Tuberculosis that are resistant, *in vitro*, to both rifampicin and isoniazid, with or without resistance to other drugs (National Department of Health, 2009).

Non-compliance: is defined as when a patient who interrupted TB/HIV treatment for more than two months consecutively, at any time during the treatment period (Jaggrajamma et al., 2007).

Perception: The Oxford Advanced Learner's Dictionary (2010), defines perception as "the way an individual notices things especially with the senses; the ability to understand the true nature; an idea, belief or an image individuals have as a result of how they see or understand".

Tuberculosis (TB): A disease caused by a bacterium belonging to the *Mycobactrium* Tuberculosis complex. The disease usually affects the lungs, although in up to one third of cases other organs are also involved (Jetan, Jamaihah & Nissapatorn, 2010).

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DEDICATION

This study is dedicated to all my friends, family and colleagues that I have lost to TB and HIV, those who are living with the conditions and those that are directly affected and had to take responsibility for everything in their families.

I am grateful and thank the almighty God for the willingness of the participants to take part in this study, giving a voice to the millions of those who remain silent on the experiences and perceptions on TB/HIV treatment.

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ABSTRACT

Background: Adequate levels of adherence to treatment for tuberculosis (TB) and HIV at the same time poses a problem for public health in South Africa. TB/HIV co-infected patients face many potential barriers to adherence to treatment for both conditions. There is a need for more knowledge about factors influencing treatment adherence in co-infected patients on concomitant treatment. The aim of this study was to explore the barriers and facilitators to treatment adherence among people co-infected with TB/HIV living in the Alfred Nzo District, Eastern Cape, in order to identify the barriers and facilitators to adherence.

Methodology: Exploratory qualitative methods were used to explore the barriers to Treatment adherence in TB/HIV co-infected patients in Mount Frere, Eastern Cape. In-depth, semi-structured interviews were conducted in isiXhosa with 17 non-adherent participants to TB/HIV treatment and three key informants who are health workers from Gateway clinic. The interviews were audio-recorded, transcribed and translated into English. The data was analysed using inductive thematic analysis.

Results: Health facility and individual factors emerged as barriers to treatment adherence. Difficulties of taking treatment due to side effects, problems with monetary resources resource, patient's education about treatment, associating TB with HIV and social support and stigma were all factors related to treatment barriers identified by both key informants and the participants. Health facility related to treatment barriers were availability of medication and workload and staff shortages resulting in long waiting times.

Conclusion: Despite program integration of TB/HIV programs and free availability of medication, barriers to adherence still exist. Most of barriers have been articulated in previous research that focussed on treatment adherence in patients who are on both TB/HIV medication. The fact that the barriers remain suggests that these barriers are complex and

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therefore addressing them will require tackling financial resources, health system factors and social support and stigma that pose a significance barrier to adherence.

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CHAPTER 1: OVERVIEW OF THE STUDY

1.1 Introduction and Background

Globally tuberculosis (TB) and human immunodeficiency virus (HIV) are still relatively high. The global burden of TB/HIV remains significantly high, with overreliance on biomedical interventions and inadequate exploration of the socioeconomic and cultural context of the infected population (Nyasulu et al., 2018). TB remains the leading cause of death among people living with HIV, accounting for around one in three HIV related deaths (UNAIDS, 2020). In 2018 an estimated 10.0 million people developed TB and approximately 9% of whom were living with HIV (UNAIDS, 2020). The number of persons with both incidents and prevalent TB remained highest in the WHO South-East Asia and African regions (MacNeil et al., 2020). Worldwide, the TB incidence rate is falling at 2% per year with South Africa at 4-8% per year (WHO, 2018).

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South Africa experiences high burden of TB and HIV diseases. One in six adults in South Africa is HIV positive and the country’s TB burden is the third highest in the world with about 1% of the population of about 50 million developing active TB disease each year (Sinai, Cleghorn & Kinkel, 2018). The general prevalence of TB is 12.6% South African population (Stats SA, 2017). Tuberculosis (TB) is the most common and often the first opportunistic infection to occur amongst those infected by HIV (NIAID, 1994). A study by Naidoo et al. (2018) states that in HIV infected individuals with latent TB infection, the lifetime risk of TB reactivation disease is 10% per annum. A study by Cramm et al. (2010) cites TB as a global health concern fuelled by HIV.

Mazinyo et al. (2016) indicated that South Africa had an incidence rate of 509 new cases co-infected with TB and HIV per 100.000 persons in 2014. This leads to a substantial number of

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people with TB/HIV who require concurrent treatment for both diseases. The worsening in condition of both epidemics is resulting in increased morbidity and mortality of co-infected patients. In March 2018 Statistics SA reported that TB/HIV was indicated as the cause of death on the death notifications of 21 830 people in 2016 (StatsSA, 2018). Morbidity and mortality rate among TB/HIV co-infected patients is still prevalent. The intertwined epidemics of TB/HIV have exacerbated each other and have been further compounded by the growth of Multidrug-Resistant TB (MDR/TB) and the emergence of extensively drug resistant TB (XDR-TB) (Abdool Karim et al., 2009).

The Eastern Cape province of South Africa is also affected by TB/HIV co-infection. According to Provincial Strategic Plan, 2012-2016, HIV incidence in the Eastern Cape is 19.9% among men and women aged 15-49 years. The province is not on track to meet the target of reducing TB/HIV co-infection. A study conducted by Cramm et al. (2010) cites that the Eastern Cape is known as a province with high TB incidence, prevalence and with one of the worst cure rates of South Africa. However, the provincial vision for the Eastern Cape is to have a province that is free of new TB/HIV infections with full coverage of services, high quality of care and support for all those affected by TB/HIV infection (Strategic Plan of Action, 2007-2011).

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Alfred Nzo District is one of the Districts in the Eastern Cape that is burdened by TB/HIV co-infection. It is located in the north-eastern corner of the Eastern Cape Province and has a population of 828 711, with a population density of 77.2 people (DBH, 2014). It is among the poorest districts in Eastern Cape (Westaway, 2012). HIV related causes of deaths are at 7.2% and TB at 4.7% in the ages between 15-64 years). The leading cause of death in the province is TB followed by HIV related causes (DBH, 2014). TB treatment success rate in the district was ranked among the ten worst performing in the country (DHB, 2014). Gateway clinic is among the healthcare facilities in Alfred Nzo situated in a small town called Mount Frere.

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The rationale for my study to be conducted in this clinic was to explore the perceptions and experiences of people among this community about treatment adherence.

Patients with TB are expected to have adherence levels greater than 90% (Amuha et al., 2009). Failure for the patient to be cured increases the risk of development of drug resistance which in turn increases morbidity and mortality. The TB is worsened by concurrent infection by HIV (Amuha et al., 2009). One of the greatest challenges facing post-apartheid South Africa is the control of TB/HIV epidemics (Abdool Karim et al., 2009). In order to win the battle of TB/HIV co-infection patient has to be put at the centre of TB/HIV related programs.

Despite directly observed therapy, adherence remains a problem that is not easy to overcome as a result of several factors including drug availability, socio-economic conditions, literacy and stigma (Kana & Churchyard, 2013). Long term illnesses like TB/HIV needs adherence in order to be controlled despite side effects that are common amongst those who are co-infected (Amuha et al., 2009). Poor adherence may lead to poor health status and one may be in a risky position of acquiring drug resistance (Nachega et al., 2011).

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1.2 Problem statement

In Mount Frere, Eastern Cape adherence on TB/HIV treatment is still a problem. This is seen in the high rate of antiretroviral treatment (ART) re-initiations coupled with non-adherence to TB treatment by co-infected patients (NERVE Centre, 2019). This has caused Alfred Nzo district to have high referral rate of patients to Khotsong MDR-TB hospital based in Matatiele (Loveday et al., 2018). This is due to drug resistance caused by non-adherence to treatment. According to World Health Organisation (WHO), drug resistance leads to treatment failure and the need for second and third line treatment which is costly particularly in resource-poor settings (WHO, 2014). Most patients that are admitted in TB ward in Madzikane KaZulu Memorial Hospital which is in Alfred Nzo district are co-infected and

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have not been adherent to their treatment (MKZMH Stats, 2019). This has increased the mortality rate in this unit. It is hoped that this study will contribute to the body of knowledge regarding barriers to TB/HIV treatment adherence on co-infected patients. The knowledge gained can be used to provide recommendations to improve adherence on TB/HIV treatment.

1.3 Purpose

The purpose of this study was to gain a better understanding of the experiences and perceptions regarding treatment adherence among TB/HIV co-infected patients. This knowledge could hopefully assist in finding ways to improve adherence in order to reduce the burden of TB/HIV related morbidity and mortality.

1.4 Significance of the study

The South African government has made tremendous medical interventions in an effort to support co-infected patients on treatment adherence with the aim of improving patient outcomes for TB/HIV programmes (Karim, Churchyard, Karim & Lawn, 2009). This study's findings will provide policy makers with useful information from patients' view as well as that of health professionals on what they perceive to be their causes of their treatment non-adherence and how it should be improved. Consequently, this information will be useful to the Professional Nurses in supporting and monitoring co-infected patients' adherence on treatment something that will hopefully be transmitted to the entire nursing fraternity.

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1.5 Chapter outline

Chapter 1: Overview of the study including the background.

Chapter 2: Literature review

Chapter 3: Research methodology of the study

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Chapter 4: Data analysis

Chapter 5: Discussions of the results

Chapter 6: Recommendations, conclusions and study limitations.

1.6 Conclusion

This chapter gave a brief description of the background of the study, defined key concepts, outlined the problem statement, purpose, and significance of the study and provided an overview of the chapters. The following chapter will give a full description of the research literature review adopted in the study.

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CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

The following literature review explores some of what has been written on TB/HIV co-infected patients, specifically focussing on experiences and perceptions regarding TB/HIV treatment in those with co-infection. It begins by citing the patient related factors, followed by health system factors that contribute to treatment non-adherence by TB/HIV co-infected patients.

The purpose of this literature review is to expand the researchers' understanding of the phenomenon from multiple perspectives (Burns & Grove, 2007). The literature review enabled an appraisal and discussion of the findings of this study.

2.2 Patient related factors

This section will focus on pill burden, association between TB and HIV, disclosure, treatment literacy, stigma and financial constraints as factors that contribute to how patient's perceive treatment.

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2.2.1 Pill burden

Pill burden is the number of tablets, capsules or other dosage forms that a person takes on a regular basis (AIDSinfo, 2020). A high pill burden can make it difficult to adhere to treatment regimen. Co-infected patients experience pill burden because they have to take TB/HIV drugs at the same time. In a study conducted in KwaZulu-Natal, the authors concluded that short course treatment regimens for drug-resistant TB (DR-TB) with lower pill burden may increase adherence (O'Donnell et al., 2014). Patients only have to deal with HIV treatment when they are cured of TB, this would reduce their pill burden.

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Gebremariam, Bjune and Frich (2010) conducted a study about barriers and facilitators of adherence to TB treatment in patients on concomitant TB/HIV treatment in Ethiopia. In this study one of the patients described how they forget to take their drugs and when they do, they mix them up. These studies illustrate how having a high pill burden can be a significant barrier to treatment adherence to TB/HIV co-infected patients.

2.2.2 Association between TB and HIV

The perceived links between TB and HIV have complicated effects on how patients with these illnesses approach and adhere to their treatment. In a study from Ethiopia, it is noted that patients are aware of the association between TB and HIV. Some patients in the study had a perception that they have HIV because of TB and believed that HIV follows TB. This association according to the study findings is affecting their disclosure of testing positive for TB (Gebremariam, Bjune & Frich, 2011). According to their understanding should one test positive for TB it is well known that such a person has also got HIV. They hide that they have tested positive for TB so that people will not think that they are also HIV positive due to the stigma associated with HIV. In addition, this affects their treatment adherence. Patients' association of TB and HIV has led them to be non-adherent to their treatment as they feared being labelled as HIV positive by the community. This association has affected the way they take their treatment (Gebremariam, Bjune & Frich, 2011).

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In a quantitative study conducted in Lesotho, Malawi, Namibia and Zambia, association of TB and HIV including misconceptions contributed to treatment non-adherence as those who were affected feared to be isolated and discriminated against (Musuka, Teveredzi, Mutenherwa, Chingombe & Mapingure, 2018). Similar findings were reported in an Ethiopian study where participants believe that TB and HIV have similar symptoms and people are afraid of TB patients because of the associated HIV infection. This contributed on

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how patients adhered to their treatment because they feared to be labelled as HIV positive (Deribew et al., 2010).

2.2.3 Stigma

HIV related stigma refers to prejudice, negative attitudes and abuse directed at people living with HIV (Sidibe, 2019). Stigma can result in people living with TB/HIV being insulted, rejected, gossiped about and excluded from social activities (Pebody, 2018). This affects their adherence on treatment as they hide their status making it difficult for them to take their treatment at due times.

In a qualitative study in KwaZulu Natal, patient's healthcare experiences and stigma attached to TB/HIV contributed to their non-adherence to treatment (Daftary, Padayatchi & O'Donnell, 2014). This is the stigma that patients experience from their communities. Elbireer et al. (2011) conducted a case-control study in Uganda to identify health facility and patient-specific factors associated with TB treatment default in HIV infected patients. In their study they found barriers to adherence included stigmatization as one of the factors that contributed to non-adherence (Elbireer et al., 2011). Stigma was also found to have negative effect on treatment adherence for TB/HIV co-infected patients in Ethiopia (Gebremariam, Bjune & Frich, 2010).

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2.2.4 Disclosure

A retrospective study in the North West and Western Cape Provinces about TB/HIV rates of treatment adherence found that the majority of patients with TB/HIV co-infection were adherent to concurrent treatment (Mazinyo et al., 2016). However, this study found that HIV-positive patients who did not disclose their status were less likely to adhere to their treatment. Some reasons why patients often find it difficult to disclose their HIV status are: fear of rejection by their loved ones or family members or the fear of unfair dismissal from jobs as

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well as the fear of taking the blame of infidelity which may lead to divorce especially in societies where HIV stigma and discrimination persist (Cloete et al., 2010).

2.2.5 Treatment literacy

TB/HIV patients may have little knowledge regarding treatment which may negatively affect their adherence. A qualitative study from Namibia exploring the factors that contribute to treatment non-adherence amongst TB/HIV patients showed that patients' non-adherence was a result of a lack of knowledge and information on the treatment (Endjala, Mohamed & Ashipala, 2017). Giving patients' information about their disease and the treatment they are taking is empowering them to know the benefits of taking treatment and the consequences of not adhering to the prescribed treatment. Studies conducted by Skhosana et al. (2006), Hardon et al. (2006) also report that proper treatment literacy has been shown to increase the number of patients sticking to a treatment plan.

