Exploration of experiences of patients with the adverse-drug effects of multidrug-resistant tuberculosis treatment in a primary health care facility in the Western Cape.

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the degree of Magister Curations (structured) in the School of Nursing,

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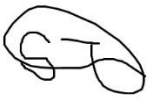
Date: 13 Feb 2017

DECLARATION

I declare that: *The explorations of experiences of patients with the adverse-drug effects of multidrug- resistant tuberculosis in a primary health care facility in the Western Cape* is my own work and it has not been submitted for any degree or examination at any other University and that all the sources have been indicated and acknowledged by complete references.

Siphokuhle Tinzi Feb 2017

Signed …….  ……

KEYWORDS

- Multi-drug resistant tuberculosis (MDR-TB)
- Tuberculosis (TB)
- Adverse drug effects
- Experiences
- Patients
- Primary health care
- Facility
- Treatment
- Western Cape
- Exploration

LIST OF ABBREVIATIONS

MDR- multi drug resistant

TB- tuberculosis

WHO- world health organization

HIV- human immune virus

AIDS- acquired immune deficiency disease

XDR-TB- Extremely drug resistant tuberculosis

DEDICATION

I dedicate this work to everyone who has played a positive role in my life: My late grandmother, my mother, my brother and my partner.

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I wish to convey my sincere gratitude to:

- My supervisor, Prof Brian van Wyk for his expert guidance, patience and constant motivation throughout this research journey.
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ABSTRACT

Multidrug resistant TB (MDR-TB) is a form of TB caused by bacteria (germs) that are resistant to the usual drugs that are used to treat "normal" TB. The duration of treatment for MDR-TB is a maximum of 22 months. People with MDR-TB are treated in specialized tertiary hospitals and in out-patient clinics in the PHC facilities. The treatment includes a six months injectable phase with a wide range of TB drugs. The adverse effects of MDR-TB drugs are among the worst side-effects ever reported by patients.

The aim of the current study was to explore the experiences of adverse effects of MDR-TB treatment amongst patients in a primary health care facility in the Western Cape.

An explorative qualitative study design was used to explore the experiences of patient with the adverse effects of MDR-TB treatment in a primary health care facility in the Western Cape. In-depth interviews were conducted with 12 MDR-TB patients. Data analysis was done by using the Tesch's method of content analysis.

The study revealed that participating MDR-TB patients experienced various emotional, financial, physical and social challenges. Participants explained that the experience of being on MDR-TB treatment is emotionally draining; the pain and discomfort of the adverse effect of treatment makes a person to feel anxious and depressed. Financially they depended on social grants because they had to stop working after starting treatment. They could not function well physically because of the toxic nature of the adverse effects of treatment; which resulted in fatigue, dizziness and burning sensation on the feet and hands. They were faced with a lot of stigma from the community and even family members because of their illness. The study also revealed that in spite of the challenges and obstacles the participants were all motivated to complete their treatment and get cured.

It is recommended that more support structures be made available for patients who are being treated for MDRT-TB such as; psychotherapy, social support and counselling on health education. Provision needs to be made for patients who are receiving daily injection; for it to be given in their homes. Health care providers treating MDR-TB patients need to do home visits together with MDR-TB adherence counsellors, to monitor the physical wellbeing of patients at home. This will also provide patients with the platform to discuss their health concerns in a more

accommodative and relaxed environment. New drug regimen with fewer tablets and less treatment duration is needed for MDR-TB.

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CHAPTER ONE

Introduction

1.1 Background

Infection by mycobacterial tuberculosis continues to be a growing global public health problem that afflicts large numbers of human populations across the globe, and particularly those in sub-Saharan Africa (WHO, 2008). Out of all the people who are diagnosed with tuberculosis (TB) for the first time, 1% (1 in 100) will have multidrug-resistant tuberculosis, and out of all those who are diagnosed with tuberculosis after having been treated for tuberculosis before, 4% (4 in 100) will have multidrug-resistant tuberculosis (MDR-TB).

Multidrug-resistant tuberculosis (MDR-TB) is defined as a tuberculosis disease where there is in vitro resistance to both isoniazid and rifampicin, with or without resistance to other anti-TB drugs (WHO, 2011). According to the World Health Organization (WHO, 2012), the primary cause of MDR-TB is mismanagement of TB treatment and person-to-person spread, inappropriate or incorrect use of antimicrobial drugs, or use of ineffective formulation of drug and premature interruption. MDR-TB poses difficulties in diagnosis and treatment, including increased frequency of adverse reactions to anti- tuberculosis drugs. In some countries it is becoming increasingly difficult to treat MDR-TB, as treatment options are limited and expensive, and recommended medicines are not always available (WHO, 2012).

South Africa has the world's third highest TB burden, behind countries with significantly larger populations, China and India (Isaakidis, Varghese, Mansoor, Cox & Saranchuk, 2012). South Africa is ranked the fifth highest for incidence of drug-resistant tuberculosis in the world. In addition, the numbers of MDR-TB or XDR-TB patients have increased due to the concurrent HIV epidemic and inadequate management of TB (WHO, 2012).

1.2 Problem Statement

The standardized MDR-TB treatment is recommended for all newly diagnosed MDR patients. This regimen consists of an intensive phase also called "injectable phase" of at least 6 months with 5 drugs followed by a continuation phase of 18 months with four drugs (Seung, 2009). The duration of treatment is relatively long and the drugs used have a high frequency of extremely uncomfortable and even life threatening adverse effects. This gives rise to a very small number of patients who actually complete their treatment (high defaulter rate).

The problem is that there is poor understanding of how adverse effects of MDR-TB treatment affect TB patients. Previous research has focused on describing the type of adverse-effects that patients on MDR-TB treatment experience (WHO, 2012) not so much on how these adverse effect affect their quality of life and the influence it has on the long-term retention to the treatment regimen

1.3 Aims and Objectives of the Study

The aim of the study was to explore the experiences of adverse effects of MDR-TB treatment among patients in a primary health care facility in an urban setting in the Western Cape.

The objectives of the study were to:

Explore the challenges faced by patients who are on MDR-TB treatment.

To explore the social impact that MDR-TB has on patients who are on treatment.

To explore the challenges encountered with the MDR-TB drugs.

1.4 Outline of the Thesis

Chapter 1: This chapter serves to introduce the reader to the study and include the problem statement and aim and objectives of the study

Chapter 2: This chapter discusses a literature review on TB, history of TB in South Africa, diagnosis of TB in South Africa, the early development of TB epidemic in South Africa, incidence of TB in South Africa, TB deaths in 2012 and 2013, global TB control, challenges to

TB control, MDR-TB, MDR-TB treatment, adverse effects of MDR-TB treatment, recommendations moving forward and summary.

Chapter 3: This chapter presents the study design, sampling, data collection, analysis and ethics considerations that were used in the current study.

Chapter 4: This chapter presents the findings and discussion of the findings from the current study.

Chapter 5: This chapter presents the conclusions, recommendations and limitations to the study.

CHAPTER TWO

Literature Review

2.1 Introduction

In reviewing the literature, the researcher embarked on an extensive search using the online library at UWC. The databases included Ebscohost, CINAHL, Google Scholar and PubMed. The literature revealed that there are a number of quantitative and qualitative research studies done on the topic worldwide, however the studies focused on how MDR-TB emerges treatment of MDR-TB, the adverse-drug effects of MDR-TB treatment and the prevalence of MDR-TB. During the literature review, the researcher identified a gap in the existing literature with regards to qualitative studies about the experiences of patients with regards to the adverse-drug effects of MDR-TB treatment in the own words. Existing literature simply listed the adverse-drug effects reported and identified in patients; patients are not given the opportunity to relate their own experiences, including challenges they encounter.

2.2 Tuberculosis

Tuberculosis (TB) is a multi-systemic infectious disease caused by mycobacterium tuberculosis that most often affects the lungs. TB is spread from person to person through air. When people with lung TB cough, sneeze or spit, they propel the TB germ into the air. A person needs to inhale only a few of these germs to become infected (WHO, 2011).

About one-third of the world's population has latent TB, which means people, has been infected by TB bacteria but are not (yet) ill with the disease and cannot transmit the disease. When a person develops active disease, the symptoms (cough, night sweats, weight loss, fever etc.) may be mild for months. This can lead to delays in seeking care, and results in transmission of the bacteria to others. People ill with TB can infect up to 10-15 other people through close contact over the course of one year (WHO, 2011).

TB is a global health concern, as it is a major cause of illness and death world-wide especially in low-and middle-income countries where it is accompanied by human immunodeficiency virus/acquired immune deficiency syndrome (HIV/AIDS). About 1.1 million to 1.7 million people die from it each year worldwide (DOH, 2011).