In one of the Ethiopian studies it was reported that TB/HIV co-infected patients were not educated on TB treatment but only on Antiretroviral Therapy (ART) and its side effects at the ART sites (Gebremariam, Bjune & Frich, 2010). Similar findings were reported among TB patients who were ill informed and educated about the disease, how to behave and how to prevent transmission of the disease to other people (Carlsson et al., 2014).

2.2.6 Financial constraints

Financial constraints can affect treatment adherence in TB/HIV co-infected patients. The rate of unemployment is still reported to be high in the Eastern Cape especially in rural settings. Daftary and Padayatchi (2012) in their study mentioned that sustained access to food and money were imminent concerns for co-infected patients. Many were unemployed and therefore could not afford funds for transport as a result several patients walked for hours to reach their clinics despite physical debilitation. Those who were employed prior to being

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diagnosed temporarily stopped work to access medical care. According to this study financial constraints directly impact on TB/HIV treatment adherence as patients lack funds needed for food and transport (Daftary & Padayatchi, 2012). Since food insecurity is a major health problem in many sub-Saharan communities thus adherence to treatment in these communities will be hindered if proper majors are not taken into consideration to alleviate the existing food insecurity (Uthman, 2008). In a study conducted in Black Township in Cape Town, findings revealed that HIV is one of the major social stressors threatening people living in everyday poverty (Cloete et al., 2010).

2.3 Health system factors

This section will mainly focus on factors that contribute to TB/HIV treatment adherence and how these factors are perceived by co-infected patients. Attention will be on availability of medication, disclosure of patient’s information and long waiting times.

2.3.1 Availability of medication

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Medicine shortages are often cited in the literature as affecting adherence, especially in poor-resource settings (Patel et al., 2010). Medicine shortages maybe exacerbated by an increase in the number of people initiated on TB/HIV treatment. In addition poor procurement and supply in resource-limited countries further undermine ART provision (Patel et al., 2010).

A study in Lukhanji district in the Eastern Cape about perception of TB and HIV co-infected patients regarding quality of care found that majority of participants never experienced problems with not receiving the lifelong medication (Mngcozelo, 2016). In other studies, it is reported that patients who came to fetch their TB/HIV treatment had to go home without their treatment and were told by nurses to go and buy treatment from private facilities due to stock outs. This is contradicting to the findings of the above study. A cross-sectional survey by

Hwang et al. (2019) suggests that TB/HIV treatments stock outs are widespread in South Africa. Similar incidences were reported in a study by Pasquet et al. (2010); Koomen, Burger & van Doorslaer (2019); Stop stock outs (2014) who reported TB/HIV treatment stock out as a major problem in Africa.

2.3.2 Disclosure of patients' information

The study described above, also reported that nurses were not keeping patients' information safe from being disclosed to other patients (Mngcozelo, 2016). TB/HIV patients perceived the lack of trustworthiness of the nurses regarding confidentiality as negatively impacting adherence to treatment as they get discouraged by the nurses disclosing their statuses in the presence of other patients. Disclosure of patients' information result in patients deciding on not attending their follow up appointments and thereby missing out on their treatment (Mngcozelo, 2016).

Similar incidences were reported in a study by Makoae (2008) who reported TB/HIV co-infected patients did not feel at ease with the nurses regarding their confidential information. They feared that they would disclose their health status without their consent and that affected their adherence on treatment as they decided not to go to the clinic.

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2.3.3 Long waiting times

Long waiting times are a persistent challenge facing healthcare systems across Africa and have been linked to a variety of undesirable outcomes (Miller et al., 2010). Smart (2007) also reported that patients travelled long distances to clinics and wait for service all day. This discouraged patient to come back for another month's supply of medication. According to this study patient perceived waiting time as an indicator of bad quality of care and the discouragement in going to the clinics. The experience they had regarding waiting time at the health facility proved to be a constraint in treatment adherence.

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In the Eastern Cape study patients expressed their discontent with the way the nurses delayed giving them attention in the health services (Mngcozelo, 2016). According to her findings, patients perceived the waiting time as being too long. Mngcozelo highlighted in her study that long waiting times might affect TB/HIV co-infected patients' adherence to their treatment (Mngcozelo, 2016).

In other studies, it is reported that patients who came to fetch their TB/HIV treatment had to wait for more than two hours before being attended to at a consulting room (Mahlangu, 2014).

2.4 Facilitators of treatment adherence

This section will focus on factors that facilitate treatment adherence to TB/HIV co-infected patients. Special attention will be given to program integration, nurses' role and also receipt of ongoing counselling.

2.4.1 Program integration

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To address the TB/HIV associated epidemic, in 2004 the World Health Organisation (WHO) published the interim policy on collaborative TB/HIV activities (Page-Shipp et al., 2015). This document was to assist policy makers to understand what should be done to decrease the joint burden of TB and HIV. It also assisted in drawing guidelines for monitoring and evaluating collaborative TB/HIV activities. A retrospective study conducted by Mazinyo et al. (2016) in North West and Western Cape Provinces about TB/HIV rates of treatment adherence demonstrated the capacity to achieve high level of adherence to TB/HIV treatment in an integrated setting. Historically, TB/HIV patients were treated in separate programs and facilities. According to the findings of the study, evidence supports the integration of TB and HIV services in primary health settings due to improved adherence rates Mazinyo et al. (2016).

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A quantitative study in Cape Town, measured the degree of integrated TB and HIV service delivery and found many HIV-related services were highly integrated into clinics where TB services were available, indicating that TB clinics are efficient sites to integrate ART services as co-infected patients are already engaged in care (Uyei et al., 2012).

A study about improving management of TB in people living with HIV in South Africa through integration of HIV and TB services concluded that TB services can be easily integrated into existing HIV care programs (Sinai, Cleghorn & Kinkel, 2018). However, a possible shift in the service provider's workload, including administrative tasks must be tackled and effective infection control must be ensured (Wentzel, 2008).

2.4.2 Nurses' role

Nurses are perceived to be providing the patients with empowering information regarding their condition, treatment and the side effects they may experience from taking concomitant TB/HIV treatment. In a study by Dean et al. (2008), health professionals felt that informing patients about how to manage their condition was a duty that came with their role and also believed that health education was worthwhile in promoting better adherence to treatment.

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2.4.3 Receipt of on-going counselling

Lack of on-going counselling has a negative impact on adherence. Communication skills as well as the actual information given out during counselling all impact on adherence (Chopra, Doherty, Jackson & Ashworth, 2005). In resource poor settings, lay counsellors are used to provide pre-and post-test HIV counselling in order to alleviate the burden for health workers (Kagee et al., 2011). However, lay counsellor training is often poor and they may end up only providing information rather than recognising and changing patients' behaviour such as non-adherence (Kagee et al., 2011).

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In a study conducted by Gebremariam, Bjune and Frich (2010) about barriers and facilitators of adherence to TB treatment in patients on concomitant TB and HIV treatment suggests that adherence counselling might facilitate adherence. TB/HIV clinic should work in collaboration to provide patients with uniform and complete information. Patients should be well informed about co-infection and concomitant treatment. This ongoing counselling should also include topics like side effects of the treatment, pill burden and duration of the treatment (Chaiyachati et al., 2014). HIV treatment in the course of TB should be thoroughly addressed. Included in this information should be the importance of social support for adherence to treatment. On-going counselling will assist even those patients who are not motivated to continue their treatment to remain adherent on their TB/HIV treatment (Musayon-Oblitas, Carcamo & Gimbel, 2019; Chaiyachati et al., 2014; Webb, DeRubeis & Barber, 2010).

2.4.4 Social support

In one of the Ethiopian studies social support was found to be crucial for patient's treatment (Gebremariam, Bjune & Frich, 2010). According to the study some of the patients were seriously ill when they were initiated on treatment and therefore needed someone to accompany them for treatment. Some of the patients are not working and need assistance from the family members for food and transportation money. Lack of this social support would lead to non-adherence to TB/HIV treatment as the patients lacks motivation especially when ill to take treatment. Families can also be the source of encouragement and comfort for those patients who had lost hope (Gebremariam, Bjune & Frich, 2010).

2.5 Summary

From the literature review it is clear that TB/HIV is a complex disease where patients have various experiences and perceptions of non-compliance with TB/HIV treatment. These

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include themselves as clients and health system factors as leading cause to non-compliance with TB/HIV treatment. In these I have also included facilitators of treatment adherence as they also contribute in treatment adherence. Healthcare providers should support patients with their problem-solving skills to enable TB/HIV patients to be adherent to their treatment in order to reach a state of wellness or health. The rationale for my study is to try and see if the situations at other areas with TB/HIV treatment adherence is still the case in the Alfred Nzo district. The rationale for my study is to try and see how deep the situation is regarding TB/HIV treatment adherence in the Alfred Nzo district. Furthermore, this study intends to add to the existing knowledge on experiences and perceptions of TB/HIV co-infected patients on treatment. The next chapter will describe the methodology that was used in this study.

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CHAPTER 3: METHODOLOGY

3.1 Introduction

The previous chapters introduced the study and summarized some of the literature related to TB/HIV co-infected patient's failure to adhere on treatment. This chapter presents the methodology used to conduct the study. It sets out the aim and objectives of the study, the study design, the study setting and population. It then describes the sampling of the study population. Methods used to collect and analyse data, ensure rigour and ethical considerations are also presented in this chapter.

3.2 Aim and objectives

Aim

The aim of this study is to explore the experiences and perceptions of treatment adherence among people co-infected with TB/HIV in Alfred Nzo district in Mount Frere.

Objectives

1. To explore the treatment experiences of people co-infected with TB/HIV.
2. To explore the perceptions of people co-infected with TB/HIV about treatment.
3. To explore provider's perception of treatment adherence among TB/HIV co infected patients.

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3.3 Research design

For the purpose of this study, the researcher is focussed on the subjective experiences and views of the participants. A qualitative explorative design was therefore adopted as this approach enables the researcher to establish the meaning of a phenomenon from the perspectives of the participant (Burns & Grove, 2013). It is used to describe life experiences of people as well as stressing the uniqueness of the individual (Parahoo, 2014). According to Nieswiadomy (2011), qualitative research is concerned with in depth descriptions of people

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or events where non-numerical data is collected through such methods as unstructured interviews and in observations. This approach was therefore chosen because it assisted the researcher in her quest to explore and describe the perceptions and experiences of TB/HIV co-infected patients regarding treatment adherence at a Primary Health Care (PHC) setting in Alfred Nzo District.

An exploratory design was relevant for this study as the researcher intended to learn more about the experiences and perceptions of patients who did not adhere to their TB/HIV treatment in order to have a better understanding and insight regarding this phenomenon (Babbie & Mouton, 2004).

3.4 Research setting

The study was conducted in the Umzimvubu sub-district a local municipality in Alfred Nzo District in the Eastern Cape. Alfred Nzo District is one of the Districts in the Eastern Cape that is burdened by TB/HIV co-infection. Currently, Alfred Nzo district has very high rates of HIV with poor outcomes. HIV- related causes of deaths accounted for 7.2% of deaths and TB accounted for 4.7% of deaths in the ages between 15-64 years (DHB, 2014). The leading cause of death is HIV followed by TB related causes. The TB treatment success rate in the district was ranked among the ten worst performing in the country (DHB, 2014).

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3.5 Study population

The literature describes the population as all the people or objects that are of interest to the researcher, that is, meet the researcher's study criteria (Brink, Van der Walt & Van Rensburg, 2006). The population for the study were TB/HIV co-infected patients who are on treatment for both conditions for at least two months because they are more likely to be physically and mentally able to undergo an in-depth interview. The study participants were currently adherent to their treatment but they had demotivating factors and some had interrupted

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treatment at some point. The accessible or study population were those who lived in Mount Frere and received treatment from Gateway clinic (Brink et al., 2006). The sample included participants over 18 years who do not need parental permission. They were selected from the clients both males and females who were coming for treatment collection and reviews from Gateway clinic in Mount Frere. I was referred to the patients who fit my criteria by staff working in TB/HIV program within the facility.

3.5.1 Key informants

The study population included key informants who as a result of their skills and knowledge were included. This is because they have insight into the perceptions and experiences of TB/HIV co-infected patients on treatment adherence (Marshall, 1996). Nurses were chosen as key informants for this study as they are directly involved with the TB/HIV co-infected patients.

3.6 Study sample

This research was guided by literature on sample size which states that a suitable sample size is one that adequately addresses the research question (Marshall, 1996). In this study, the sampling was homogenous in nature. The study made use of purposive sampling allowing for participants who had experience with the phenomenon of interest to be selected for the study (Endjala, Mohamed & Ashipala, 2017). I used homogenous purposive sample because the participants that I was more interested in are those who were currently on TB/HIV treatment. They were selected from the clients, both males and females, who were coming for treatment collection and reviews at Gateway clinic in Mount Frere. The researcher was also guided by the fact that once new themes stopped emerging from the data, data saturation had been reached and the number of participants recruited was therefore sufficient (Marshall, 1996).

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A total of 20 participants were recruited for this study including 3 key informants. The participants ranged between 26 and 52 years. Of these, 17 participants who were currently receiving TB/HIV treatment were interviewed of which 12 were males and 5 were females. Only 4 of these participants were employed permanently. The rationale behind having 20 participants for this study is that, this is an exploratory study where the researcher was interested in gaining detailed insight into the experiences and perceptions of TB/HIV co-infected patients in a specific context

Inclusion criteria

The participants were patients who met the following inclusion criteria at the time the study was conducted:

TB/HIV co-infected who had been on treatment for at least two months,

Eighteen years of age and older as they are able to consent without parent or guardian permission.

Criteria for key informants was those who work closely with TB/HIV co-infected patients. Only those who worked in TB/HIV program for at least six months who had experience of TB/HIV patients.

Exclusion criteria

The researcher excluded all TB/HIV patients who were who were ill, and those who were not willing to take part in the study. Key informants who had not worked in the TB/HIV program for six months and more were excluded in the study and those who were not willing to participate.

3.7 Data collection

Data collection occurred over a period of one month in January 2020. Data was collected in

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one facility, namely Gateway clinic in Mount Frere. The researcher went to the facility for an introductory visit. This assisted in explaining what the study is all about, what will be needed for data collection and also to meet the facility managers. Recruitment of participants was also discussed and both the managers and the researcher agreed on on-site recruitment. They occurred at the consulting rooms where patients are seen and history is taken. Staff assisted with the recruitment. A total of 20 participants were recruited and interviewed. Operational manager of Gateway clinic was asked to provide a room which would be conducive to conduct interviews. Tables and chairs were arranged in such a way that allowed face-to-face interviewing.