2.3 History of Tuberculosis in South Africa

There is no evidence from South African literature that TB was occurring in South Africa at the time of the arrival of Dutch settlers at the Cape in 1652 (Kanabus, 2016). There are different views though as to whether the disease was occurring in the native population prior to this. Many have held the view that most natives had not been routinely exposed to the disease before and therefor offered little biological resistance to it. This is the theory that the native black people were so called "virgin soil" for TB. However oral history and linguistic studies have suggested that the disease had been occurring among some black people such as the Zulu's although at a very low level. By around the 1860 there had been outbreaks of TB in places like Butterworth and Queenstown, and wherever military, trading or missionary outposts existed. It was in such places that the African population came into close contact with white settlers and began to contract their diseases (Kanabus, 2016).

2.4 Diagnosing Tuberculosis in South Africa

South Africa has a large network of microscopy centers and laboratories with the capacity for culture and drug susceptibility testing using the MGIT liquid culture system (DOH, 2011). In 2011 the Gene-Expert system was introduced as a placement for sputum smear microscopy for diagnosis of pulmonary TB. Between March 2011 and April 2013, more than 1.3 million Genexpert MTB/RIF tests were done which accounted for more than half of the global usage of the system.

However, there have been some difficulties with its implementation, it has not been universally utilized and there has been poor adherence to the algorithm. Ensuring an uninterrupted supply of cartridges remains a challenge as does the reporting of results (Kanabus, 2016).

2.5 The Early Development of Tuberculosis Epidemic in South Africa

It is unclear exactly when TB began to spread to reach epidemic proportions but certainly the period between 1895-1910 seems to be critical in the early development of the epidemic in South Africa (Kanabus, 2016). Black mortality rates in Cape Town rose from 5.5 to 8 per 1,000 between 1896 and 1906. In Port Elizabeth the situation was even worse with rates as high as 15 per 1,000 at the end of the nineteenth century. In the smaller towns of the Western Cape black

deaths rates exceeded 10 per 1,000 while in Cradock and Beaufort West, two of the so called 'resort' towns, rates between 12 and 14 per 1,000 were common during this period (Kanabus, 2016).

2.6 Incidence of Tuberculosis in South Africa

According to the World Health Organization (WHO, 2011), South Africa ranks the third highest in the world in terms of TB burden after India and China. Approximately 1% of the South African population develops TB every year (Kanabus, 2016).

TB continues to be the leading cause of death in South Africa with an estimated 25000 deaths in 2011 (WHO, 2012) and it is the most common infection for the estimated 5.5 million South Africans living with HIV/AIDS (in a national population of some 52.98 million). The rate of HIV is estimated at 73% in all TB cases. The estimated incidence of TB in South Africa is 692 per 100.000 people, a rate that WHO classifies as a serious epidemic (Cramm, Finkenflugel, Moller & Nieboer, 2010).

2.7 Tuberculosis Deaths in 2012 and 2013

According to the World Health Organization (WHO), out of the 450,000 incident cases in South Africa, it is estimated that about 270,000 (60%) people have both HIV and TB infection (Kanabus, 2016). In 2013 TB was the leading cause of death in South Africa with over 40542 deaths notified. These figures exclude deaths from TB and HIV Co-infection which are internationally classified as HIV deaths (WHO, 2015).

Table 1: Deaths occurred in 2012 and 2013

	HIV – People	**HIV+ People**	**Total Deaths**
2013	25000	64000	89000
2012	31000	88000	119000

2.8 Global Tuberculosis Control

In 1994 the World Health Organization (WHO) announced a new strategy, called DOTS (Directly Observed Treatment Short course) for the world wide control of TB. All countries with a TB problem were to provide standardized short course drug treatment to all sputum positive TB patients. Until 2006 DOTS was to be the internationally recommended approach to global TB control. DOTS had five components which were initially as follows:

- Sustained political and financial commitment
- Diagnosis of TB by quality ensured sputum smear microscopy
- Standardized short course anti TB-treatment given under direct and supportive observation
- A regular uninterrupted supply of high quality anti TB drugs
- Standardized recording and reporting

In 1996 WHO claimed that where the health system is working moderately well, the DOTS strategy is effective, achieving cure rates over 90%. However in sub-Saharan Africa TB programs seemingly were not implementing all five parts of the DOTS strategy because it was not very effective (WHO, 2006).

2.9 Challenges to Tuberculosis Control

Tuberculosis remains a formidable threat to human health, despite the availability of effective drugs and treatment regimens. Major obstacles to successful tuberculosis management include long treatment duration, poor adherence, increasing identification of drug-resistance tuberculosis, and concurrent HIV infection (WHO, 2012).

Drugs that have different mechanisms of action are needed to kill the TB bacteria; hence the first line and second line treatment regimens consist of different classes of tablets. The TB bacteria are very persistent, which is why the treatment duration is longer. The above mentioned impacts negatively on patient adherence- patients default treatment and fail to complete the six month period that is required to cure the TB bacteria. It also has a direct impact on the increasing identification of drug-resistance tuberculosis- treatment default results in resistance to one or

more of the first line TB drugs. With concurrent HIV infection, the risk of being infected with the TB disease is estimated to be on an average fifty-fold higher in HIV+ individuals compared to HIV- persons because of the immune suppression of an HIV+ person (Laurenzi, Ginsberg & Spigelman, 2007).

2.10 Multidrug-resistant Tuberculosis

Multi-drug resistant tuberculosis (MDR-TB) is defined as disease due to Mycobacterium tuberculosis that is resistant to isoniazid (H) and rifampicin (R) with or without resistance to other drugs (Prasad, 2005).

After 2011 the number of MDR cases continued to increase by 15,419 and 1,596 patients respectively diagnosed in 2012 (Kanabus, 2016). The treatment success rate for adult MDR remained low at 42% for those diagnosed in 2010. In 2013 there were 10,691 people on treatment for MDR-TB and in 2014 there were 11,500 on treatment. The MDR-TB program has continued to face many challenges: low rates of follow- up of patients, inadequate bed capacity, poor infection control and limited availability of appropriate second-line drugs (Kanabus, 2016).

2.11 Multidrug- resistant Tuberculosis Treatment

According to Caminero (2006), amongst the few drugs available for the treatment of TB, only isoniazid (INH) and rifampicin (RMP) are highly effective. Curing TB patients with resistance to either of these drugs is therefore very difficult. There are discrepancies in the literature when it comes to the management of MDR-TB. It is therefore essential to analyze these discrepancies before developing rational, uniform recommendations. The analysis should encompass the essential and controversial issues regarding the management of MDR-TB patients which include:

- Confirmation of diagnosis in a suspected MDR-TB patient, and determination of the value of drug susceptibility testing
- The number of anti-tuberculosis drugs required to treat MDR-TB
- The most rational use of effective drug against TB
- The advisable length of drug administration or of the initial phase of treatment
- The contribution of surgery to the management of MDR-TB patients

- The optimal regimen for treating MDR-TB: standardized vs individualized regimes. The evidence and controversies regarding each of the above questions are analyzed with the aim of facilitating decision making in the treatment of these complex patients.

Sagwa *et al.* (2011) also reported on the guideline principles for the treatment of drug-resistant tuberculosis by the national tuberculosis program which outlined the following aim for treatment:

- Cure the patient and restore the quality of life and productivity
- Prevent death from active TB or its late effects
- Prevent the recurrence of TB and relapse of the patient
- Reduce the degree of transmission of drug resistance

These guidelines encourage the regular monitoring of patients in order to facilitate the completion of treatment and allow the identification and management of any adverse effects from the anti-TB medicines.

According to Sagwa et al. (2011), there are five groups of anti-TB drugs that are recommended for the treatment of MDR-TB. Anti-tuberculosis drugs in Group 1 are the first line oral agents; Group 2 are injectable agents; Group 3 are fluoroquinolones; Group 4 are oral bacteriostatic second line agents, and Group 5 are agents with an as-yet unclear role in the treatment of TB. In composing a regimen for treating drug-resistant TB, the following basic principles must be adhered to:

- Use any first-line drug that is likely to be effective (Group 1)
- Include aminoglycoside or Capriomycin (Group 2)
- A fluoroquinolone should always be used if deemed likely to be effective (Group 3)
- Use the remaining Group 4 drugs to make a regimen of at least effective agents
- Use Group 5 drugs as needed to make a regimen of at least four effective agents
- The initial phase of second -line therapy should occur in a referral hospital
- All doses of second-line therapy must be directly observed for the entire duration of therapy. Use a common-based DOT approach where possible.