Data collection was done using individual semi-structured interviews conducted by the researcher. Christensen (2004) suggested that the technique has the advantage of allowing the interviewer to clear up any ambiguities in the question asked or to probe for further information and clarification if the interviewee provides an inadequate answer. Semi-structured interviews enabled the researcher to interact with the respondent and to get the feel of how the respondent reacted to questions. The researcher paid attention to the participants' body language and other cues to identify when a participant was unclear about the meaning of a question, questions were rephrased to enhance understanding. Some of the participants asked questions when they were unclear about something and the researcher explained in more detail to ensure that they understood.

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When using semi-structured kind of an interview, it is easy for a researcher to maintain curiosity regarding what she might not know and the participants are allowed to express themselves freely (Chan, Fung & Chien, 2013). Interview guide was prepared which consists of list of questions that allowed the researcher to consider the range of issues that needed to be covered during the interviews. The questions were developed around the research aim. The interview was started with more specific questions like asking the name and age of the

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participant. The interviews were pursued in an area of interest guided by the questions while also allowing the participants to introduce their issues that the researcher had not previously thought (Chan, Fung & Chien, 2013)

The interviews were conducted in isiXhosa and English for those respondents who were not familiar with isiXhosa. The participants were asked about the duration of their treatment as one of the questions to check if they know how long they are supposed to take their treatment. They were also asked how the treatment makes them feel. This was to check if there are any side effects that they may have to the treatment.

Interviews for the patients were conducted when the patients were seen by the nurses and issued their treatment to encourage them to relax during the interview without panicking about the queue. With the consent of the participants, the interviews were audiotaped and at the same time the researcher was taking down additional notes. The interviews lasted between 25-30 minutes. They were later transcribed and translated into English by the researcher. To enhance the quality of data, field notes were used as the quality check in order to ensure transcripts were reflective of the audio.

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Key informants who fit the inclusion criteria were identified and enrolled. They were interviewed in the afternoon when most of their duties were completed to prevent loss of work time. Their interviews were conducted by the researcher in the private room at the clinic where privacy was ensured. Interviews were conducted in English using interview guides but there was flexibility to use isiXhosa if required.

3.8 Data analysis

Analysis of data in a qualitative research is an active and interactive process (Polit & Beck, 2010). For this study I used thematic analysis which is mostly suitable for this study as it is an exploratory study. Thematic analysis is a good approach to research where a researcher is

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trying to find out about people's experiences and knowledge as is the goal of this study (Braun & Clarke, 2006). It allows the researcher to approach data sets more easily by sorting them into broad themes (Caulfield, 2019). It also allows flexibility in interpreting the data and allows the researcher to focus on the data in numerous different ways depending on the specific purpose of the study. With Thematic analysis the researcher can legitimately focus on analysing meaning across the entire data sat, or the researcher can examine one particular aspect of a phenomenon in depth in this case treatment adherence (Braun & Clarke, 2012). I transcribed and translated all data from isiXhosa to English for analysis.

I firstly familiarised myself with the collected data which is the first step (Braun & Clarke, 2006). The recorded data was transcribed which helped in familiarizing. After transcribing data, I repeatedly read it so as to be familiar with it (Braun & Clarke, 2006). Codes were generated manually and the generated codes were written on the margins of the transcript (Robson, 2011). Examples of what was coded included the reasons for non-adherence as experienced by the participants (descriptive) as well as the meanings and interpretations they place on these actions (analytical) (Robson, 2011). Words or sentences were used as codes. Examples of the codes that were derived at this stage include disclosing to partner, feelings of changing clinics and problems around finances. After coding all the data, codes were grouped in categories so that themes were identified (Braun & Clarke, 2006).

When the themes were generated, I grouped similar themes together. This means that they were refined to ensure a coherence making it easy to analyse them, those with similar meaning were grouped together by cutting and pasting them onto one sheet. I presented the themes to an expert qualitative researcher for verification to ensure quality. This final refinement of themes aims to identify the essence of what each theme is about (Maguire & Delahunt, 2017). It was also important to ensure that the themes were an accurate reflection

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of the data (Vaismoradi et al., 2013). Finally, each theme was named in order to accurately reflect the data relating to that particular theme.

3.9 Rigour

Rigour is an important aspect of qualitative research methods which is used to ensure the quality of research findings in qualitative study. The goal of rigour in qualitative research is to accurately report study participants' experiences (Speziale & Carpenter, 2011). According to Creswell (2009), the suggested four criteria for developing the trustworthiness of a qualitative inquiry are credibility, conformability, transferability and dependability.

Credibility is ensuring that those participating in research are identified and described accurately (Polit & Beck, 2012). Shenton (2004) states that one of the ways of ensuring credibility is to obtain an honest account of events from participants. Some strategies were employed by the researcher to ensure that the accounts provided by the participants were true. A review of literature on studies that sought to describe the barriers to TB/HIV treatment adherence was conducted prior to data collection. During the interview session the researcher had an engagement with the participants to enable them to be familiar with the setting, to build rapport and also to get rich data. Participants were encouraged to support their statements with examples and the interviewer asked follow-up questions.

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Interviewing TB/HIV co-infected patients as well as key informants was used as a way of triangulating data sources. Triangulation of data sources was used to verify participant's experiences against information provided by the key informants, thereby providing a detailed and accurate description of the barriers to adherence (Korstjens & Moser, 2018).

According to Polit and Beck (2010), member checking is a method of validating the credibility of data through discussions with the informants. Member checking was conducted by taking the analysis of the data and summary of the findings back to some of study

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participants that can be reached for affirmation and validation of the findings. Member checking strengthens the data especially because researcher and respondents look at the data with different eyes (Korstjens & Moser, 2018). They fully agreed to my interpretations and had no problems or questions that followed.

Conformability refers to the objectivity, which is the potential for congruence between two or more independent people about the data's accuracy (Polit & Beck, 2012). Conformability was attained through maintaining a reflexive journal during the research process. This assisted in keeping notes and documenting daily introspections that would benefit the study. Being a professional nurse, I see patients who fail to adhere to their treatments almost on a daily basis and that has implanted some ideas about non-adherence. Through the reflexive journal I was always on guard of my biases, assumptions and beliefs that might have influenced the study (Cypress, 2017).

Transferability refers to the potential for extrapolation (Polit & Beck, 2012). Transferability was ensured through providing information about the fieldwork site to enable the reader to make a transfer (Shenton, 2004). This will assist the reader in determining if they can transfer the study to their own setting (Lincoln & Guba, 1986). Furthermore, transferability was ensured through inclusion of the study methodology, study design, data collection and analysis to enable readers to assess the transferability of the study (Anney, 2014).

Dependability refers to stability of data over time and under different conditions (Lincoln & Guba, 1986). Dependability was ensured through detailed description of the research methodology was included in this report to further ensure dependability. This will allow the reader to assess the extent to which proper research practises have been followed (Shenton, 2004).

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3.10 Ethical considerations

Ethical approval for the study was sought and obtained from the University of the Western Cape Bio-Medical Research Ethics Committee (see Appendix 13 attached). Permission was also granted by Eastern Cape Department of Health (see Appendix 14 attached) to conduct the study. After receiving permission from the Eastern Cape Department of Health, the District office was informed about the study and the researcher called the operational manager of Gateway clinic and explained the background of the study.

Prior to interviews, all participants were given a participant’s information sheet within which the purpose of the research was explained. For those who are illiterate the participant information sheet was read for them by the researcher. I made sure that the participants are adequately aware of the type of information I required from them (Kumar, 2005).

The informed consent process ensured that participation in the study was voluntary and the participants became involved in the research out of their own free will. Before commencing the interviews, I made sure that the consent form was signed both by the participant and myself. Confidentiality and privacy were ensured. Particulars of the participants and personal information provided were not available to anyone other than myself. I explained about confidentiality and re-assured the participants that their identity was not to be revealed. Pseudonyms and numbers were used during presentation of results.

There were no guarantees that no harm was to be experienced by those who took part in the study as harm can be in any form, including psychological and emotional (Neuman, 2006). The researcher recognises that this is a sensitive topic as it deals with the health of an individual including HIV status which people do not find easy disclosing. I was sensitive to any signs of distress and allowed the participant the option of not responding. Nursing training provided me with necessary skills to conduct sensitive interviews therefore my

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respondents were treated with care. Those who needed further support and counselling were referred to appropriate places. Some of the participants were referred to Chief Medical Officer of a nearby hospital for assessment and possible refer to a South African Social Security Agency (SASSA) for grant application.

At the time of data collection, the researcher was employed by the Eastern Department of Health at Madzikane KaZulu Memorial Hospital as Skills coordinator. Therefore, the researcher is not directly involved with the TB/HIV co-infected patients thus limiting bias.

3.11 Summary

Chapter three gave a full description of the research methodology used in this study. A qualitative exploratory design was applied. Data was collected using semi-structured interviews and analysed using thematic analysis. Rigour was ensured through the use of strategies such as triangulation, reflexivity and maintenance of an audit trail. Ethical approval was obtained from the University of the Western Cape. The next chapter will present an in depth description of data analysis and interpretation of the research finding.

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CHAPTER 4: RESULTS

4.1 Introduction

In the previous chapter, I discussed the research design and methods that underpin this study. This chapter reports on perceptions TB/HIV co-infected patients have regarding treatment adherence.

4.2 Demographic characteristics of the sample population

The sample consisted of 17 individuals who were undergoing treatment at the facility at the time of the study and included both males (12) and females (five). The participants ranged in age between 26 and 52 years. Of these 17 participants, only five of them were employed permanently. Amongst the five participant was a male participant who was working for a private company in Pretoria but came to Eastern Cape due to ill-health. The other three participants were working as domestic workers and one was working for a private sector also in the Eastern Cape. The rest of the participants were unemployed depending on casual employment. One of them was working in Durban and stopped as a result of ill-health. Most of the participants depend on their family to support their livelihood. Only two of them were married at the time of data collection but the majority were in relationships with partners. One was divorced and two were widowed. Of the 17 participants only one of them had a tertiary education, one completed grade 12 and the rest were below matric and two who were not educated. All participants resided in Mount Frere during data collection. The one who was working in Pretoria collected his treatment there but when he was in Mount Frere he was also seen at Gateway clinic.

Key informants were also interviewed. I also interviewed three professional nurses employed at Gateway clinic. I selected them for the interviews because they worked closely with TB/HIV co-infected patients.

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In the interviews several concepts emerged in codes, sub-themes and main themes. Based on the coding process, first I identified main themes. Second, I grouped interrelated topics into sub-themes relevant to the main theme. Findings are presented and discussed according to the identified themes and codes that emerged from the analysis of the collected data summarised in Table 1.

Table 1: Themes and sub-themes resulting from thematic analysis of data collected

	Themes	**Sub-themes**
Patient related factors	Difficulties of taking treatment: Challenges that result in patients to be reluctant in taking treatment.	Side effects
	Socio-economic challenges: Challenges that involve social and monetary issues and cost of accessing health services	1) Food insecurities and experience of hunger 2) Transport cost versus distance
	Patient's knowledge about treatment: Education given to a patient to enhance knowledge about the treatment	
	Disclosure: Sharing of personal information with another person including intimate partner dynamics	

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	Associating TB with HIV: Integrating TB with HIV as if it is the same disease	
Community level factors	Social support: The early days after diagnosis and treatment initiation	1) Family support 2) Partner support 3) Stigma
Health system factors	Availability of medication	
	Workload and staff shortages	Inadequate management of waiting times
	Patient-provider interaction: The relationship between the patient and the health care worker that promotes adherence	Nurse's role and receipt of on-going counselling Program integration

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Although the study sought to explore perceptions and experiences on treatment adherence in TB/HIV co-infected patients of TB/HIV, there were some findings that do not necessarily relate to taking medicines but have an impact on the overall well-being of the patients. In keeping with ethical requirements regarding confidentiality and anonymity, pseudonyms have been used. I am now going to discuss the themes which were identified as part of my thematic analysis and they will be grouped together by first looking at patient related factors, community factors and finally health system factors.

4.3 Patient related factors

Many of the challenges to adherence that the participants raised during the interviews centred on their personal experiences and understandings linked to accessing treatment. The purpose of this section is to describe the experiences and perceptions encountered by TB/HIV patients regarding their treatment. In this section I am going to discuss about difficulties of taking treatment, problems with monetary resources, education to patients and lastly myths about TB/HIV.

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4.3.1 Difficulties of taking treatment

Participants reported several challenges that affected their experiences with treatment adherence such as side effects. Participants did not always share the same difficulties and some of the participants in fact had no difficulties with treatment. This current study observed that males are the ones who mostly complain about the side effects especially those that are above 30 years of age. Some of those that experienced difficulties resorted in interrupting taking their treatments.

4.3.1.1 Side effects

Participants were asked how they feel about taking concomitant treatment. Most of them reported that they experienced side effects mostly when they started their TB/HIV treatment but subsided as they were getting used to it. Patients especially males reported that they were demotivated to take their treatment as a result of the side effects that they experienced at first when they started TB/HIV treatment. These side effects included diarrhoea, painful feet, tiredness, drowsiness and rash. Most of the participants reported to have side effects due to the concurrent treatment that they were taking. The participants mostly complained about TB treatment saying that it is the one that mostly caused side effects.

> *"I experienced lots of side effects when I started treatment in so much that when I even lost weight I thought of stopping at first but then I decided not to."* (29-year-old male)

This was supported by the key informants that I interviewed, they said most of their patients were reluctant to take their treatment due to the severity of side the effects that they experienced.

> *Some of the clients I see in the clinic reports that the side effects from taking both treatments are unbearable and they mention most of the time vomiting, peripheral neuropathy and some even mention discoloration of their urine.* (Key informant No. 1)

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Some of the participants that I interviewed ended up not adhering to their treatment due to side effects as they reported being demotivated to adhere by them at some point.

4.3.2 Socio-economic challenges

Ten of the participants were unemployed with no stable income. This contributed to their challenges with treatment adherence. This was the case because they lacked money to buy food and for transport to travel to the clinic whenever they were due for treatment collection.

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4.3.2.1 Food insecurities and experience of hunger

Participants faced a challenge of inaccessibility of food due to unemployment. Their experience of lack of food affected the way they adhered to their treatment as they were faced with a challenge of how to take their treatment on an empty stomach. This affected their adherence as many of them resorted to stopping treatment due to hunger and lack of food. Most of them were dependent on their families for financial support and food and sometimes they were faced with days of having no food.

> *I am staying alone dependent on my mother who is also staying alone and gets old age grant. She refuses to give me food sometimes and I am unable to take treatment because of not having food.* (52-year-old male).

One participant mentioned that as a mature male it is difficult to care for self because of a lack of money. According to this participant, it is uncomfortable to always ask for assistance knowing that the other person has got problems of her own.

> *My mother is also struggling because I am not the only one at home and she is also not working.* (31-year-old male).

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According to the key informants most of the patients do not adhere to their treatment because of lack of food at home and also financial constraints. They also reported that they encourage the patients to have vegetable gardens at home and also as a support group they should assist each other with vegetable gardens.