2.12 Adverse-effects of Multidrug-resistant Tuberculosis

The adverse- drug effects associated with MDR-TB treatment have been well described, and play an important role in treatment because they impact regimen choice, medication adherence, and retention in care (Brust, Ning, Bamber, Shah, Van der Merwe, Hea, Moll & Gandhi, 2013). According to Van der Walt et al. (2013), one of the challenges facing patients on second line drugs (SLD) is the toxic nature of these drugs. Second line drugs are frequently associated with high rate of unacceptable drug adverse reactions, needing frequent interruption and change of regimen. Patients often complain of the following adverse effects; rashes, gastrointestinal symptoms (nausea, vomiting, diarrhea), psychotic symptoms (psychosis, anxiety, depression), jaundice, ototoxicity and peripheral neuropathy (Verma &Mahajan, 2007).

According to Brust et al. (2013), the adverse-effects of MDR-TB treatment range from mild to severe. In a study conducted in Kwazulu Natal they reported that adverse-effects were extremely common with 99% reporting at least one adverse effect. The most common were peripheral neuropathy, injection site pain, rash, and nausea/vomiting. The most common severe adverse-effects were psychosis, hearing loss, and peripheral neuropathy.

Nathanson, Turasi, Vink, Jaramillo and Espinal (2004) also reported on the adverse-effects of MDR-TB treatment in the Philippines: nausea/vomiting, diarrhea, dizziness, vertigo and hearing disturbances being the most common adverse-effects.

According to Van der Walt et al. (2013), severe adverse-effects amongst HIV infected patients who are not yet on ART and uninfected patients are similar. Forty percent of the severe adverse-effects experienced are related to decreased hearing, making it the most frequent reported second line related adverse-effect. The second most common adverse-effect is psychotic episodes.

2.13 Recommendations on Moving Forward

To combat tuberculosis, new drugs and regimens are needed that can shorten treatment, manage MDR and XDR tuberculosis without frequency of intolerance and adverse-effects seen with existing regimens, and be used for patients with HIV without interaction or the need to adjust dosing in the tuberculosis regimen or treatment therapy. It is also very important to gain insight into the views of people regarding TB, especially among high risk populations. Achieving a high

level of TB awareness is critical for the success of prevention and treatment efforts in high risk populations (Cramm, Finkenflugel, Moller & Nieboer, 2010). There need to be active outreach campaigns that will continuously raise awareness and educate communities on TB, emphasize to how to identify symptoms of TB in order to allow for early detection. Mobile clinics are needed to target high risk populations, bring the service to the people and do TB screenings and sputum tests. The initiative might exist in some areas but not nearly enough, as some high risk areas are still not covered. So it is up to the government to prioritize and provide resources that are needed to fight the struggle against TB (Verve et al, 2004).

2.14 Summary

There appears to be little literature with regards to studies that have been conducted to look at the social impact of MDR-TB treatment on patients. Studies that have been done have looked at the social impact of TB with regards to patients, communities and the health care workers. A study was conducted in Thailand that explored how TB is perceived or experienced (Sengupta et al, 2006). The study revealed that stigma was the notion that caused TB patients to be more secretive and prevented them from advocating for their health care. There is a wide and extensive literature pertaining to TB and MDR-TB in South Africa, enough to give a better understanding of its origin, statistics, challenges and developments. MDR-TB is still a threatening disease that needs constant work and attention. Hence this research aimed to explore a different angle that has not yet been extensively exposed. There is a big gap in literature when it comes to research done focusing on what patients experience and how they cope with the adverse effects of MDR-TB treatment. Getting to understand the struggles and challenges that patients experience will help to implement better management and support structures that will assist patients to cope better and successfully manage the disease and decrease the burden of TB in South Africa.

CHAPTER THREE

Methodology

3.1 Introduction

This chapter presents the methodology of this research study; which is the steps and procedures employed in this study. The following will be discussed: qualitative approach, study design, research setting, study population, sampling, data collection, pilot interviews, and data analysis.

3.2 Qualitative Approach

The research process for qualitative research is emergent, as the key behind qualitative research is to learn about the problem or issues from participants, and to explore the research to obtain the information (Creswell, 2013).

This approach allowed the researcher to have a deep understanding and vivid description of the exploration of the experiences of patient with the adverse effects of MDR-TB treatment from their own perspective. Hence the participants were given the opportunity to describe their experiences in their own words; this way the researcher was able to generate rich, detailed information.

3.3 Study Design

In this study a descriptive qualitative approach was used to explore the experiences of patients with regards to the adverse-drug effects of MDR-TB treatment. A qualitative research methodology is defined as a systematic, subjective approach used to describe life experiences and offer them meaning (Burns & Grove, 2009). It allows the researcher to be close to the study subjects, and as a result in-depth information is obtained. This type of research aims to study people in a natural, social setting and collects naturally occurring data (Burns & Grove, 2009; Brink, 2006).

According to Lambert, (2012) basic fundamental qualitative descriptive design is a valuable method. It is less interpretive than an "interpretive description" approach because it does not require the researcher to move as far from or into the data; and, does not require a conceptual or highly abstract rendering of the data, compared to other qualitative designs.

Qualitative descriptive studies are least "theoretical". The goal of qualitative descriptive studies is a comprehensive summary, in everyday terms, of specific events experienced by individuals or group of individuals. Qualitative descriptive studies tend to draw from naturalistic inquiry, which purports a commitment to studying something in its natural state to the extent that it is possible within the context of the research arena. Thus there is no pre-selection of study variables, no manipulation of variables and no prior commitment to any one theoretical view of a target phenomenon. This approach is very useful when the researcher wants to know, regarding events, who were involved, what was involved, and where things took place (Magerman, 2015).

The inquiries are based on direct description from (or observations of) the people who have experienced the phenomenon. Data are most often derived from loosely structured interviews. Qualitative descriptive designs tend to be eclectic methodologically and are based on the general premises of constructive inquiry (Elliot & Timulak, 2005).

The main purposes of this type of research are to describe, offer explanations and then test or validate those explanations. Many research studies call for the description of natural or man-made phenomena such as their form, structure, activity, and change over time, relation to other phenomena and so on. The description often illuminates knowledge that we might not otherwise notice or even encounter. Several important scientific discoveries as well as anthropological information about events outside of our common experiences have resulted from making such descriptions (Lambert, 2012).

This study design was chosen for this study because it enabled the researcher to illuminate knowledge that was not known about the experiences of patients with the adverse effects of MDR-TB treatment. The interviews were loosely structured which enabled the participants to share what ever details about their experiences that they wished to.

3.4 Description of Research Setting

The research setting refers to the place where the data is collected (Grove, Burns & Gray, 2012). This study was conducted in a clinic facility which is situated in the middle of the informal settlement of Samora Machel (Philippi/Mitchell's Plain). There is a section of the area that has brick houses with running water supply and sanitation but 80% of the area consists of shacks with running water and bucket system for sanitation. There is easy transport access and

convenient shops around. The facility accommodates patients from infants to adults, and renders more than six health services: Child health, TB management of adults and children, adult and child management of HIV, PMTCT, immunisation of children and basic antenatal care. It comprises of a total of 20 nursing staff, 1 doctor on a daily basis, 2 pharmacists and 3 counsellors. Operating hours are from 08h00-16h30 Monday-Friday.

3.5 Study Population

According to Roscoe (1969, cited in Mouton, 2002), a study population is a collection of objects, events or individuals, having common characteristics that the researcher is interested in studying. In this research, the study population consisted of all MDR-TB patients who were on MDR-TB treatment at the facility; from patients who had started treatment from April 2015 to April 2016. There were no exclusions for this study; all MDR-TB patients who were on treatment were included in the study (Magerman, 2015).

3.6 Sampling

Purposive sampling was used in this study. Purposive sampling means that the inquirer selects individuals and sites for the study because they can purposefully inform an understanding of the research problem and central phenomenon in the study (Creswell, 2013). Purposive sampling refers to the selection of participants for the purpose of describing an experience in which they had participated (Lincoln &Guba, 1985). In this study, individuals, who provide information to the researcher about their experiences, are called participants throughout the study (Polit, Beck & Hungler, 2001).

The researcher selected a number of appropriate participants (12), who were able to give rich and appropriate information about their experiences (Silverman, 2000). The researcher used a purposive sampling method because of its suitability in a qualitative investigation where the focus is on studying a small number of individuals (Patton, 2007). The researcher then proceeded to select the names of the participants from the list of all MDR-TB patients recorded at the facility through the Premise database with the help of the facility data capturer.

The study sample consisted of 12 participants, however the researcher reached saturation after 10 participants as no new information emerged from the interviews.

3.7 Data Collection

The data for the purpose of this study was collected through the use of in-depth interviews. An in-depth interview is a conversation with the intent to obtain answers to questions and not to evaluate or to test hypotheses (De Vos, Strydom, Fouche & Delport, 2007).The basis of an in-depth interview is an interest in understanding the experiences of other people and the meaning they attach to those experiences (Abubu, 2010). Using in-depth interviews for this research study enabled the researcher to get rich information and deep understating of the experiences of patients with the adverse effects of MDR-TB treatment.