> *It is important to eat well balanced diet with green and yellow vegetables in order for the patients to improve but that is not the case with some of the patients we see. We encourage them to plant vegetables at home to assist with their nutrition.* (Key informant No. 2).

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Food insecurities and experience of hunger affects treatment adherence as participants reported that they found it difficult to take treatment on an empty stomach. Participants reported that having no food affected their adherence on treatment. They felt some side effects like nausea and vomiting when taking treatment in an empty stomach. According to them this affected how they were taking their treatment. They had days of not taking treatment when they had nothing to eat.

> *At some point I was forced to stop taking my treatment because there was no food at home and my mother had no means to provide for me. When I tried taking treatment without eating first I experienced problems with nausea and vomiting.* (29-year-old male).

This issue of hunger and not being able to afford food comes up again when participants discussed the impact of long waiting times at the clinic and how this lead to hunger and therefore non-adherence. Participants reported that they missed their treatment collection dates especially when they had no money to buy food at the clinic. They were not motivated to go to the clinic with no provision for food because of the time they spent in the queue. This further contributed to their non-adherence to treatment.

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4.3.2.2 Transport cost versus distance

Most of the participants that were interviewed narrated that the distance to the clinic is a barrier to their adherence. This was the case for those who were unemployed and also those staying very far from the clinic especially. Those participants who are unemployed with no support system found difficult to get transport money. They reported that they spent too much money on transport and that it was not easy for them to walk due to the long distance that they travel to get to the clinic. This becomes even worse when one is not feeling well. Sometimes they resort to travelling by foot when they feel well enough just to honour their

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treatment appointments. Many of them became demotivated after sometime and were not adherent to their treatment due to the distance they travel by foot and lack of money for transport. Missed appointments means missed picking up treatment and therefore poor adherence. Transport cost and distance they travelled contributed largely to them stopping taking their treatment.

> *I take my treatment at Gateway clinic and it is far from where I am staying. I use transport to come and it is expensive and there is no other clinic nearby. I do not come when I have no money because I depend on piece jobs.* (45-year-old male)

Another person also noted,

> *I take my treatment at Gateway clinic and it is very far, there is no other clinic nearby and when I have no money for transport I use my feet to travel.* (31-year-old male).

Key informants confirmed that patients were missing appointments due to transport related costs.

> *"…it is a problem because we do call them when we check the online records for follow up but when they say they have no money for transport it becomes a problem and some of them are staying very far and it is not possible for them to walk".* (Key informant No.3)

4.3.3 Patient's knowledge about treatment

Before patients are initiated on lifelong therapy which is HIV treatment, they are meant to be educated about their treatment. This education includes information about the indications for taking the treatment, duration of the treatment, how to take the treatment and also about the side effects of the treatment and this is the case with both TB/HIV treatment. This is important so that patients have knowledge of the treatment before starting it. Not all the patients I interviewed were aware of the treatment they were taking and why they were taking

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it. Educating patients regarding their treatment plays a role in treatment adherence as some of the patients that were interviewed were sometimes not adhering on treatment due to lack of information.

> *….Aah they did not tell me anything about the treatment except the time for taking HIV treatment and that the treatment may have some side effects in the beginning as a result on one instance I felt physically fit and I stopped taking my treatment.* (34-year-old male)

Most of them agreed that they were only educated on HIV treatment but never got any education about TB treatment. They were just given treatment to take at home as a result they did not always understand that TB is curable. Others reported that they were educated about HIV treatment and how they may experience some side effects on initial stages of taking the treatment.

> *TB is not curable because it is the third time that I am taking this treatment and I finished my course each time. If it is curable why am I having it again?* (33-year-old male)

> *Nurses told me that HIV treatment may cause some side effects in the beginning but they forgot to tell me that I may experience that with TB treatment as well.* (45-year-old male).

Most of the patients that were interviewed who did not get proper education on both treatments interrupted it. This clearly shows that patient education affects adherence as patients have no insight of why they are taking their treatment and see no reason to adhere.

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> *When I started both my treatments I never got extensive education about the benefits of taking the treatment and what I should try and avoid whilst I am on treatment as a result at some point I interrupted both my treatments and unfortunately I fell ill again.* (50-year-old male).

Treatment education was not reported as one of the topics during preparation of patients for treatment by key informants too. This means that there is a gap in education that affects adherence to treatment. Key informants also mentioned that the patients that they see have no idea that not adhering to TB treatment results in other opportunistic infections and also MDR-TB which is difficult to treat.

> *Most of my patients have agreed that they do not want to take TB treatment because people associate having TB with being HIV positive. They fear their HIV status to be known as a result most of them end up having MDRTB and admitted in Khotsong Hospital.* (Key informant No. 3)

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Education for patients regarding their treatment plays a role in treatment adherence as some of the patients that were interviewed were sometimes not adhering on treatment due to lack of information.

4.3.4 Disclosure

Disclosure can play a role in supporting treatment adherence when partners are accepting of the person undergoing treatment and are invested in helping them to adhere. Some participants disclosed their status to supportive partners and this was found to be very beneficial to treatment adherence. However, not all partners were supportive and many who did disclose faced rejection from their partners. This had a negative effect on adherence.

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> *Ever since I fell sick my partner refused to visit me we only talk on the phone and that demotivated me from taking my treatment because I felt it was the reason why my partner was neglecting me.* (29-year-old male).

None of them reported being non-adherent to treatment but they somehow felt unmotivated towards treatment adherence as a result of rejection they felt after disclosure.

> *I was not motivated at all to take my treatment because somehow I felt it was to be blamed for all the rejection I got from my family members after finding out that I was on HIV treatment but then again I was scared of falling ill due to me stopping my treatment.* (52-year-old male).

Disclosure of status is beneficial to treatment adherence as some of the participants that were interviewed revealed that it benefited them to disclose their status.

For those who did not disclose their status, treatment adherence was difficult as they had no support and somehow felt demotivated in taking their treatment. Participants reported different scenarios that demotivated them from disclosing. One participant reported that, he does not feel comfortable sharing his diagnosis with his family because he fears his condition to be known by everybody as he does not trust that they can keep it to themselves.

> *I decided to keep my status a secret because I do not trust my family members in keeping secrets and I don't want everybody to know that I tested positive for HIV*. (40-year-old male)

This meant he was non-adherent at some point to his treatment and as a result he had to be re-initiated on treatment after he fell sick.

Although the decision to disclose or not is an individual one, a number of community level factors had an influence on how this decision was made and experienced this section focused

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on the participant’s experiences of disclosing their status and in the section on community factors more attention will be paid to the restrictions resulting from the role of families and communities more generally.

4.3.5 Associating TB with HIV

Many participants reported that TB was associating with HIV. To them these conditions are the same and as a result they were not motivated to take their TB treatment because they were scared of being labelled as being HIV positive. One participant reported that it was the third time that he was having TB, he admitted that he had not been adhering to his TB treatment due to the fear of being labelled also HIV positive.

> *I stopped taking my treatment for TB before I finished the course because people associated TB with HIV and I did not want them to find out that I was also HIV positive.* (52-year-old male).

Some participants decided to stop taking their treatment because they did not want to be associated with being HIV positive. This was due to the fact that they associated TB with HIV.

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4.4 Community level factors

This section has been titled community level factors because there were certain issues relating to the community that were barriers to adherence. These include social support with family support, partner support and stigma as sub-headings.

4.4.1. Family support

Family support emerged as one of the barriers to treatment adherence during data collection. Some of the participants who had disclosed their status to their families reported that their families had a difficult time accepting the diagnosis. Most participants reported that they were demotivated by their family members who did not support them during their treatment

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journey and mostly they were on their own. This affected how they were taking their treatment as they had no one to care and support them. Some of the participants ended up not adhering at all to the treatment and missed their follow up dates.

Since their families had a difficult time accepting their diagnosis, they withheld financial and emotional support due to the stigma that HIV has. The participants reported that their family members would not give them money for transport to travel to the clinic whenever they had to collect their treatment or for reviews. This then affected adherence.

> *I stay alone at home and have no close relative whom I can ask to collect my treatment and my sister who is married refuses to give me money for transport to the clinic because of the stigma that the disease I contracted has. My brother is working and cannot be able to come each time I need him.* (40-year-old male).

One participant reported that he is staying with his elderly mother who is also sickly and depends on old age pension. This participant reported that he does not have anyone to support him because he has no one whom he trusts.

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Key informants reported that those patients who have family support are easy to trace even when they are not coming to collect their treatment. According to the key informants it is rare for a patient who has got a family support to be non-adherent on treatment.

> *I call their treatment supporters should they do not come when it is their day of collecting treatment to find out what might be the reason and most of the family supporters are easy to work with but for those who do not have no family support it is difficult to trace and they are mostly not adhering on their treatment.* (Key informant 1)

Key informants also encouraged family support as they say non-adherence is unlikely in those patients with solid family support. Family support plays a huge role in treatment adherence whether this is financial or emotional.

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4.4.2. Partner support

Many participants reported that they were not supported by their partners. These participants reported that their partners ended the relationship once they knew about their health status. Some of the participants were hesitant to disclose to their partners once they found they were HIV positive. They feared that their partners would blame them for infecting them with the virus and end the relationship. Some of the participants ended up not disclosing their status to their partners. This affected their treatment adherence as they had to hide the treatment from the partners as a result there are days when they missed taking their treatment.

> *I could not tell my girlfriend about my status because I feared that she was going to leave me and as a result I had to hide my treatment from her and I had to miss my doses some other days.* (45-year-old male).

Even key informants acknowledged that support both from home and also from the partner assists in treatment adherence. Key informant added that patients who do not have partner support are more likely to be non-adherent on treatment than those who are supported by their partners.

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> *Failure to disclose results in patients not to adhere on their treatment because of lack of support from their partners and loved ones.* (Key informant No. 2)

4.4.3. Stigma

Problems with support were mostly linked with stigma. Stigma emerged as one of the barriers experienced by the participants to adherence on treatment as it reduced social support. Stigma according to the participants was due to the fact that HIV is a sexually transmitted infection and people have a tendency to assume that those with HIV were promiscuous.

> *I decided on stopping taking my medication because my family members were discriminating me saying that I was looking for HIV when I was changing boyfriends.*

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> *This made me uneasy to take my treatment as each time I was going to collect my treatment they called me names like isifebe (loose woman).* (31-year-old female)

Stigma has negative consequences as it led to participants being reluctant in adhering to their treatment, some of them even decided to stop taking their treatment due to lack of social support caused by stigma and that affected their health.

> *I stopped taking my treatment because I was tired of being ridiculed by those close to me of being HIV positive as a result I felt sick and I was diagnosed with TB and it was a battle to take both treatments.* (40-year-old male).

According to key informants' patients are no longer afraid of the stigma related to the disease as a result few of them come to the clinic having been not adhering to their treatment as they are no longer laughed at in their communities.

> *I no longer have patients who stop their treatment because of problems related to stigma and that shows that people in the communities are accepting of those who are having HIV.* (Key informant 3)

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Stigma affects treatment adherence as some of the participants decided to stopping taking their treatment due to the stigma attached to HIV.

4.5 Health system factors

Health system factors also contribute to treatment adherence. Health system factors that are to be discussed are availability of medication, workload and staff shortages and patient-provider interaction.

4.5.1 Availability of medication

The study found out that a shortage of drugs sometimes resulted in non-adherence to treatment by some participants. Other participants reported that when they were going to the mobile clinics to collect their medication they could not get it because the nurses said there was no medication for HIV with them. This forced them to stop their treatment because they could not afford to go to other clinics sometimes because of distance.

> *I went to the mobile clinic that usual comes at my location but I was turned away because the nurses said there are no ARVs with them, I should go to Rode clinic to fetch them and it is far*. (45-year-old male)

According to one participant a week lapsed when he was hospitalised without him receiving his HIV treatment.

> *I was in hospital and a week passed without receiving my HIV treatment and the nurses said the treatment was not available in the hospital.* (34-year-old male)

It is evident that availability of treatment at all health facility plays a vital role in treatment adherence. Participants were non-adherent on their treatment due to unavailability of treatment caused by health system related factors.

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4.5.2 Workload and staff shortages (Inadequate management of waiting times)

Workloads of staff at facilities emerged as a huge barrier to treatment adherence during. The facility where interviews were conducted had a high volume of patients. One key informant reported that more than 2000 patients accessed the facility every month which she indicated as a high number compared to the number of staff.

> *Personal challenges I could say it is the workload. For one client that we see we take so much time because we also have to update the system apart from doing one-on-one with the client*. (Key Informant 3)

Some of the participants blamed staff shortages as one of the reasons why they are demotivated in going to the clinics to fetch their treatments. One participant reported that in

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another clinic he used to go to nurses are only two and as a result the queue is long and thus prolonging waiting time.

> *Sometimes we stay for more than 4 hours in the queue waiting to be seen because the queue is long and nurses to attend us are few and this makes me to be reluctant to come for the next appointment (*30-year-old female).

Long queues were a significant barrier to adherence. Participants reported that they spent the entire day at the clinic, from early hours of the morning and leave in the afternoon. Participants mentioned that in the clinic there is no one who is responsible for monitoring the queue and waiting times and that the nurses take time to attend to them because they are lazy to work.

> *Queue is slow and people are many and it takes time to be seen. The last time I was here I was told that today I was not going to queue but I queued again today and it is depressing and these nurses are lazy they don't want to work.* (34-year-old male).

Even key informants acknowledge that long queues are a problem in the clinic as patients wait in the queue for long hours before they can be seen and that demotivates them to go to the clinic to collect treatment.

> *Ahh…. it is taking a long time to consult one patient because there is information that I have to enter in the registers and in the computer for each patient I see. This delays the queue and patients end up staying in the queue for long hours before they can be seen*. (Key informant No. 2)

Key informants and participants reported how long waiting times were a barrier to keeping appointments at the clinic given that they were asymptomatic. Some of the participants reported that they were non-adherent at some point as they chose between spending a long time at the clinic or attend to other things of their importance. These participants reported that

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because they did not feel sick, they would sometimes delay going to health facilities if there were competing priorities.

The waiting times also affected adherence through the impact on participant experiences of hunger. Most participants reported that long waiting times resulted in experiences of hunger whilst queuing to be seen in the clinic. Long waiting times therefore contributed largely in people missing their review dates and fetching of treatment due to the experience of hunger whilst waiting to be seen whilst being hungry with no food or even money to buy food. This also affected how they take their treatment because they would go for days with no treatment and that affected their adherence on treatment as they were demotivated to go to the clinic for treatment collection.