Permission to interview the MDR-TB patients at the facility under study was granted by the relevant university structures. The manager of the clinic was approached by the researcher to gain access to the MDR-TB patients. The researcher was informed by the Sister in Charge at the TB section of the times that the patients start to arrive at the clinic for their medication. The researcher obtained permission from the Sister in Charge to be present for at least two days, from morning until the afternoon when patients come to the clinic for their medication. It is during that time, that the researcher was able to inform the patients about the study.

The researcher handed out copies of the information sheet to all the MDR-TB patients present. The contact details of the researcher were included on the information sheet so that the participants would be able to contact the researcher at any point should the need arise. The researcher also accessed the contact details of all the MDR-TB patients from the TB Sister, in order for the researcher to contact the patients, should the need be.

The researcher received the first response from two patients on that day. Appointments for interviews were arranged according the patient's suitable times. Names of the participants and their contact details were compiled in the researcher's note book. The names were ticked off in the book by the researcher after each participant's interview and of those who later decided to retract from participating in the study.

The researcher experienced a challenge whereby two of the participants who had already agreed to participate on the study, were referred to the tertiary hospital for admissions just before the scheduled dates of the interviews. The researcher had to find other volunteers and it was not a quick process to replace the volunteers.

Data was collected by the researcher by means of in-depth interviews. Collecting the data allowed the researcher to gain first-hand knowledge of the experiences shared by the participants. Conducting in-depth interviews also allowed the researcher to gain an inside perspective into the life and world experienced by each participant individually. The researcher also used the opportunity to observe the participants closely during the interview process, for non-verbal communication as well. Data saturation was reached after 10 interviews were conducted.

Pilot Interviews

The first two interviews were used as pilot interviews. The purpose of the pilot interviews was to test the ability of the researcher, to conduct an accurate in-depth interview with the sample of participants who was purposefully selected to participate in the research study. The researcher had five questions that were formulated as the 'interview guide questions" for this study. The questions were formulated in such a way that they will address the research question for this particular study. The first question asked to the participants was an open-ended question; which was sort of an introductory question. This question aimed to ensure that the participant speaks freely. The second question was a follow-up question which aimed to get more information from the participant's previous answer. The next questions that followed were probing and structured questions, which aimed to gain further information and to ensure that arears that are relevant to the research question are covered.

No changes were made on the interview guide questions after the pilot interviews. The amount of information that was obtained from the two pilot interviews was enough to give an indication that sufficient data will be obtained from the questions asked. The two pilot interviews formed part of the actual study.

Conducting In-depth Interviews

The in-depth interviews were conducted at a date and time which was convenient to the participants, the same venue was deemed convenient for all participants because it is where they all receive their MDR-TB treatment so all interviews were conducted at the facility under study. All interviews were conducted in Xhosa, as it was the primary language used in the community; except for one interview in which the participant preferred to speak English.

The researcher was allocated a private room at the facility for each interview. During each interview, the researcher prepared a bottle of still water for the participant and a box of tissues. The researcher made use of an audio tape recorder to record the interviews and notes were taken by the researcher during this time to capture important details. Audio tapes were number coded as (Participant 01, 02 etc.) to ensure the anonymity of the data so that the data could not be traced back to the name of the participant.

The researcher observed a similar trend in the non-verbal communication amongst most of the participants; their energy levels were down- and they looked lethargic. This was observed when they approached the room walking very slowly, taking long pauses when responding to questions and pulling facial expression of pain now and again when sitting.

At the start of the interview all participants were asked the question "What is your experience of the adverse-drug effects of MDR-TB treatment?" this open-ended question as well as many other probing questions such as, "How has your life changed since the start of MDR-TB treatment?" were used by the researcher during the interview process to help participants to share how they were experiencing the adverse-drug effects of MDR-TB treatment. The in-depth interview of patients continued until data saturation was reached.

Reflective summaries were written by the researcher after each interview and were submitted to the researcher's supervisor. The (12) interviews were conducted between 04 April and 20 June 2016.

3.8 Data Analysis

Analysing data usually involves two steps: firstly, reduce the wealth of data collected or available, into manageable proportions; and secondly, identify patterns and themes in the data (Mouton, 2002). The process of data analysis in qualitative research, according to Creswell (2013), involves organising the data, conducting a preliminary read-through of the data base, coding and organising themes, representing the data, and forming an interpretation of them. The researcher used Tesch's method of phenomenological data analysis (1990, cited in Babbie &Mouton, 2014). While there is no neat and tidy approach to qualitative data analysis, nor even one approach to each specific type of qualitative data analysis, Tesch's method does provide a

particularly useful structure, through which some order of qualitative data analysis types may be created (Babbie & Mouton, 2014).

The researcher first listened to the audio recordings of the in-depth interviews more than once. The first audio recording was transcribed by the researcher and sent to the researcher's supervisor for verification then the researcher continued the process for the rest of the in-depth interviews. Recorded interviews with the participants were transcribed verbatim (word for word). Soon after data collection was completed, the researcher went back to each participant and handed them a copy of the transcript for verification to whether their words were captured exactly the way they wanted. This was done by visiting the participant's homes after hours, with the assistance of the MDR-TB counsellor of the clinic who accompanied the researcher. The researcher was not able to reach all 12 participants during the first visit, only after two days was the researcher able to reach all participants.

The researcher advised the participants to contact her if there is any corrections that needed to be made on the transcripts, there were no participants that came forward so no changes were made on the original transcripts.

The transcript was analysed by both the researcher and the researcher's supervisor, in order for the researcher to have a clear understanding of the analysis process of qualitative data. The entire analysis process was done in continuous consultation with the researcher's supervisor. The researcher started analysing the data by carefully reading through all the transcripts, in order to gain a sense of the whole. The transcripts were then organized into piles, from the first interview at the top and the last interview at the bottom. While reading through the transcripts, the researcher started jotting down emerging thoughts in the margin of the transcript paper to assist in finding meaning to the information read. This process was repeated until all the transcripts were meaningfully read by the researcher.

A list of all topics that emerged from the information in the transcripts was compiled and similar topics were clustered together. The topics were formulated into a list of columns and taken back to the transcripts. The topics were then abbreviated as codes which were written next to the segment of the text. This was done by the researcher to explore the new categories and themes that might emerge from the data. The complete lists of categories as well as the transcripts were

read several times again in order to group topics that relate to each other. A final decision was made on the themes, codes and description of codes in consultation with the researcher's supervisor (Magerman, 2015).

3.9 Rigour

Brink et al (2012) define rigour as openness, relevance, epistemological and methodological congruence, thoroughness in data collection and data analysis process and researchers understanding. Burns and Grove (2011) support the idea that the researcher needs to be willing to let goof preconceived ideas and judgements about the phenomenon or the participants and participate with openness in the research (Siganga, 2013). The researcher used to work as a professional nurse at the facility where this research study took place and has managed MDR-TB patients before. The researcher thus attempted to put aside any ideas/knowledge about MDR-TB which might influence the study, and approached the participants with an open mind about their experiences.

Conformability

Brink, *et al* (2012) describes conformability as a guarantee that the findings, conclusions and recommendations are supported by the data and there is internal agreement between the investigator's interpretation and actual evidence. The documented procedure rechecking data can indicate the conformability of this study. The transcripts were read more than once and copies were distributed to the participants to verify that the information was captured accurately (Singanga, 2013).

Dependability

To ensure the accuracy of the study, Lincoln and Guba (1985) suggest that an audit trail be kept. An inquiry must also provide its audiences with evidence that if it were to be repeated with the same or similar respondents (subjects), in the same or a similar context, its findings would be similar (Babbie & Mouton, 2014).

During this study the researcher and the supervisor did the co-coding to minimise chances of biasness during the analysis process of data. The researcher was able to make use of field notes

during the interview process, and specifically recorded entries, based on the interviews as soon as was possible after the conduction of each interview.

Credibility

Credibility ensures that there is consistency between participant's views and researcher's interpretation of their views (Rayan, Coughlan & Cronin, 2007). Credibility in this study was obtained by returning to the participants soon after data collection was completed, they were each given a copy of the transcripts to verify whether their words were captured according to how they pronounced them.

Transferability

According to Rayan et al. (2007) transferability refers to whether the study findings can be applied outside the context where the study was undertaken. The findings of this study can be applicable to similar participants. The researcher provided detailed description of the study setting (See 3.4), to allow the readers to have a proper understanding of it.

3.10 Ethics Considerations

Permission to conduct interviews with the MDR patients in Weltevreden Valley Clinic was granted by the relevant university structures.