> *You will find one nurse working and the line is long and I become hungry with no money to buy food that is why I sometimes become reluctant to come for treatment, I have no money to buy food.* (29-year-old male)

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Key informants reported that long waiting times were a barrier in keeping appointments. For example, in interviews key informants narrated stories of how patients they counselled reported demotivation for follow up treatment because of the time they spend on the queue while hungry. This interfered with treatment adherence as patients sometimes stay at home without treatment.

> *The patients always report that they are demotivated to come for their appointments due to the fact that they experience hunger due to long queues and have no money to buy food whilst awaiting to be seen.* (Key informant No.1)

The participant's and key informant's descriptions illustrate how health system issues of staff shortages interact with individual level issues of hunger and inadequate monetary resources to make adhering to treatment more difficult.

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4.5.3 Patient-provider interaction

The interaction between patients and providers played an important role in contributing towards treatment adherence. Specifically, program integration, the nurses' role and also receipt of ongoing counselling were noted by the participants as particularly important.

4.5.3.1 Nurse's role and receipt of on-going counselling

Nurses provide the patients with care and support regarding their condition, treatment and the side effects they may experience from taking both TB/HIV treatments. This is possible through on-going support and counselling. Some of the participants reported that they never received any attention from the nurses regarding treatment and the side effects of taking TB/HIV treatment.

> *Even when I decided to stop treatment I had no reason to continue because I received no on-going counselling about importance of adhering to treatment and I eventually stopped because of alcohol. I really had no reason to stop treatment except alcoholism but I think if I did receive the on-going counselling I was going to think twice.* (45-year-old male).

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The reasons for not receiving on-going counselling according to the key informants were that of staff shortages in the clinic and that meant that time spent with each patient was restricted. This made patients to feel that they are not taken care of and as a result did not receive adequate education and support regarding their medication and possible side effects from the medication.

Other participants reported that nurses became angry with them because of not taking treatment well instead of counselling them on treatment adherence.

> *Nurses talk because sometimes I do not come for treatment and by doing that they are not ill-treating me but they are showing support and guidance but other nurses*

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> *become impatient with me and that demotivates me from coming to collect treatment again.* (52-year-old male)

A key informant also supported on-going counselling of patients to facilitate treatment adherence but she mentioned that it is difficult sometimes to give on-going counselling because of challenges.

> *Health education and on-going counselling will improve adherence to TB/HIV co-infected patients but we are over-worked and end up having burn-out that affects how we perform our duties.* (Key informant No.3).

On-going counselling increases the chances of treatment adherence and if it is not done it becomes a barrier to treatment adherence.

4.5.3.2 Program integration

The study found out that integration of TB/HIV services was beneficial to treatment adherence with the exception of few participants. There are participants who reported that they take their TB treatment from one clinic and HIV treatment from another clinic.

> *…. nurses tried to talk to me about taking the treatment at one clinic but I am not comfortable with doing that as I am planning to relocate. I feel safe with the way things are.* (34-year-old male)

This affected how they adhere to their treatment because they sometimes miss the dates for taking treatment from the other clinic. According to them, this is due to matters of relocation due to work and is impacting negatively on their health.

> *…I ended up having no treatment most of the time because I took my treatment in different clinics because I did not want to take my ARVs in the same clinic as the one I*

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> *was taking my TB treatment at as I am not planning on staying for long at my present location.*

Key informants acknowledges that program integration is assisting because clients come once to collect both treatments. This is important given the fact that most of the patients are unemployed and often cannot afford the costs of transport.

> *Whenever the client comes I know that I have to service him on both TB and HIV and take bloods and sputum when they are due that way clinic visits are minimised. It is also easy to monitor these patients because now at clinics we practise one stop shop.* (Key Informant No.1)

Treatment integration assists in treatment adherence as most of the participants were taking their TB/HIV treatment from the same facility. This motivated them to adhere to their treatment more as they are no longer expected to visit the facility more often.

4.6 Summary

This chapter discussed the themes which were identified through the analysis of the interview data. It discussed adherence as perceived and experienced by the TB/HIV co infected patients. Participants described their experiences with treatment as being not favourable due to various conditions that included individual factors, community factors as well as facility factors. This study found that it is not only about time when it comes to the clinics but that broader issues like poverty and hunger also impact decisions about health. It also included health workers' perceptions to treatment adherence and facilitators of treatment adherence. Both key informants and participants identified several factors that contributes to treatment non-adherence such as problems with money, side effects that are as a result of taking both TB and HIV treatment concomitantly and problems of social support among other factors. Out of the 17 patients that were interviewed, 11 of them had interrupted both their treatments

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at some point mainly due to socioeconomic problems. The remaining six never interrupted treatment since being initiated on.

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CHAPTER 5: DISCUSSION

5.1 Introduction

This study explores the perceptions and experiences of patients who are TB/HIV co-infected and are on treatment for both. In the previous chapter I presented the results from the analysis of the experiences and perceptions of these patients as gathered from participant's responses. I will discuss the study's results according to the main themes and sub-themes which are, challenge of side effects of concomitant treatment, socio-economic challenges, patient's knowledge about treatment, disclosure, associating TB with HIV, social support, availability of medication, workload and staff shortages and patient-provider interaction that emerged from the analysis I conducted, contextualising them within the existing literature and exploring the potential implications of these findings. Some factors that contribute to non-adherence are both individual as well as systemic factors, for example issues of hunger is caused by poverty and requirement to travel to clinic, impacts of job scarcity which is further enhanced by poverty negatively affect treatment adherence.

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5.2 Challenge of side effects of concomitant treatment

Participants in this study cited several difficulties that impede their willingness to take treatment. Some of these difficulties are related to the occurrence of side effects which did not lead to non-adherence, but which participants experienced as demotivating them from adhering to their treatment.

The occurrence of or fear of side effects have also been found to be a barrier to TB/HIV treatment adherence in other studies done in similar socioeconomic contexts especially where there is inadequate counselling and poor understanding of them (Merten et al., 2010; Kim et

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al., 201; Gebremariam, Bjune & Frich, 2010; Mazinyo et al., 2016; Dong et al., 2007; Merten et al., 2016).

A study in sub-Saharan Africa found that TB/HIV participants reported experiencing peripheral neuropathy, chest tightness and loss of weight after taking both treatments (TB/HIV treatment) (Merten et al., 2010). Similarly to our findings, these participants continued to adhere to their treatment even though they felt demotivated due to the experience of side effects (Merten et al., 2010).

Side effects were also cited in another study in sub-Saharan Africa a challenge (Kim et al., 2016). Respondent's expectations were for treatment to make them feel healthy, so the occurrence of side effects was identified in this study as a barrier to adherence (Kim et al., 2016).

Although side effects tend to disappear with time, increased patient load and poor quality counselling may result in patients not receiving adequate information about side effects, which impacts adherence (Merten et al., 2016).

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In this study participants still chose to adhere to their treatment even though they felt uncomfortable due to side effects they experienced whilst on treatment. This study found that one treatment affected the other as participants treated both TB/HIV treatment the same. To them the treatment is not supposed to have any side effects and they expected to feel well within a shorter period.

5.3 Socio-economic challenges

Despite TB/HIV drugs being freely available to patients, costs associated with accessing these medications were found to be a barrier to adherence. Patients reported that costs associated with transport and food interfere with their treatment adherence. Participants reported that they missed appointment dates at the clinics due to unavailability of money for

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transport. Others narrated stories of long distances they walk to the clinic as they often cannot afford to pay for transportation.

In addition, the patients also suffered from hunger whilst awaiting for service because queues at the clinics and other health facilities were long. Many participants spoke of having to ask for money from their family members in order to access health facilities since they are not working. This also contributed to the demotivation they experienced toward taking their treatment.

These findings are supported in the literature, a study in KwaZulu-Natal found that sustained access to food and money were imminent concerns for co-infected patients because many participants were unemployed and therefore could not afford funds. Several patients also reported walking for hours to reach their clinics despite physical debilitation (Daftray & Padayatchi, 2012).

Another study conducted in mostly urban South Africa showed that TB/HIV co-infected patients faced a large economic burden. The researchers concluded that people with TB/HIV in South Africa are at risk of catastrophic costs, defined as costs exceeding 10% of participant income (Skhosana et al., 2006).

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5.4 Patient’s knowledge about treatment

In this study patients appeared to have low levels of treatment literacy and inadequate or incorrect information about TB and HIV and their treatment which impacted on adherence. This is evident from their responses when asked about the duration of the treatment they are taking and how to take it. For example, some participants reported that TB is not curable. Some of the participants also reported that they had little knowledge about the treatment they were taking suggesting the information provided to them was limited.

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A study of TB/HIV co-infected patients in Ethiopia also found that TB/HIV co-infected patients are not well educated about TB treatment but only about Antiretroviral Therapy (ART) and its side effects. The current study has similar findings as some of the patients reported that they were educated about HIV treatment and how it may cause some side effects but no education was given about TB treatment in this regard. A study conducted in KwaZulu-Natal also emphasised that treatment literacy training is mandatory for all patients starting ART and thus represents an ideal opportunity to incorporate TB education because many patients starting ART are co-infected with TB (Dong et al., 2007).

The study conducted in an urban South Africa setting had similar findings (Skhosana et al., 2006). Giving patients information about the disease they are fighting and the treatment they are taking make them knowledgeable about what needs to be done but they cannot always do so because of some of the challenges that they face. All these studies support on-going counselling between the health care worker and the patient. This current study found that males are more lacking in knowledge compared to their female counterparts.

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5.5 Disclosure and Associating TB with HIV

The results suggest that disclosure played a role in supporting treatment adherence when the participant’s family members were accepting of the person undergoing treatment and were invested in helping them to adhere. Some participants disclosed their status to supportive partners and this was found to be very beneficial to treatment adherence but this was not the case with other participants. Fear of rejection was articulated during the interviews as the reason behind non-disclosure. Non-disclosure led to non-adherence as participants were not free to take their treatment at home.

One of the studies conducted in KwaZulu-Natal with TB/HIV co-infected patients also found that participants had problems with disclosing their status as they feared being terminated

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from their jobs (Daftary & Padayatchi, 2012). As a result, they encountered greater difficulty adhering to clinic appointments and that affected their adherence to treatment.

These findings were not supported by some other South African evidence, some participants did not disclose their status but were adhering to their treatment (Skhosana et al., 2009). According to these authors other factors were more influential than disclosure for adherence, such as a positive attitude and change of lifestyle (Skhosana et al., 2009). In the current study some participants did not disclose their status but because of positive attitude they continued taking their treatment without interrupting it.

Despite participants getting counselling on disclosure so as to have support from those around them, this study has identified that there are still participants who did not feel comfortable in disclosing their status without knowing whether they would be supported or not after disclosure. The results also show that caution should be exercised in encouraging disclosure if the patient has good reason to suspect that family, friends or community members may not be supportive as this could also have negative consequences (Obermeyer et al., 2011).

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This study found that myths about TB/HIV may impact on adherence. To some respondents the conditions seemed the same and as a result they were not motivated to take their TB treatment because they were scared of being labelled as being HIV positive. This resulted in some of the participants stopping taking their TB treatment because they associated it with HIV.

Although there is limited literature addressing the role of myths around TB and HIV and their role in adherence, the present study is not the first to note an association. In a study conducted by Gebremariam, Bjune and Frich (2011) about beliefs regarding TB and TB/HIV co-infection in Ethiopia, the authors noted that the association between TB and HIV

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negatively impacted adherence. Some patients in the study believed that they have HIV because of TB. Since people felt that they have to hide their results, condition, and treatment, treatment adherence was negatively affected because of the associating TB with HIV (Gebremariam, Bjune & Frich, 2011).

5.6 Social support and stigma

Regarding social support and its impact on adherence, the researcher identified three distinct things that affected treatment adherence. These were family support, partner support and stigma. Participants may have not adhered to their treatment as a result of poor social support or may have been demotivated to adhere due to challenges with social support.

Social support was also important for treatment adherence in other studies such as the Ethiopian one where social support was found to be crucial for patient's adherence. In this study the researchers found some of the patients were seriously ill when they were initiated on treatment and therefore needed someone to accompany them for treatment (Gebremariam, Bjune & Frich, 2010). Similarly, the current study, some of the patients needed assistance from the family members for food and transportation money. Families can also be the source of encouragement and comfort for patients.

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Participants feared being stigmatised. Stigma has been identified in the literature as a barrier to adherence with participants more reluctant to disclose to their partner's family members compared to their own family members because of fear of stigma (Duffy, 2005; Medley et al., 2004).

In this present study, fear of stigma arose because HIV is a sexually transmitted disease and many people associate it with having many partners. These findings are similar to those of Pebody (2018) who reported that stigma can result in people living with TB/HIV being insulted, rejected, gossiped about and excluded from social activities. Daftary, Padayatchi and

O’Donnell (2014), Rowe et al. (2005) and Gebremariam Bjune and Frich (2010) all noted similar findings. Stigma affected participant’s adherence to treatment as they hide their status making it difficult for them to adhere to treatment.

An interesting outcome of this study was the difference between the participant’s experiences with their diagnosis and treatment and the health worker’s perception of the same. Health workers were of the opinion that stigma around HIV no longer existed and that the participants readily accepted their diagnosis and treatment. The participant’s experiences did not align with these ideas. Stigma according to the participants still impacts on treatment adherence.

The significance of this finding is that the health worker’s perception of stigma may influence their interaction with participants. This may also affect strategies or policies that are adopted at health facilities to address stigma. Delva et al. (2006) reported that a counsellor’s sensitivity to the participant’s fears about stigmatisation determines the success of counselling and adherence to ART.

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5.7 Availability of medication

Participants in this study encountered problems with treatment availability especially at mobile clinics, but they also highlighted problems with treatment access in other facilities such as hospitals. Similar findings were made in Kenya where TB/HIV co-infected patients experienced periods of drug unavailability and results in poor adherence (Muture et al., 2011; Hwang et al., 2019; Pasquet et al., 2010; Koomen, Burger & van Doorslaer, 2019). Contradictory findings were reported in the Eastern Cape where participants did not experience problems with receiving medication (Mngcozelo, 2016).

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Shortage of TB/HIV treatment in health facilities impacts badly on treatment adherence as it leads to missed doses especially because participants are unable to afford treatment sold privately.

5.9 Workload and staff shortages and patient-provider interaction

Staff shortages and increased workload emerged as huge barrier to treatment adherence. The facilities where interviews were conducted had a high volume of patients. This led to patients being seen after many hours of being at the clinic and that affected their motivation towards honouring their treatment appointments.

Participants' primary concern seemed to be hunger. The participants reported that they would go hungry while waiting at the facility but they were unable to afford to buy food due to financial constraints. This is supported by other evidence where participants mentioned that sustained access to food and money were imminent concerns for co-infected patients (Daftary & Padayatchi, 2012).

Hardon et al. (2006) and Gourlay et al. (2013) also reported that long waiting times were a barrier to adherence. Another study also found that patients travelled long distances to clinics and waited for service all day. This discouraged patient from coming back for another month's supply of medication (Smart, 2007). According to this study long waiting times were viewed as an indicator of bad quality of care and discouraged patients from going to the clinics.

Long waiting times are a persistent challenge facing healthcare systems across Africa and have been linked to a variety of undesirable outcomes (Miller et al., 2010). In this study, however key informants and the participants differed as to their perceptions of the cause of the waiting times. Key informants attributed it to increased workload and staff shortages. The participants attributed it to negative health worker attitude. Their perception was that, the

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long waiting times at the facility was because nurses were deliberately causing the delay due to their laziness.

Adding to the complexity of staff shortages according to the key informants is the fact that each patient has to be enrolled in the different programs on the computer and also in the register which takes up more time. At times some patients also need extensive on-going counselling especially those who are not adherent to their treatment. This further exacerbates long waiting times.

Nurses are meant to provide patients with care and support for their condition, and information about treatment and side effects. Patient-provider interaction emerged as one of the reasons why patients were demotivated at some point in adhering to their treatment. A lack of adherence counselling is one of the factors identified in this study that contributes to non-adherence especially among participants that had no social support. This is supported by literature for example from Ethiopia where results suggest that adherence counselling might facilitate adherence (Gebremariam, Bjune & Frich, 2010). Other studies also support that counselling encourages patients to take their treatment without interruption (Musayon-Oblitas, Carcamo & Gimbel, 2019; Chaiyachati et al., 2014; Webb, DeRubeis & Barber, 2010).

Key informants attributed the lack of comprehensive counselling to staff shortages.

5.10 Limitations

The study aimed to get a better understanding of the experiences and perceptions of treatment adherence among TB/HIV co-infected patients.

However, this study has some limitations. For instance, this study's participants who are co-infected by TB/HIV and were accessing health care facilities. This means that this research excludes non-adherent patients who stopped visiting the health facility. Experiences of the

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people who were no longer accessing health services are likely different from those of the people who participated in this study. Future research could examine the barriers to adherence experienced by the patients who no longer engages with health facilities.

The study only included those aged 18 and above, future research should engage younger population of TB/HIV co-infected patients to understand the specific realities experienced by the age group.

The nature of the topic where participants were asked to discuss their behaviour that may have been detrimental to their health (poor adherence) means that their responses may have been subject to desirability bias. Sensitive interviewing and a comprehensive informed consent process should have assisted to ensure this was not the case.

5.11 Summary

The findings of this research were discussed and compared with existing literature in this chapter. This research has explored and shown some factors that may affect adherence to treatment in this specific group of people co-infected. Many of these findings were supported by existing and the literature however, there were some discrepancies.

The next chapter, will highlight recommendations from the study and end with concluding statements.

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CHAPTER 6: CONCLUSION AND RECOMMENDATIONS

6.1 Conclusion

The purpose of the study was to examine the experiences and perceptions about treatment adherence among TB/HIV co-infected patients. The study uses data collected through semi-structured interviews and analysed using thematic analysis.

The findings highlight that non-adherence to treatment may result from issues related to poverty and context. Problems with resources affect adherence because participants reported being unemployed or struggling to access support and so could not always afford transport and food. This study also found that health care facilities are not always located close to people's homes complicating access to facilities to collect treatment.

Side effects also emerged as a factor in treatment adherence. Participants described being demotivated due to discomfort resulting from the medication's side effects. Even though none of the participants decided to stop treatment but they mentioned that they were tempted not to adhere to their treatment due to these side effects.

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Social support has been found as one of the facilitators of adherence. Those who did not disclose their status had limited support. This in turn led to missed doses when the participants hide their treatment to avoid inadvertent disclosure from their families and partners. Despite this, most participants who disclosed their status were well.

Patient-provider interactions also proved to be a barrier to treatment adherence as sometimes participants did not receive on-going counselling and support. Health care workers attitudes also affected the counselling and impacted on adherence.

Education and the information provided to patients about the treatment was found be a problem as many participants did not know about their treatment and how to take it and as a result had a limited understanding of the importance of treatment adherence.

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Heavy workloads due to shortages of staff in the facility resulted in long queues and hunger experienced by the patients affecting adherence.

6.2 Recommendations

The following recommendations arise from the study's findings:

One way to improve the quality of care at facilities would be to increase the number of nurses employed in health facilities that provide TB/HIV services. Also enabling continuous professional development to enable nurses to give total patient care in the form of ongoing counselling.

In addition, improving the working conditions of health workers such as addressing staff shortages may reduce the burden on health care workers. Equipping community health care workers with necessary skills to perform adherence support through patient education. This will assist in relieving some of the duties from nurses.

Given the finding about hunger both in general and at the clinic one suggestion could be the use of support groups and community health care workers to encourage women to carry food to the clinic to alleviate hunger while waiting at the facility. Increasing the number of health workers may take longer to achieve especially in this covid-19 era, therefore this strategy provides a short-term solution to the issues associated with long waiting times as defined by the participants.

Shortage of treatment especially in the mobile clinics was an issue and these especially should be well stocked with ART and TB treatment for easy accessibility for the patients.

TB/HIV clinic should work in collaboration to provide patients with uniform and complete information. Patients should be well informed about co-infection and concomitant treatment. This ongoing counselling should also include topics like side effects of the treatment, pill burden and duration of the treatment. Included in this information should be the importance

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of social support for adherence to treatment. Also to support patients with regard to treatment information, review dates and side effects, a low data application that can be installed in their phones would assist in reducing the burden of non-adherence.

Stigma remains a barrier to adherence. Public education and interventions to reduce TB and HIV stigma would be beneficial. More needs to be done to encourage and educate the community on HIV and the importance of accepting those with the diseases. Implement interventions to encourage partner and family support for patients initiated on TB/HIV treatment.

The findings and recommendations of this study should be reported back to the clinic where data collection was done so that healthcare workers can be aware of some of the issues which were raised.

6.3 Recommendations for further research

Based on the research findings and conclusions, it is evident that there is potential for further research in the field of TB and HIV co-infection as research on experiences and perceptions of TB/HIV co-infected patients on concurrent treatment is still needed. In order to better understand the barriers to adherence on TB/HIV treatment further research in the following areas will be required:

- Barriers to TB/HIV treatment adherence need to be investigated in patients who are no longer visiting the health facilities.
- An in-depth look at barriers to ART adherence during the early days of treatment.
- An exploration of the perceptions of healthcare workers regarding adherence on TB/HIV treatment by patients.
- An in-depth look on strategies on how to reduce patient waiting times at the facilities.

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Appendix 1: Patient interview guide

1. Can you tell me how old are you?
2. Are you a male or female? (Just for the record)
3. Please specify your ethnicity.
4. What is the highest level of school you have completed?
5. Are you married or are you in a committed relationship?
6. Are you currently employed?
7. Can you tell me how long have you been on both TB/HIV treatment?

   Probing questions
   - How do they make you feel?
8. Which clinic do you collect them from?

   Probing question
   - How far is it from where you are staying?
   - Which mode of transport do you use to go to your clinic/hospital?
   - How do you feel the service is at the clinic?
9. Do you experience any side effects when taking your treatment?
   - Can you please mention the side effects that you experience while taking your treatment?
10. What motivates you to take your treatment?
    - Are there any times that you feel demotivated in taking treatment?
11. Did you disclose your status to anyone? If yes who.
    - How was their reaction after your disclosure?
    - How did it make you feel?
12. Did you somehow disclose to your partner?
13. How was the relationship after the disclosure?
14. What sort of support do you get from home about your status and the treatment?
15. How is the support from healthcare workers?
    - How do you find the service where you take your treatment from?
16. What sort of challenges do you experience from the community members?
17. What do you think can be done to motivate you to adhere to your treatment for life?

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Appendix 2: Isikhokelo sodliwano-ndlebe somguli

1. Ungandixelela ukuba mingaphi iminyaka yakho?
2. Ingaba uyindoda okanye umfazi? (ndilungiselela irecodhi).
3. Ndicela undichazele uhlanga lwakho?
4. Leliphi ibanga eliphezulu oluphumeleleyo esikolweni?
5. Ingaba ukhona umntu oncumisana naye ozinikeleyo kuye okanye ingaba utshatile na?
6. Ingaba uyaphangela?
7. Ungandixelela uba lixesha elingakanani uthatha ipilisi zako ze TB/HIV?

   Ngcaciso ethe vetshe
   - Zikwenza uzive njani?
8. Yeyiphi iklinikhi ozithatha kuyo?

   Ngcaciso ethe vetshe
   - Ikude kangakanani kulendawo uhlala kuyo?
   - Loluphi uhlobo lokuhamba olusebenzisayo ukuya khona?
   - Uva ngathi uhlobo oncedakala ngalo lunjani eklinikhi/esibhedlele?
9. Yeyiphi imiphumela uhlangabezana nazo ngenxa yepilisi?
   - Miphumela mini ohlangabezana nayo?
10. Ukhuthazwa yintoni ukuba uthathe ipilisi zakho rhoqo?
    - Akhona amaxesha wokuba uzive unganqweneli ukuthatha ipilisi?
11. Ukhona umntu okhe wamxelela ngesimo sakho sempilo? Ukuba ukhona ngubani?
    - Emva kokuba umxelele waye waziva njani yena ngezindaba?
    - Indlela awaziva ngayo yakwenza ukuba wena uzive njani?
12. Umntu oncumisana naye wamxelela yena?
13. Ukuba wamxelela yaye yabanjani imeko yodlelwano lwenu?
14. Ufumana ncedo luni ekhaya malunga nesigulo sakho kunye namapilisi wakho?
15. Injani indlela abasebenzi bezempilo abakunceda ngayo?
    - Injani indlela oncedwa ngayo xa uyothatha amapilisi wakho?
16. Ufumana ziphi ingxaki ekuhlaleni?
17. Yintoni ocinga ba ingenziwa ukuncedisana nawe ukuze ukwazi ukuthatha ipilisi zakho rhoqo ubomi bakho bonke?

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Appendix 3: Key informant interview guide

1. What is your highest level of education?
2. How long have you been employed in this clinic/hospital?
3. What is your role in the clinic/hospital?
4. What kind of training did you get regarding TB/HIV treatment?
5. Do you have TB/HIV co-infected patients in your facility?
6. How do you integrate TB/HIV programs in your facility?
7. Before initiating patients on treatment how do you prepare them?

   Probing question

   - When the patient is not ready what do you do?
   - What information do you give to the patients before initiating them on TB/HIV treatment?
8. How do you measure their treatment adherence?
9. What do you think is causing patients to adhere on treatment?
10. How do you support those who have not been adherent on their treatment?
11. What do you think are the problems that patients are faced with that contribute to their adherence in the community?
12. In your view, what do you think can be done to encourage patients to be adherent on treatment?
13. How do you find staffing in your facility and how it affects treatment adherence?
14. In your view, is the crime rate affecting treatment adherence?
    - Please support your answer.

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Appendix 4: Isikhokelo sodliwano-ndlebe lwabanolwazi oluphangaleleyo

1. Leliphi ibanga eliphakamileyo oliphumeleleyo emfundweni?
2. Lixesha elingakanani usebenza kule Klinikhi/kwesi sibhedlela?
3. Yintoni inxaxheba yakho kule klinikhi/kwesi sibhedlela?
4. Luqeqesho luni owalifumanayo malunga ne TB/HIV?
5. Unazo izigulane ezichaphazelekileyo kwintsholongwane kagawulayo kwakunye nesifo sephepha ngaxesha linye kwindawo oxelenga kuyo?
6. Uzihlanganisa njani inkqubo zikagawulayo kunye nezo zesifo sephepha?
7. Uzilungisa njani izigulane phambi kokuba uziqalise kunyango?
   Ngcaciso ethe vetshe
   - Xa isigulane singekakulungeli ukuqalisa unyango wenza njani?
   - Loluphi ulwazi olunika izigulane phambi kokuba ziqale unyango?
8. Uzijonga njani izigulane ukuze wazi ukuba ziyazisebenzisa rhoqo ipilisi zazo?
9. Ucinga ukuba yintoni eyenza ukuba izigulane zizikhutalele ipilisi zazo?
10. Ubaxhasa njani abo bathe abazikhuthalela ipilisi zabo?
11. Ucinga ukuba zingxaki zini ezihlangabezana nazo ekuhlaleni izigulane zibonakale zingalukhuthalelanga unyango lwazo?
12. Kwezakho imbono, ucinga ukuba yintoni enokwenziwa ukuze izigulane zikhuthalele unyango lwazo?
13. Ubona imeko ophangela phantsi kwayo injani malunga namanani enu apha ekliniki. Iluchaphazela njani unyango?
14. Ngokokucinga kwakho, ingaba ubundlobongela bunegalelo kwindlela ekukhuthalelwe ngayo unyango?
    Ngcaciso ethe vetshe
    - Ndicela uxhase impendulo yakho.

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Appendix 5: Patient Information Sheet

UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

Tel: +27 21-959 2809 Fax: 27 21-959 2872
E-mail: soph-comm@uwc.ac.za

Project title: Treatment adherence in TB/HIV co-infected patients in Mount Frere, Eastern Cape.

What is the study about?

This is a research project that is being conducted by Lungelwa Mbunyuza a research student doing Master of Public Health with the University of the Western Cape. In this study I will be exploring people's experiences and perceptions on treatment. You are invited to take part in this research as your participation will assist in getting information about the research topic.

With the information that you will provide possibly a quantitative study will be conducted to check the severity of the problem in Alfred Nzo and maybe come up with recommendations on how to assist those on TB/HIV treatment to adhere to them and possible assist health professional in areas where there is a gap.

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WESTERN CAPE

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

As a participant, you will be asked to respond to a set of questions from an interview guide. In order to gain understanding of what you, as a patient perceive to be the reasons that motivate or demotivate people to take their treatment. With your permission, I will be recording the interview so as to make sure that I miss not the important comments.

Even though I will be taking notes during our session, I may not be fast enough to get everything you say down hence I will use the tape. Please be sure to speak up so that I do not miss your comments. The interview will not be recorded if you do not agree on this aspect. Recording can be stopped at your request at any point. Attached please find a summary of questions that will be asked.

http://etd.uwc.ac.za/

Would my participation in this study be kept confidential?

The interview will be kept completely confidential and anonymous as I will not be asking for your name or any identifying information. I will at all times refer to you and your words by a participant number/ pseudonym. I shall keep any other records of your participation locked away at all times, and destroy them after the data has been collected.

What are the possible risks and benefits of participation?

There may be some harm such as psychological harm from participating in this study. You are expected to voice out your feelings concerning treatment adherence but when you feel you are overwhelmed by the questions you can withdraw from participating. Also this research is not designed to help you personally, but results may help the research investigator learn more about your perceptions and lived experiences concerning the problem of treatment adherence.