Ethical approval was obtained from the University of the Western Cape (UWC) Research ethics committee (Appendix D). During this study, the researcher was fully aware of the rights of the participants and fully respected and protected them by adhering to the following:

Consent: The participants were given adequate information pertaining to the study to make sure that they were fully aware of their right to consent or decline participation freely.

Confidentiality and Anonymity:

The researcher ensured that the information shared by the participants is kept in a safe place and can only be accessed by only the researcher and the supervisor and not discussed with anyone and this included all audio tape recordings, transcripts, researcher's reflective notes, which will be kept for five years after which they will be destroyed. The researcher made use of codes for participants, to protect their anonymity; the codes were also used as identification tools on the

transcripts. The researcher also made sure that all identifiable information was removed from the transcripts.

Autonomy: The participants had a choice to withdraw from the research study at any given moment without fear of prejudice.

3.11 Conclusion

This chapter discussed the research method used during this study. The researcher made use of the qualitative approach with a descriptive type to explore the experiences of the participants. In-depth interviews were used to allow participants the opportunity to share their experiences.

CHAPTER FOUR

Findings and Discussion

4.1 Introduction

This chapter presents the findings of this study which aimed to explore the experiences of patients with the adverse effects of MDR-TB treatment in a primary health care facility in the Western Cape .The following will be discussed; Description of participants, themes that emerged from the analysis,

4.2 Description of Participants

The participant's ages ranged between 21 and 58 years old. There were (9) females and (3) males. Only 3 female participants out of the 9 were married, the 3 male participants were all single. Only 4 participants out of the 12 have completed matric; there was no participant with a professional qualification. 1 participant was still in high school, 1 participant was self-employed (Has a hair-salon business), 6 participants had informal jobs and 4 participants were unemployed. There was a wide gender composition because there were more female MDR-TB patients on treatment in the clinic at the time the study was introduced in the facility, most of the participants that voluntarily agreed to join the study were females.

Duration on treatment ranged between (1) month and (18) months. The participant's expressed themselves very uniquely in their responses and direct quotes were used to elicit the meanings that they ascribed to their experiences of the adverse-drug effects of MDR-TB treatment. The body language (non-verbal communication) of the participants was also illustrated on the transcripts. The results are presented as themes and codes with their related descriptions. The participant's experiences ranged from experiences to perspectives on the health care services.

4.3 Themes and codes

Eight themes and fourteen codes emerged during data analysis of this study. They are illustrated in the table below with description of all fourteen codes.

Table 2: Themes, Codes and Description of Codes

THEME	CODES	DESCRIPTION OF CODES
Incorrect and late diagnosis	**Misdiagnosis**	Clients started on the incorrect treatment regimen; given normal TB treatment instead of MDR-TB treatment leading to clinical deterioration.
	Late diagnosis	Inability to pick up early signs of TB by patients, leading to delayed start of treatment and high risk of infecting others i.e. family members.
Co-infection causing increased burden of medication	**Dual treatment**	Patients who are dually infected; having MDR-TB and being HIV positive have to receive treatment for both illnesses at the same time.
	Increased anxiety	The large amount of tablets that patients have to take on daily basis makes them anxious because of increased adverse-effects with both medications combined.
Inability to function properly	**Personal hygiene**	Patients reporting that they lack energy to get up and bath in the mornings.

	Mobility	Patients find it difficult to move around the house and do daily house chores
Life adjustments	**Losing jobs**	Patients lost their jobs because they were put off work while on treatment.
	Moving close to family	Those that were staying alone had to move close to family members while sick.
Social challenges	**Social Grant**	Patients found it very hard to survive on the social grant money. It is not sufficient to cover all their financial responsibilities as many of them are breadwinners
	Discrimination	Patients received negative remarks from their communities; people gossiped and it made it difficult for them to show their faces in to the public.

	Disconnect	Those that were in relationships reported that there was a change within their relationships. They drifted from their significant others; this was validated by the lack of intimacy.
Adverse-Effects	**Different Adverse-Effects**	Hearing loss Nausea Vomiting Increased appetite Fatigue Dizziness Burning feet Brain freeze
Little time for doctor consultation	**Clinic under staffed**	Patients complain that they don't get enough time during doctor consultation and they are unable to ask all the questions they wish to ask. The doctor has to see more than 20 people per day.
Wanting to recover	**Motivation**	Patients described this experience as one of the toughest experiences. They have endured and persevered because they want to recover completely and regaining their independency is the motivation for all.

Theme 1: Incorrect and Late Diagnosis

Misdiagnosis

Diagnosis of MDR-TB is done through a laboratory confirmation of sputum results of a patient; sensitivity tests are performed. In those results, it is then possible to see which first line TB drugs the patient is resistant to. Any discrepancy in this process might result in an incorrect diagnosis, which was a common factor for some of the participants in this study. Participants were started on the normal TB treatment instead of MDR-TB treatment and were later changed to the correct treatment. The participants shared briefly information regarding what had happened. A study was done in one of the American hospital in Los Angeles regarding the incorrect diagnosis of MDR-TB patients.

The study results showed that pulmonary MDR-TB was misdiagnosed in 9 (13%) of 70 patients. Reasons why the diagnosis appeared to be erroneous was the growth of MDR-TB from an old tuberculous lesion in a patient who was never treated for TB and whose diagnosis predated anti-TB drugs (1 case), documented contamination with mycobacterium avium complex (1 case), suspected specimen mislabelling (1 case), successful treatment using drugs to which the isolate was reportedly resistant (4 cases), discrepant susceptibility tests results on additional specimens submitted by the patient (2 cases) and no clinical evidence of TB (3 cases). The study concluded that susceptibility results alone are not enough to dictate treatment and careful clinical correct actions is necessary in making the diagnosis of MDR-TB

> *P01…. "For the first three to four months I was on the wrong treatment, I didn't even know I had MDR…. But like I was saying, I was taking the treatment but nothing happened… I kept on losing weight, kept on throwing up food…. So I went to the doctor, turned out I had double pneumonia…. But even then, they couldn't pick up that I had MDR…"*

The participant expressed a feeling of disappointment on the lack of counselling she received prior the change of her treatment.

P01… "I was in Kimberly at that stage… when I came back; they told me that I have MDR… So now I had to go on this injection which was never explained to me… I had to take about eighteen to twenty pills a day, where I'm used to just three pills…."

P04 "I treatment ye TB ndiy'qale e Joburg, but u MDR yena ndimqale e Eastern Cape… Ndifumaniswe e Eastern Cape uba ndino MDR…. I Joburg yona ibindifumanise uba ndine TB le I normal… Ndiye ndabuyela e Eastern Cape after two months, ndabe ndisagula ndingekabi bhetele…. I clinic yase Eastern Cape yandithumela esibhedlele e monti ba bandijonge yintoni erongo… Pha ndiphinde ndakhohleliswa futhi and u qgirha wabe esithi xa ejonga yena andikhangeleki ngathi ndingumntu okwi treatment at all…. So ku after ndibuye e monti apho ndiye ndacacelwa khona uba kahle-kahle ndino MDR…"

[I started Normal TB treatment in Joburg and started MDR treatment in Eastern Cape; they discovered it in Eastern Cape that I have MDR-TB….I was in Joburg, after two months I went back to Eastern Cape… I was still very sick; the clinic in Eastern Cape referred me to East London Hospital to check what is wrong with me… The Doctor told me that there is no progress at all, they took sputum again and found out that I actually have MDR-TB…]

Late diagnosis

Late diagnosis can impact negatively on the prognosis. In the information that the participants shared with regards to their experiences with the adverse-drug effects of MDR-TB treatment, there was evidence of late diagnosis. The reason for this appeared to be the lack of ability to pick up early symptoms of TB. Because of this, some of them started the treatment at a very sick stage. According to the National Department of Health (NDoH) guidelines, patients diagnosed with MDR-TB must be referred to a specialised treatment centre for effective therapy (Narasimooloo & Ross, 2012).

A study was conducted in a specialised MDR-TB treatment centre in Kwazulu-Natal to assess the delay in initiation of MDR-TB treatment. Of all the patients, 75% referred showed a mean delay of 12.4 weeks from the date of sputum collection for culture and drug sensitivity testing to

the start of treatment. Most patients were symptomatic for TB and HIV-Positive (Narasimooloo & Ross, 2012).