I hope that this study will yield some benefits in the near future in motivating patients to adhere to their prescribed treatment.

Right to refuse participation and withdrawal

UNIVERSITY of the WESTERN CAPE

You are free to choose to participate in this study. You are also allowed to refuse participation without any negative effects. You may also withdraw anytime from the discussion if you wish to do so. Should you decide on participating, you will be required to sign a consent form. The consent form is attached to this information sheet so that you can look at what you will sign before you decide to participate. If you are under the age of 18 years you are not allowed to take part in the study.

Who will I contact should I have questions?

If you have any questions about the research study, please contact:

Lungelwa Mbunyuza

Student number: 3812863

Tel: 039 255 8283

Cell: 072 819 8279

Email: lulumbunyuza@gmail.com

http://etd.uwc.ac.za/

Should you have any questions regarding this study and your rights as a research participant or maybe you wish to report any problems you have experienced related to the study, please contact:

Prof. Lucia Knight

School of Public Health

University of Cape Town

Private Bag X 17

Bellville 7535

Soph-comm@uwc.ac.za

Prof. Anthea Rhoda

Dean of the Faculty of Community and Health Science

University of the Western Cape

Private Bag X17

Bellville 7535

chs-deansoffice@uwc.ac.za

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http://etd.uwc.ac.za/

Appendix 6: Uxwebhu lolwazi lomguli

UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

Tel: +27 21-959 2809 Fax: 27 21-959 2872
E-mail: soph-comm@uwc.ac.za

Isihloko seprojekthi: Ukhuthalelo lonyango kwabo bachaphazelekileyo yintsholongwane kagawulayo ngaxesha linye nesifo sephepha eMount Frere, Mpuma Koloni.

Uphando lungantoni?

Olu phando lwenziwa ngu Lungelwa Mbunyuza ongumfundi kwezophando kwiDyunivesithi yaseNtshona Koloni. Kolu phando ndizobe ndikhangela amava kunye nokuqonda kwabantu ngonyango. Uyamenywa ukuba ubeyinxalenye yoluphando njengoko ubukho bakho buzokuncedisa ekufumaneni ulwazi ngesi sihloko soluphando.

Ulwazi ozakulinika mhlawumbi lungancedisana ngokuba kwenziwe olunye uphando oluthe vetshe ukuze kuhlolwe ubungakanani balengxaki apha eAlfred Nzo futhi kufunyanwe ingcebiso malunga nokukhuthalela unyango luka gawulayo kunye nesifo sephepha. Lungaphinde luncedisane nokuvala izikhewu ezinoba zikhona kwabo bangabasebenzi kwezempilo.

UNIVERSITY of the
WESTERN CAPE

Ndizokuncedisana entwenini ukuba ndiyakuvumela ukuthatha inxaxheba?

Nje ngomnye wabathathi nxaxheba, uzokucelwa ukuba uphendule uthotho lwemibuzo elungisiweyo ukuze sifumane umqondo kunye nengcamango zakho mayela nezizathu ezikhuthaza okanye zingakhuthazi abantu ukuthatha ipilisi zabo. Ngemvume yakho, ndizokulushicilela udliwano-ndlebe ukuqinisekisa ukuba akukho nto ibalulekileyo ndiyiphosayo. Noba ndizobe ndibhala phantsi, ndingangakwazi ukukhawulezisa ekuthatheni zonke inkcukacha ozitshoyo yiyo lonto ndizokusebenzisa nesishicileli. Ndicela uthethele phezulu khona ukuze kungabikho nto ndiyiphosayo. Udliwano-ndlebe lungangashicilelwa xa ungavumelani noko. Ushicilelo lungamiswa nanini xa ufuna njalo. Fumana isishankathelo semibuzo ozokuyibuzwa kwalapha kolugxwebhu.

Inxaxheba yam koluphando ingagcinwa iyimfihlo?

Udliwano-ndlebe luzokugcinwa luyimfihlo njengoko ndingazukubuza igama lakho kwaye nayiphi na into ediza ubuwena. Ngalolonke ixesha ndizobhekisa kuwe ngokwenani lokuthatha inxaxheba kwakho kungenjalo igama esingelilo elakho. Zonke irekhodi zenxaxheba yakhondizokuzitshixela ngalo lonke ixesha, emva kokuba idata iqokelelwe ndizokuzitshabalalisa.

Yintoni ingozi kunye nelungelo lokuthatha inxaxheba?

Ungakhona umonakalo ngokwasemoyeni onokubangelwa kukuthatha inxaxheba koluphando. Ulindeleke ukuba uzixele indlela ova ngayo malunga nokhuthalelo lonyango kodwa xa uziva ngathi iyakongamela imibuzo unalo ilungelo lokurhoxa ekuthatheni inxaxheba kuphando olu. Kwakhona oluphando aluzelanga ukuzokunceda wena ubuqu kodwa iziphumo zophando zingakwazi ukuncedisana nomphandi ukuze afunde banzi ngamava kunye nokuqonda kwabantu ingxaki zokungakhuthaleli ipilisi zabo. Ndinethemba lokuba oluphando luyakuza nenzuzo kwikamva elizayo ekukhuthazeki abaguli ukuba bakhulalele ipilisi abazibhalelweyo.

Ilungelo lokwala ukuthatha inxaxheba kwakunye nokurhoxa

Ukhululekile ukuba ungakhetha ukuthatha inxaxheba koluphando. Kwakhona uvumelekile ukuba ungabiyiyo inxalenye yalo uphando olu kube kungekho nto imbi izokwenzekela ngalonto. Unako ukurhoxa nanini kwingxoxo ukuba uziva ufuna njalo. Uba uthe wagqiba ekuthabatheni inxaxheba kuzokufuneka uzibophelele kwiphepha-mvume. Iphepha-mvume likwakhona apha koluxwebhu lolwazi ukuze ukwazi ukuba ubone lento uzozibophelela kuyo phambi kokuba uvume ukuthatha inxaxheba. Ukuba ungaphantsi kweminyaka eyi 18 ubudala awuvumelekanga ukubayinxalenye yoluphando.

Ndingaqhakamshelana nabani xa ndiye ndaba nemibuzo?

Xa unemibuzo ngophando, nceda uqhakamshelane:

Lungelwa Mbunyuza

Student number: 3812863

Ifoni: 039 255 8283

Imfonomfono: 072 819 8279

Imeyile: lulumbunyuza@gmail.com

http://etd.uwc.ac.za/

Xa unemibuzo ethe vetshe malunga nophando olu kunye nokwazi amalungelo akho njengomthathi nxaxheba koluphando okanye unqwenela ukuxela ingxaki ohlangabezene nazo eziqondene nophando olu, nceda uqhakamshelane:

Prof. Lucia Knight

School of Public Health

University of Cape Town

Private Bag X 17

Bellville 7535

Soph-comm@uwc.ac.za

Prof. Anthea Rhoda

Dean of the Faculty of Community and Health Science

University of the Western Cape

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Appendix 7: Key informant Information Sheet

UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

Tel: +27 21-959 2809 Fax: 27 21-959 2872
E-mail: soph-comm@uwc.ac.za

Project title: Treatment adherence in TB/HIV co-infected patients in Mount Frere, Eastern Cape.

What is the study about?

This is a research project that is being conducted by Lungelwa Mbunyuza a research student doing Master of Public Health with the University of the Western Cape. In this study I will be exploring people's experiences and perceptions on treatment. You are invited to take part in this research as your participation will assist in getting information about the research topic.

With the information that you will provide possibly a quantitative study will be conducted to check the severity of the problem in Alfred Nzo and maybe come up with recommendations on how to assist those on TB/HIV treatment to adhere to them and possible assist health professional in areas where there is a gap.

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

As a participant, you will be asked to respond to a set of questions from an interview guide. In order to gain understanding of what you, as a patient perceive to be the reasons that motivate or demotivate people to take their treatment. With your permission, I will be recording the interview so as to make sure that I miss not the important comments.

Even though I will be taking notes during our session, I may not be fast enough to get everything you say down hence I will use the tape. Please be sure to speak up so that I do not miss your comments. The interview will not be recorded if you do not agree on this aspect. Recording can be stopped at your request at any point. Attached please find a summary of questions that will be asked.

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Would my participation in this study be kept confidential?

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What are the possible risks and benefits of participation?

There may be some harm such as psychological harm from participating in this study. You are expected to voice out your feelings concerning treatment adherence but when you feel you are overwhelmed by the questions you can withdraw from participating. Also this research is not designed to help you personally, but results may help the research investigator learn more about your perceptions and lived experiences concerning the problem of treatment adherence.

I hope that this study will yield some benefits in the near future in motivating patients to adhere to their prescribed treatment.

Right to refuse participation and withdrawal

You are free to choose to participate in this study. You are also allowed to refuse participation without any negative effects. You may also withdraw anytime from the discussion if you wish to do so. Should you decide on participating, you will be required to sign a consent form. The consent form is attached to this information sheet so that you can look at what you will sign before you decide to participate. If you are under the age of 18 years you are not allowed to take part in the study.

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Email: lulumbunyuza@gmail.com

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Should you have any questions regarding this study and your rights as a research participant or maybe you wish to report any problems you have experienced related to the study, please contact:

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Appendix 8: Uxwebhu lolwazi lonolwazi oluthe vetshe

UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

Tel: +27 21-959 2809 Fax: 27 21-959 2872
E-mail: soph-comm@uwc.ac.za

Isihloko seprojekthi: Ukhuthalelo lonyango kwabo bachaphazelekileyo yintsholongwane kagawulayo ngaxesha linye nesifo sephepha eMount Frere, Mpuma Koloni.

Uphando lungantoni?

Olu phando lwenziwa ngu Lungelwa Mbunyuza ongumfundi kwezophando kwiDyunivesithi yaseNtshona Koloni. Kolu phando ndizobe ndikhangela amava kunye nokuqonda kwabantu ngonyango. Uyamenywa ukuba ubeyinxalenye yoluphando njengoko ubukho bakho buzokuncedisa ekufumaneni ulwazi ngesi sihloko soluphando.

Ulwazi ozakulinika mhlawumbi lungancedisana ngokuba kwenziwe olunye uphando oluthe vetshe ukuze kuhlolwe ubungakanani balengxaki apha eAlfred Nzo futhi kufunyanwe ingcebiso malunga nokukhuthalela unyango luka gawulayo kunye nesifo sephepha. Lungaphinde luncedisane nokuvala izikhewu ezinoba zikhona kwabo bangabasebenzi kwezempilo.

Ndizokuncedisana entwenini ukuba ndiyakuvumela ukuthatha inxaxheba?

Nje ngomnye wabathathi nxaxheba, uzokucelwa ukuba uphendule uthotho lwemibuzo elungisiweyo ukuze sifumane umqondo kunye nengcamango zakho mayela nezizathu ezikhuthaza okanye zingakhuthazi abantu ukuthatha ipilisi zabo. Ngemvume yakho, ndizokulushicilela udliwano-ndlebe ukuqinisekisa ukuba akukho nto ibalulekileyo ndiyiphosayo. Noba ndizobe ndibhala phantsi, ndingangakwazi ukukhawulezisa ekuthatheni zonke inkcukacha ozitshoyo yiyo lonto ndizokusebenzisa nesishicileli. Ndicela uthethele phezulu khona ukuze kungabikho nto ndiyiphosayo. Udliwano-ndlebe lungangashicilelwa xa ungavumelani noko. Ushicilelo lungamiswa nanini xa ufuna njalo. Fumana isishankathelo semibuzo ozokuyibuzwa kwalapha kolugxwebhu.

http://etd.uwc.ac.za/

Inxaxheba yam koluphando ingagcinwa iyimfihlo?

Udliwano-ndlebe luzokugcinwa luyimfihlo njengoko ndingazukubuza igama lakho kwaye nayiphi na into ediza ubuwena. Ngalolonke ixesha ndizobhekisa kuwe ngokwenani lokuthatha inxaxheba kwakho kungenjalo igama esingelilo elakho. Zonke irekhodi zenxaxheba yakhondizokuzitshixela ngalo lonke ixesha, emva kokuba idata iqokelelwe ndizokuzitshabalalisa.

Yintoni ingozi kunye nelungelo lokuthatha inxaxheba?

Ungakhona umonakalo ngokwasemoyeni onokubangelwa kukuthatha inxaxheba koluphando. Ulindeleke ukuba uzixele indlela ova ngayo malunga nokhuthalelo lonyango kodwa xa uziva ngathi iyakongamela imibuzo unalo ilungelo lokurhoxa ekuthatheni inxaxheba kuphando olu. Kwakhona oluphando aluzelanga ukuzokunceda wena ubuqu kodwa iziphumo zophando zingakwazi ukuncedisana nomphandi ukuze afunde banzi ngamava kunye nokuqonda kwabantu ingxaki zokungakhuthaleli ipilisi zabo. Ndinethemba lokuba oluphando luyakuza nenzuzo kwikamva elizayo ekukhuthazeki abaguli ukuba bakhulalele ipilisi abazibhalelweyo.

Ilungelo lokwala ukuthatha inxaxheba kwakunye nokurhoxa

Ukhululekile ukuba ungakhetha ukuthatha inxaxheba koluphando. Kwakhona uvumelekile ukuba ungabiyiyo inxalenye yalo uphando olu kube kungekho nto imbi izokwenzekela ngalonto. Unako ukurhoxa nanini kwingxoxo ukuba uziva ufuna njalo. Uba uthe wagqiba ekuthabatheni inxaxheba kuzokufuneka uzibophelele kwiphepha-mvume. Iphepha-mvume likwakhona apha koluxwebhu lolwazi ukuze ukwazi ukuba ubone lento uzozibophelela kuyo phambi kokuba uvume ukuthatha inxaxheba. Ukuba ungaphantsi kweminyaka eyi 18 ubudala awuvumelekanga ukubayinxalenye yoluphando.

Ndingaqhakamshelana nabani xa ndiye ndaba nemibuzo?

Xa unemibuzo ngophando, nceda uqhakamshelane:

Lungelwa Mbunyuza

Student number: 3812863

Ifoni: 039 255 8283

Imfonomfono: 072 819 8279

Imeyile: lulumbunyuza@gmail.com

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Xa unemibuzo ethe vetshe malunga nophando olu kunye nokwazi amalungelo akho njengomthathi nxaxheba koluphando okanye unqwenela ukuxela ingxaki ohlangabezene nazo eziqondene nophando olu, nceda uqhakamshelane:

Prof. Lucia Knight

School of Public Health

University of Cape Town

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Prof. Anthea Rhoda

Dean of the Faculty of Community and Health Science

University of the Western Cape

Private Bag X17

Bellville 7535

chs-deansoffice@uwc.ac.za

UNIVERSITY of the
WESTERN CAPE

Appendix 9: Patient Informed Consent

UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

Tel: +27 21-959 2809 Fax: 27 21-959 2872
E-mail: soph-comm@uwc.ac.za

Project topic: Treatment adherence in TB/HIV co-infected patients in Mount Frere, Eastern Cape.

The study objectives have been described to me in a language that I understand. All my questions about the study have been answered. I fully understand what my participation will involve and I agree to participate out 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 agree to be audiotaped during my participation in this study.
- I do not agree to be videotaped during my participation in this study.

Interview's name (pseudonym)……………………………………………………………..

Place at which the interview will be conducted………………………………………………….

Date …………………………….

Interviewer's signature………………………………………………………………..

Biomedical Research Ethics Committee
University of the Western Cape
Private Bag X17
Bellville
7535
Tel: 021 959 4111
e-mail: research-ethics@uwc.ac.za

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WESTERN CAPE

http://etd.uwc.ac.za/

Appendix 10: Imvume yolwazi yomguli

UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

Tel: +27 21-959 2809 Fax: 27 21-959 2872
E-mail: soph-comm@uwc.ac.za

Isihloko seprojekthi: Ukhuthalelo lonyango kwabo bachaphazelekileyo yintsholongwane kagawulayo ngaxesha linye nesifo sephepha eMount Frere, Mpuma Koloni.

Injongo yophando ibisele icacisiwe kum ngolwimi endiluqondayo. Yonke imibuzo malunga nophando sele iphendulekile. Ndiqonda kakuhle ukuba ukudingeka ntoni ekuthatheni inxaxheba kwam kunjalo ndiyavuma ukuthatha inxaxheba ngokuzifunela kwam ngaphandle kokunyanzeliswa. Ndiyayiqonda ukuba ubumna abuzukubhentsiswa nakuye nabani na umntu. Ndiyayiqonda ukuba ndingarhoxa kuphando nanini ngaphandle kokuba ndinike isizathu nangaphandle loloyiko lwemiphumela emibi okanye ukuphulukana nenzuzo.

- Ndiyavuma ukuba ndingashicilelwa ngethuba ndithatha inxaxheba kuphando.
- Andivumelani nokushicilelwa ngethuba ndithatha inxaxheba kuphando.

Igama lomthathi nxaxheba
(elingeyonyani)……………………………………………………….

Indawo apho udliwano-ndlebe luzoqhutyelwa khona………………………………………………

Umhla: ………………………………………..

Intsayino yomphandi: …………………………………………………………………

Biomedical Research Ethics Committee

University of the Western Cape

Private Bag X17

Bellville

7535

Tel: 021 959 4111

e-mail: research-ethics@uwc.ac.za

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WESTERN CAPE

http://etd.uwc.ac.za/

Appendix 11: Key Informant Informed Consent

UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

Tel: +27 21-959 2809 Fax: 27 21-959 2872
E-mail: soph-comm@uwc.ac.za

Project topic: Treatment adherence in TB/HIV co-infected patients in Mount Frere, Eastern Cape.

The study objectives have been described to me in a language that I understand. All my questions about the study have been answered. I fully understand what my participation will involve and I agree to participate out 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 agree to be audiotaped during my participation in this study.
- I do not agree to be audiotaped during my participation in this study.

UNIVERSITY of the
WESTERN CAPE

Interview's name (pseudonym)……………………………………………………………..

Place at which the interview will be conducted……………………………………………….

Date …………………………….

Interviewer's signature………………………………………………………………………..

Biomedical Research Ethics Committee
University of the Western Cape
Private Bag X17
Bellville
7535
Tel: 021 959 4111
e-mail: research-ethics@uwc.ac.za

Appendix 12: Imvume yolwazi yonolwazi oluthe vetshe

UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

Tel: +27 21-959 2809 Fax: 27 21-959 2872
E-mail: soph-comm@uwc.ac.za

Isihloko seprojekthi: Ukhuthalelo lonyango kwabo bachaphazelekileyo yintsholongwane kagawulayo ngaxesha linye nesifo sephepha eMount Frere, Mpuma Koloni.

Injongo yophando ibisele icacisiwe kum ngolwimi endiluqondayo. Yonke imibuzo malunga nophando sele iphendulekile. Ndiqonda kakuhle ukuba ukudingeka ntoni ekuthatheni inxaxheba kwam kunjalo ndiyavuma ukuthatha inxaxheba ngokuzifunela kwam ngaphandle kokunyanzeliswa. Ndiyayiqonda ukuba ubumna abuzukubhentsiswa nakuye nabani na umntu. Ndiyayiqonda ukuba ndingarhoxa kuphando nanini ngaphandle kokuba ndinike isizathu nangaphandle loloyiko lwemiphumela emibi okanye ukuphulukana nenzuzo.

- Ndiyavuma ukuba ndingashicilelwa ngethuba ndithatha inxaxheba kuphando.
- Andivumelani nokushicilelwa ngethuba ndithatha inxaxheba kuphando.

Igama lomthathi nxaxheba
(elingeyonyani)………………………………………………………………

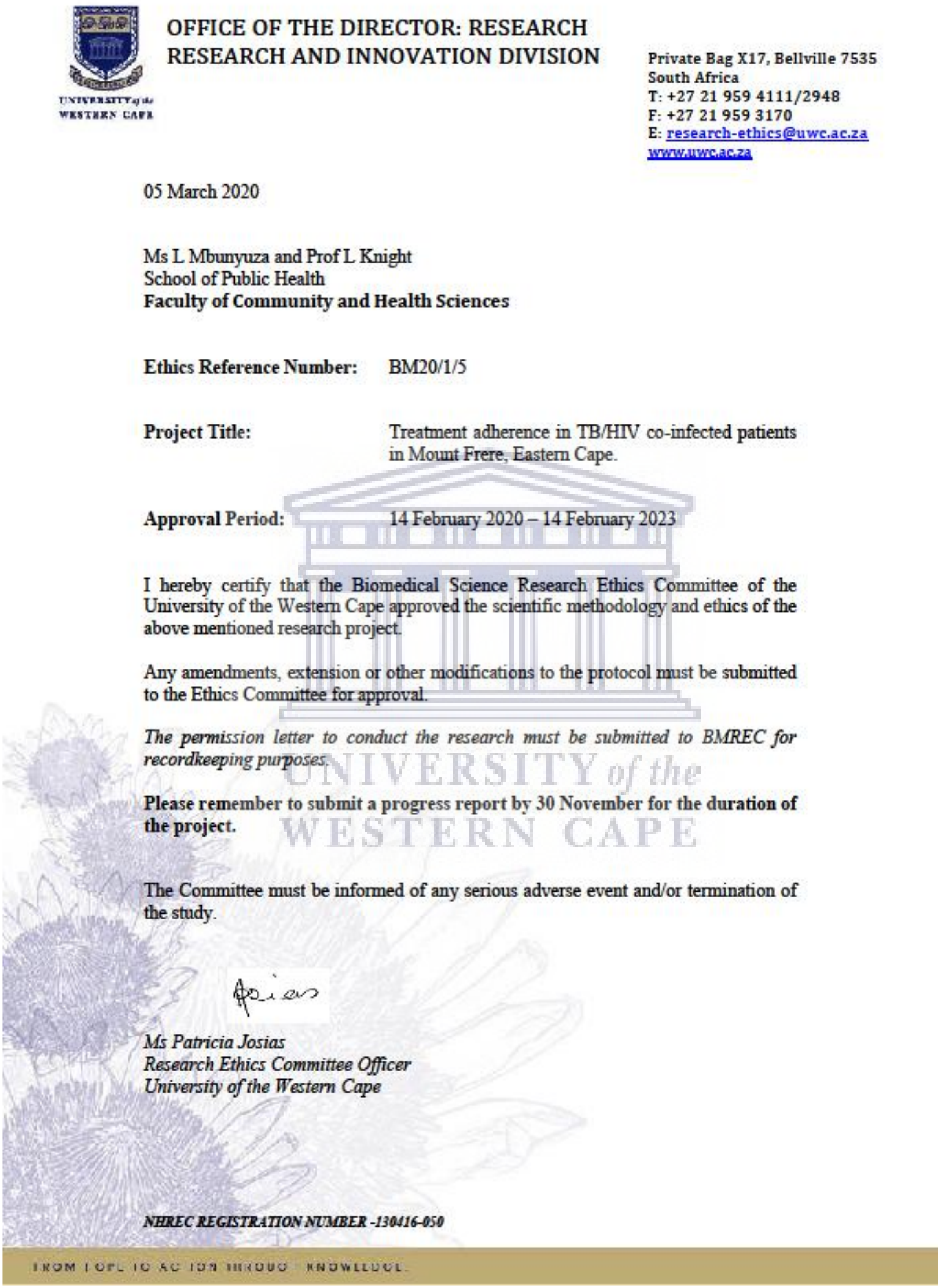
Indawo apho udliwano-ndlebe luzokuqhutyelwa khona:
…………………………………………

Umhla: ………………………………………..

Biomedical Research Ethics Committee
University of the Western Cape
Private Bag X17
Bellville
7535
Tel: 021 959 4111
e-mail: research-ethics@uwc.ac.za

UNIVERSITY of the
WESTERN CAPE

Appendix 13: Ethics approval



OFFICE OF THE DIRECTOR: RESEARCH
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www.uwc.ac.za

05 March 2020

Ms L Mbunyuza and Prof L Knight
School of Public Health
Faculty of Community and Health Sciences

Ethics Reference Number: BM20/1/5

Project Title: Treatment adherence in TB/HIV co-infected patients in Mount Frere, Eastern Cape.

Approval Period: 14 February 2020 – 14 February 2023

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.

The permission letter to conduct the research must be submitted to BMREC for recordkeeping purposes.

Please remember to submit a progress report by 30 November for the duration of the project.

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

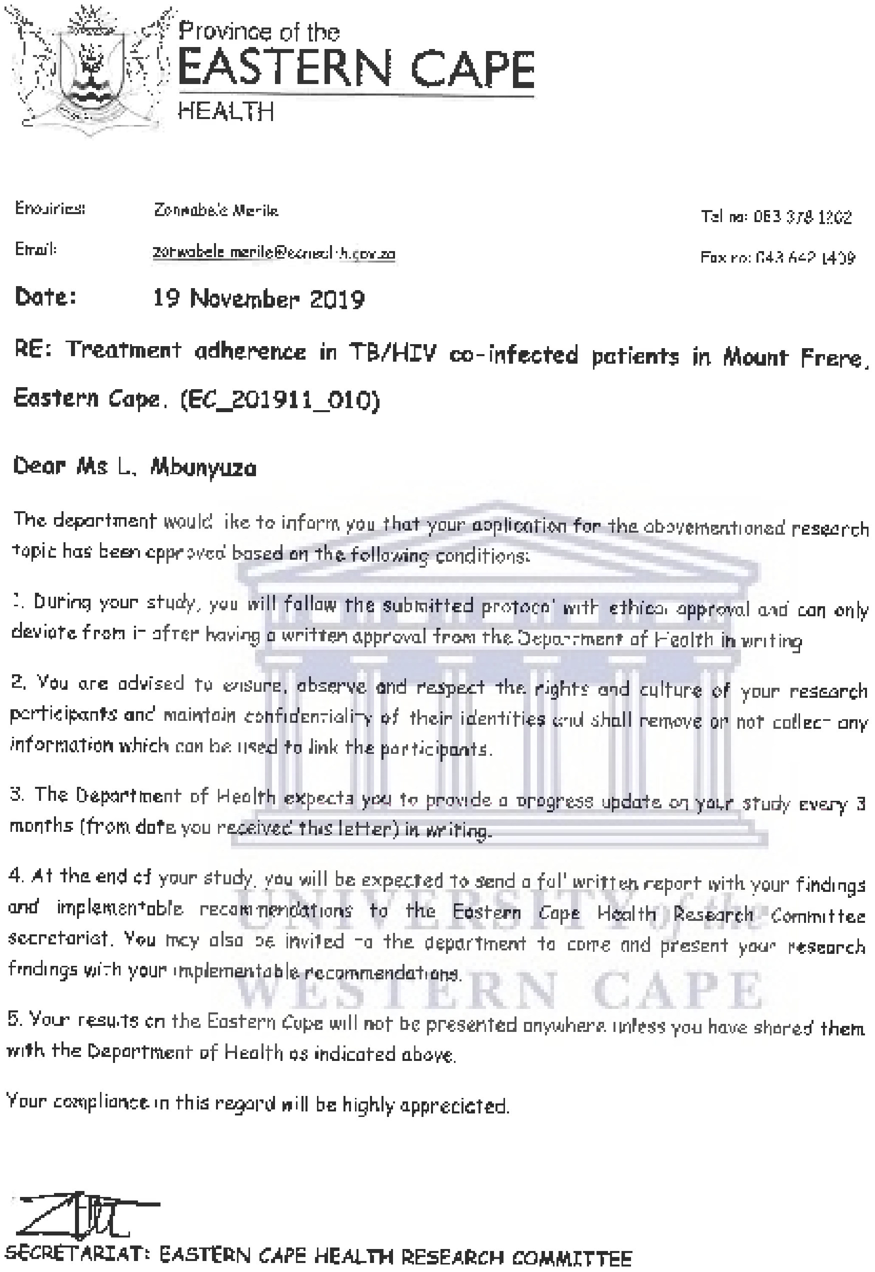
Ms Patricia Josias
Research Ethics Committee Officer
University of the Western Cape

NHREC REGISTRATION NUMBER -130416-050

FROM HOPE TO ACTION THROUGH KNOWLEDGE

UNIVERSITY of the
WESTERN CAPE

Appendix 14: Eastern Cape Ethics Approval



Province of the
EASTERN CAPE
HEALTH

Enquiries: Zonwabele Merile
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Date: 19 November 2019

RE: Treatment adherence in TB/HIV co-infected patients in Mount Frere, Eastern Cape. (EC_201911_010)

Dear Ms L. Mbunyuza

The department would like to inform you that your application for the abovementioned research topic has been approved based on the following conditions:

1. During your study, you will follow the submitted protocol with ethical approval and can only deviate from it after having a written approval from the Department of Health in writing

2. You are advised to ensure, observe and respect the rights and culture of your research participants and maintain confidentiality of their identities and shall remove or not collect any information which can be used to link the participants.

3. The Department of Health expects you to provide a progress update on your study every 3 months (from date you received this letter) in writing.

4. At the end of your study, you will be expected to send a full written report with your findings and implementable recommendations to the Eastern Cape Health Research Committee secretariat. You may also be invited to the department to come and present your research findings with your implementable recommendations.

5. Your results on the Eastern Cape will not be presented anywhere unless you have shared them with the Department of Health as indicated above.

Your compliance in this regard will be highly appreciated.

SECRETARIAT: EASTERN CAPE HEALTH RESEARCH COMMITTEE

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