Here is what some of the participants shared in this study:

> *P02… "Bendiva ba ikhona into erongo but ndingayazi ba yintoni… So ndizixelelala ba hay'maan ndode ndibe right…. Ndiye ndiba weak and ndaluza ne weight kakhulu… By the time ndiya e clinic… Besendi rongo kakhulu… Xandizijonga espilini ndingenotsho ban dim lo… Kanti all along ibizimpawu ze TB eziya but mna bendingazazi…"*
>
> *[I was so ignorant… I knew that I was not feeling well but I didn't pay attention because I didn't think it was anything serious…. I became worse over time and started to lose weight… By the time I went to the clinic I couldn't even recognise myself… All along those were TB symptoms that I was experiencing but I didn't know that…]*
>
> *P03… "Inqgele ibibuzwa apha kum, bendisoloko ndigodola but ndiphinde ndibile ngoku…. Bendifumbela noba kuyatshisa kasendigodola, abantu bade bakhuze…. Bendingalali ebusuku lukhohlokhohlo but all along mna bendizihlalela endlini, ndingayazi ba yi TB le… Ndade ndazincama ngoku sendibona ba ha a, ndiya ndiba weak…. Ndafika nyhani e clinic, first thing abandithumela kuyo ku tshekitsha I HIV than yafumaneka pha uba ndinayo then ndayo tshekisha kengoku kwicala le TB… Ndaxelelwa ke napha ba ndino MDR…"*
>
> *[I felt that something was wrong with me but I couldn't tell what it was… I had fever and chills, coughing all night…. I would wear layers and layers of clothing even when it's hot outside… I just told myself that I am going to get better over time but I got worse…. People suspected that I had TB because I had lost too much weight too… When I finally decided to go to the clinic I was already weak… They tested me for TB and told me that I have MDR-TB…]*

One of the participant's delayed diagnosis also resulted in his child being infected. When he finally went to the clinic; the whole family had to be screened and that is how the child was also diagnosed. He expressed how guilty that makes him feel.

P02…"Nomntana wam uye wa affected yi TB…. Uyiqale i treatment kwa early and uyakwazi notya and usemandleni. Zinto ezinje ezindenza uba ndibenomva ndedwa ixesha elininzi…"

[My daughter also got affected with TB but luckily for her she started treatment on time… She is not that weak… I will never forgive myself for that… I am the reason she got infected too…]

Theme 2: Co- infection causing increased burden of medication

Co- infection means that a person is living with more than one infection at a time. Most of the participants are MDR and HIV infected; they are on both MDR-TB treatment and Anti-retroviral treatment. Both TB and HIV/AIDS global pandemics are volatile and still evolving, particularly at the points of their intersection. The harmful interaction of TB and HIV/AIDS has added greatly to the suffering and loss of life caused by each pandemic. Together, the diseases expose underlying weakness in public health and social systems (Frieland et al, 2007). Participants in this study shared information about their HIV status.

P01… "This experience has taught me how to be strong and responsible in life, because I am on two different treatments now…. I am on ARV's as well, so I have to look after my health now and take my treatment…"

P02… "Si positive sobayi two nomama womntanam Sr, sitya e ARV's… Sinomntana omcinci so andifuna a safarishe yabo…

[We are both positive; me and the mother of my child, we are on ARV's… We have a small child together and I don't want our daughter to suffer…]

P03… "Ndaya e clinic, first thing abandithumela kuyo kuyo tshekisha I HIV… Ndafumaniseka uba ndinayo…. Nditya lo MDR ne ARV's kengoku but kezona ndizitya ebusuku kuphela…"

[I went to the clinic; they sent me to test for HIV… They results showed that I am HIV positive… So I am both on MDR-TB and ARV treatment…]

P06… "Yabona wena Sr, apha emini ndiyayazi ba nditya ezi zika MDR then kengoku pha late nditye… Kukho nezi ze HIV, nditya zona ke pha late…"

[You see Sr, in the afternoon I take the MDR treatment then in the evenings I take the treatment for HIV... I am on both treatments…]

Dual Treatment

Dual treatment is taking two different medications at the same time as elicited in the *'Co-infection theme'*. Participants mentioned that they sometimes forget to keep track of all the pills that they are supposed to take every day. It appeared that participants who have been on MDR-TB treatment for more than a month; they are given their medication by the nurses but have a choice whether they want to take them instantly or take it home with them.

P04…. "Kanene kubakhona ezi zase mini, kuphinde kubekho ezi zasebusuku and ziphinde zidibane ne ARV's ezi za late…. Yhoo! Zininzi maan, sometimes use ube confused ulibale nozithathileyo or ongazithathanga…."

[There are those that you take in the mornings, then there are those that you take in the evenings and you add the ARV's in the evenings… Yhoo! They are a lot… Sometimes I forget which ones I took and which ones I haven't…]

P06…. "Kukhona ezi yellow, kukhona ezibomvu… Maninzi, zii ndidi nge ndidi… Kangangoba ndikhe ndenza impazamo apha ezintsukwini…. Ndalibala utya ezi ze HIV za late…"

[There is yellow and red pills……they are so many, different types…. Sometimes I even mistake them and forget to take the ones for HIV…]

P04… "Yabona mna, ndiyazohlula xandizitya so that ndingabhideki… elinye iqaqubana ndilithatha ekuseni, elinye ebusuku…. Kuba zininzi sometimes ungabhideka… And iyanceda uba zingakugulisi kakhulu xa uzohlula"

[What I do is that I separate them… some I take in the mornings and some I take in the evenings with the ARV's, so that I don't get confused… And it helps to minimize the side-effects as well when you separate them…]

Increased anxiety

Although highly effective therapy exists for both HIV and TB, concomitant administration is fraught with difficulties. Problems arise when giving these therapies concomitantly and many physicians delay highly antiretroviral therapy (HAART) for two or more months to minimize the risk of toxic side-effects (Dean et al, 2002). Participants in this study expressed that the combination of MDR-TB treatment and ARV'S give rise to the level of anxiety because the two medications combined has increased adverse-effects which makes them very nervous and scared to take their medication most of the time. Here is what some of the participants had to say:

Theme 3: Ability to function optimally

Participants shared that their ability to function optimally has been enormously affected since the start of treatment. There are two things that came up: Hygiene and Mobility.

Hygiene

Participants mentioned amongst the difficulties that taking a bath requires an amount of effort, they either have to ask a family member to assist or have to go on the whole day without a bath.

P02… "The funny thing is that…. You can't even do the simplest things which you took for granted before… Your whole body is sore; you just want to lie down on your stomach on something cold… You can't even bath…"

P04… "Kubakho ixesha loba ungakwazi nothini… awukwazi novuka apha ebhedini uhlambe isiqu esi sakho…"

[Sometimes I can't even do anything….I can't even wake up and bath myself…]

P06…. "Andisakhono nozenzela nto…. Kunzima nokuthini Sr…. nditsho novuka oku kusasa uvase xa uzoya e clinic… Uthatha ixesha ngoba alok umzimba awuvumi…"

[I can't even do anything on my own anymore… It's always a mission to get things done, even waking up in the mornings to bath; I have to take time because my body feels very strange…]

Mobility

The participants shared information on how they struggled to move around and to perform daily chores:

P01… "You can't walk; you just want to sleep the whole day… I couldn't do anything around the house…"

P06… "Ndincedwa ngumntana pha endlini…. If kufuneka kuphekiwe, nguye ophekayo… Hayi apheke ke torhwana andiphakele…"

[My grandchild is the one who helps me… If I need to cook, she will do the cooking for me; she cooks and dishes out for me….]

P09…. "Kunzima because xandiqgibozisela, kufuneka ndilale ndingenzi kwanto…. Akhonto endiphinde ndikwazi uyenza apha endlini

[It's difficult because after I have taken the medication, I need to sleep for a few hours… I am not able to do anything after that….]

P10… "Zikhoona izinto endingakwazi uzenza ngoku pha endlini… Ndiyadinwayabo.. Ekuseni ndivuka ndi fresh, ndipheke I parish nditye…. Kodwa pha, xandiqgibosela ezipilisi…

Ndiyayoba…. Ndingakwazi nokuthini

[There are things that I am struggling to do around the house… I am always lethargic… I wake up in the mornings and manage to cook myself some porridge then I go take the medication… After that, my body totally shuts down… I am not able to do anything….]

Theme 4: Life Adjustments

This theme refers to the changes that took place in the lives of these participants since they started on MDR-TB treatment. The participants reported that they lost their jobs, moved close to family members and relied on social grant.

Job Loss

Participants reported to have lost their jobs. When patients are diagnosed with MDR-TB, they embark on a 2 year treatment journey which involves very close monitoring and frequent visits to the clinic at least for the first six months. At least that is what should be happening even though that might not always be the case. It is also preferable that the patient is booked off from work until culture conversion; meaning they are no longer infectious and also allowing the patient to adapt to the treatment.

Unfortunately some work places to do not accommodate provision for employees to stay absent from work for a very long time, hence most of the participants were released from their duties by their employers and some simply had to quit; participants shared information with regards to that.

P01… "I had to quit work, because I was on the injection now when I first started and I took the injection for six months…"

There was a clear sign of frustration as the participants shared the details of losing their jobs

P02… "Andifuni ukuxokisela… Ungandithathangomso siye pha emsebenzini… I contract yam after ndiyofaka laleta ye grant echaza into yokuba ndine TB… Ivele ya terminatethwa… Umsebenzi ngoku andinawo at all…"

[I don't want to lie to you… We can even go to where I work tomorrow… My contract was terminated after I took the grant letter that specified that I have TB… I no longer have a job right now…]

P03… "Umsebenzi wam mna Sr ibikuqhuba e heist, la machine inkulu yosebenza pha phandle… Ndithe ndawuqala ugula nda strugglisha uyiqhuba yabo, ngoba andina power… Ngoku bavele bandixelela pha emsebenzini ba makhe ndiyeke, ngoba andikho fit anymore for lomsebenzi…"

[My job was to drive heist, that big machine that you drive in contraction sites… When I got sick, I couldn't drive it anymore because I don't have power… My employers told me to rather stop working because as they see it, I am no longer fit for this type of job…]

P10… "Bendingekho permanent emsebenzini, so ndithe ndisogula ndayekiwsa…"

[I was not permanent at work, so when I got sick…. I lost my job…]

P11... "Andiyazi nangoku emsebenzini ba kuzokwenzeka ntoni because ndisebenzela e private campany…. Ndikhe ndathetha-thethana ne managers' zam… Ingathi bebendibhatha okokuqgibela kulenyanga… Then kule izayo, akhothemba loba ndizobe ndisaqhubeleka nosebenzela phaya…"

[I am not sure what's going to happen to my job…. I work for a private company… The last time I spoke with my managers, they told me that they are probably paying me for the last month now… they don't want me to continue with work…]

Moving close to family members

Participants reported that this is not something that one can cope with alone; they emphasized the importance of 'family support'. Those that were living alone reported that they had to move close to family members during this time

P02… "Yabona ngoku, ndihlala nomninawa wam ngoku ndigulayo…"

[I am now staying with my brother]

P12… "Ndithe ugula kwam, ndabuyela ekhaya so that umama akwazi undinakekela…"

[I moved back home when I got sick, so that my mom can be able to take care of me…]

It was not a smooth change for some participants. One participant shared that it was not easy for him to stay with his family. He preferred being alone, but because of his condition he didn't have a choice.

P03… "Kuye kwanyanzeleka ndizohlala nomalume wam… Ungumntu otshatileyo, zikhona ezazinto ufumanise uba kukho e query ekhoyo… Umamekhaya kunento ezithile azithethelayo, yabona moss into ze family zibanjani…. So aphethe naye ehlisa unyawo even though efuna undinceda…"

[I had to go and stay with my uncle… He is married and his wife had a problem with me being there, she would have certain query's…. You know moss how it goes with married people…. So it is difficult for my uncle to help me the way he wishes to…]

Theme 5: Social Challenges

MDR-TB patients are often faced with various social challenges. Stigma is a complex social construct that can be perceived and /or experienced, and has been documented in many countries. Felt and experienced stigma has been linked to negative patient experience in different social

settings (Sengupta et al, 2006). One of the social challenges expressed by the participants in this study was the following:

Social Grant

MDR-TB has a huge adverse economic impact on patients due to the long duration and complexity of treatment. The socioeconomic barriers include inaccessibility of treatment, distance, transport costs incurred during hospitalisation and reduction in salary due to absenteeism (Thomas et al, 2016).

The government makes provision for people who are on TB treatment to apply for temporary social grants for the period that they are on treatment. The treating doctor has to make a recommendation based on the medical diagnosis of the patient and SASSA follows up the process and either approves or declines it; based on their own assessment. This was rather a challenging adjustment for the participants who had to now depend solely on the social grant after having lost their jobs; they reported it was not enough to sustain their families as a number of them are breadwinners.

> *P01… "For now I am dependant on the government grant, where 'as I'm used to getting a certain amount of money.... I don't have any children but I am still the breadwinner at home… I provide for my family because my mom doesn't get paid a lot of money where she works, so I cover most of the things…"*
>
> *P02… "Le amli ndiyifumanayo ye grant ayikho enough… Kufuneka ndithenga izinto zomntana, funeka ndi grosalile, ndibhatale I rent, ndithumele imali ekhaya… Sibayi six kumama wam, ndim omdala… Umama uphila ngothengisa ama apile estratweni…"*
>
> *[The grant money is not enough… I have to support my child, buy groceries, pay rent, send money home… I am the eldest of six children… My mother sells fruit in the streets to make a living…]*
>
> *P11… "Ndim ndedwa umntu ophangelayo ekhaya… Ndine loan e bank, ndine family ekufuneka ndiyi sapotile… Azikwazeki ukwenzeka zonke ezinto ngale mali ye grant…"*

[I am the only one who is working at home… I have loans that I need to pay, family to support… I am not able to cover all that with the grant money…]

Discrimination

Participants shared that they felt judged, treated unfairly by neighbours, church members etc.

P02… "Ufumanisa uba abantu apha ekuhlaleni bayathetha yabo… Noba uya e clinic kukhonjwana ngawe and abantu noba uthetha nabo ingasekhe unxibe I mask oko kubo…"

[You find people gossiping about you… When you go to the clinic people are watching you and saying things that are not nice… Even when you speaking to them, they want you to always wear a mask…]

P05… "Bekunzima nophuma apha endlini ngamanye amaxesha ngoba kaloku abantu uhleli nje bayathetha ngawe, bakhombisana ngawe… bajonga indlela le ubhutye ngayo and bavele bayazi uba ugula yintoni…"

[It was difficult at first to even show my face in public because of the things that people say to you… they look at you and come up with their own speculations about your illness…]

P11… "Yabona abantu basekuhlaleni abekho right… kokhonjiswana ngawe oko, kuthethwa ngesis gulo sakho… that is why abantu end up beyeka utya I treatment bezifihla endlini… Bonqena izinto ezi ziphuma ebantwini ohlala nabo… kunzima noya nase caweni le yambala…"

[People from the community are not good… people look at you and say things that are very discouraging… they treat like you're from another planet… that is why people end

up defaulting, locking themselves up and afraid to go to the clinic… It's the remarks… Even at church it's the same thing…]

Disconnect

Participants shared details about their relationships, putting emphasis on how this whole experience has negatively impacted their love life.

P02… "Siye sane ngxaki kakhulu no mama wontana… Apha ekuguleni kwam ndiye ndafumanisa intoyoba uye wathandana… Ndihlala ndizibuza nam, ndizixelela intoyoba ebebona mhlawubi imeko endikuyo so efuna ufumana oluthando angasalifumaniyo kum…"

[I had problems with my girlfriend… I found out that she cheated on me… I consoled myself and accepted that I am the reason she went outside our relationship… She was looking for the intimacy that I am not able to give her because of my condition….]

P03… "Kunzima for ubanomntu ongusisi for thina abantu abangotata xa ukulemeko…. Uye ubone ba awusakwazi umonwabisa umntu wakho and iya stressa lonto…]

[It's difficult to be in this positions as a men… it's a big frustration when you are unable to please your woman like you used to before… that is what make you weak… And it turns her away…]

P10… "Oko ndiqale le treatment, izinto azisafani pha endlini ne boyfriend yam… Sometimes uyandinika uthando, sometimes angabinathando for mna… unamaxesha ndimbone be akekholapha

[Since I started this treatment, things are not the same between my boyfriend and I… Sometimes he is able to show me love but sometimes he distances himself from me… He has become so cold towards me…]

Theme 6: Adverse-effects

Second line drugs are frequently associated with very high rates of unacceptable adverse-drug reactions, needing frequent interruption and change of regimen. Close monitoring of the patient is necessary to ensure that adverse-effects of second line drugs are recognised quickly. The physician should be trained to screen patients regularly for symptoms of common adverse-effects: rashes, gastrointestinal (nausea, vomiting and diarrhoea), symptoms, psychiatric symptoms (psychosis, anxiety and depression), jaundice, ototoxicity and peripheral neuropathy (Verma & Mahajan, 2007).

One of the second line drugs includes an intramuscular injection daily for six months. Participants in this study shared that the injection causes lumps on the injection site and described it as one of the worst adverse-effects:

Lumps on injection site

The participants described the lumps from the injection as being the worst side-effect.

> *P01… "The injection is the worst because it causes such lumps in your buttock… they are so painful… you can't sit up straight, you have to lie on your side the whole time…."*

> *P02… "Lamaqhuma enziwa yi injection… Abuhlungu kanobom, awukwazi ulala ebusuku, kunzima uhlala ngembudu…"*
>
> *[The lumps caused by the injection… They are painful, it's difficult to sleep at night, and it's difficult to sit down…]*

> *P05… "Yhoo ha a, ngalamaqhuma alapha ezimpundu… Athatha ixesha uphola… qho xa uqgibohlaba funeka ulale ngesisu ungahlali ngempundu…"*
>
> *[It's definitely the lumps on my buttocks because of the injection… They take long to heal… after you have had the injection they start to swell up and you can't even sit down, you have to always lie on your stomach…]*

P07… "Amaqhuma la ngekeh, awsaziva na sexy uyintombaza ngoba impundu ezi zigcwele amaqhuma and awabuhlungwanga kanje…Akwenza ubene chuku…"

[You don't even feel sexy as a woman, because of these lumps on the buttocks and they are so painful… they make you so irritable….]

Theme 7: Little time for doctor consultation

A patient who is on MDR-TB treatment at the primary health care facility has to been seen by a medical officer at least once month. These doctor visits helps in monitoring the progress of a patient and design a plan going forward as each individual is different. It is a standard procedure but it might not always happen that way everywhere.

Under-staffed

Participants raised a point that they are not happy with the time that is allocated for them to see the doctor; in that once in a month consultation it is not even 15 minutes that they spend with the doctor and yet they have a lot that they needs clarity on from the doctor but they don't get answers because of the large number of clients that the doctor has to see on the day.

P07… "Ingxaki yam ipha ku qgirha… U fumanisa into yoba abantu baninzi abafolileyo, abazobona uqgirha… uqgirha inoba ubona abantu aba pha ku thrity ngemini, kungena lo kuphume lo and kengoku uvele ajonge nje abhale… Wena as uyi patient ungafumani xesha loba ubuze izinto ofuna uzibuza, especiilay ngezi side—effects…

[My problem mostly is with the doctor… There is always a long line, too many people that are waiting for her…. It's one in and quickly out, another one follows and so on and so on… She just writes quickly and sends you on your way so you don't even get to the opportunity to ask things that you wish to ask, especially concerns about the side-effects]

P05… "Ngenye imini sajikiswa singabanye, asakwazi umbona uqgirha ngoba kugcwele… So sometimes alibikho ixesha loba ukhe uhlale noqgirha ubuze ngempilo yakho

[I was turned back at once; they told me I am not going to see the Doctor on that day because the doctor has many patients to see already… So it's clear to me that there is not enough time to sit with the doctor and discuss your health]

Theme 8: Wanting to recover

Motivation

When participants responded to the question asked '*What has kept you motivated to continue taking the treatment despite all the challenges?'*, the number one motivation was to recover and regain their full independence.

P01… "I told myself that I'm going to fight this battle and win it… I am not going to let this get me down… My goal is to get better and get back to my normal life…"

P02… "Ndifuna uphila SiSi, ndikwazi unakekela umntana wam futhi…."

[I want to get better so that I can support my child again…]

P04…. "Ndifuna uphila so that ndizokwazi uzenzela izinto again…"

[I want to get better so that I can be on my own again]

P07… "E goal yam kuqgiba le treatment so that ndibe cured… Ndizokwazi ubane mpilo engcono futhi…."

[My main goal is to finish the treatment and be cured so that I can have good health again]

4.4 Discussion

Incorrect and Late Diagnosis

According to Caminero (2006) there are discrepancies in the literature when it comes to the management of MDR-TB. It is thereof ore essential to analyse these discrepancies and address the essential and controversial issues regarding the management of MDR-TB. The first step should be the correct diagnosis, which supports the findings of this study.

A study was done in one of the American hospital in Los Angeles regarding the misdiagnosis of MDR-TB patients. The study results showed that pulmonary MDR-TB was misdiagnosed in 9 (13%) of 70 patients. Reasons why the diagnosis appeared to be erroneous was the growth of MDR-TB from an old tuberculous lesion in a patient who was never treated for TB and whose diagnosis predated anti-TB drugs (1 case), documented contamination with mycobacterium avium complex (1 case), suspected specimen mislabelling (1 case), successful treatment using drugs to which the isolate was reportedly resistant (4 cases), discrepant susceptibility tests results on additional specimens submitted by the patient (2 cases) and no clinical evidence of TB (3 cases). The study concluded that susceptibility results alone are not enough to dictate treatment and careful clinical correct actions is necessary in making the diagnosis of MDR-TB (de Koning et al, 1997).

The findings in this research study revealed that some participants had been started late on treatment or on the wrong TB treatment. A reason for the misdiagnosis of two of the patients was the incorrect sputum results from the laboratory. Three participants explained that the reason for starting treatment so late was the inability to access health care quicker due to work commitments; they were too scared to miss work and risk losing their jobs.

Additionally, participants shared their disappointment with the lack of efficiency with the medical team with regards to the incorrect TB treatment they received. They were worried that it would later have an impact on their prognosis.

Co-infection causing increased burden of medication

Literature shows that the risk of getting TB is fifty fold higher in HIV+ individuals compared to an HIV- person because of the immune suppression of an HIV+ person (Laurenzi, Ginsberg & Spigelman, 2007). There is a growing epidemic of multidrug-resistant tuberculosis and extensively drug-resistant tuberculosis associated with high mortality amongst HIV infected individuals (Prasad, 2005).

Even though treatment for MDR-TB and (ART) has been shown to improve patient outcomes, treatment of MDR-TB in HIV infected patients remains a significant challenge. Such patients are required to take large numbers of pills each day, receive intramuscular injection for extended periods of time, and are subject to potential addictive side-effects and drug interaction between antiretroviral agent and second line anti-tuberculosis drugs (Isaakidis et al, 2012).

The researcher discovered that 80% of the participants are co- infected with HIV. Participants expressed their different challenges with regards to their dual treatment. The study revealed that there needs to be a great sense of ownership and responsibility when one has to cope with more than one illness at a time, it can be so easy to neglect the other and only focus on the one that feels so deadly. Some participants revealed that the large amount of medication created a very anxious feeling, often with confusion about which tablets to take and when and the fear of having to cope with increased adverse-effects as a result of taking both medication. The researcher observed that some participants were able to cope with that type of the responsibility, while for some it was difficult. There ones that were able to, did so with the great help and support from their family members.

The researcher observed that some participants had a lack of insight with regards to the details of their illness; some didn't even know what the difference is between normal TB and MDR-TB.

Inability to function optimally

The inability to function optimally was raised by every participant; it seemed to be the most agonising aspect when coping with MDR-TB treatment. The participants displayed a sense of loss and pain when sharing the everyday physical challenges experienced as a result of MDR-TB

treatment. This study revealed the changes and challenges that come along with being on MDR-TB treatment.

A study was conducted in South India to explore the perceptions of TB patients about their physical, mental and social well-being after the initiation of TB treatment. The study revealed that; health status was perceived to be good by most patients before treatment, body pains was perceived to be a factor moderately interfering with daily activities such as cooking, doing, laundry, doing shopping and so forth (Rajeswari et al, 2005).

The study further- more revealed the importance of support from family and friends. Participants expressed how much of a big role their family and friends had played during their treatment journey. The researcher observed that the participants that had a very good support structure had made a very positive progress in their therapy. The participants expressed a sense of gratitude and a greater appreciation for physical abilities, and some made an example of how one tends to forget the value of something until its gone.

Life adjustments

A study was conducted with a group of TB patients with the aim of bringing out the adjustment problems faced by the patients in their personal, social and vocational lives in the post-treatment phase. The study revealed that some patients felt frustrated and thought that their future was not bright; they were dissatisfied by comparing themselves with normal persons, lost interest in their living, were affected by the negative reaction of family members and their reduces status in the family, felt guilty for not contributing to the family income (Arora et al, 1992).

The findings of the study revealed that being diagnosed with MDR-TB is a life changing moment because it affects different aspects of one's life. The participants expressed their different adjustments and what needed to happen in order to accommodate the changes.

The researcher discovered that amongst the life adjustments that were revealed, the most difficult one was the loss of income by various participants and yet nine of the participants were reported to be the breadwinners. The participants expressed their dissatisfaction with the Department of Social Development. Even though the government has made provision for social grant assistance for people on tuberculosis treatment, it is no always a success story. Four of the participants

revealed that their social grant application had been declined at home affairs without their having been provided with reasons.

The researcher discovered that 10 of the participants had not completed matric hence; there is very little understanding of the proper channels to follow when faced with a challenge that requires further intervention. The researcher further discovered what kind of challenges our low income communities are facing.

Social Challenges

MDR-TB patients are often faced with various social challenges. Stigma is a complex social construct that can be perceived and /or experienced, and has been documented in many countries. Felt and experienced stigma has been linked to negative patient experience in different social settings (Sengupta et al, 2006)

The findings of the study revealed that the stigma towards MDR-TB is still a concern. The participants expressed encounters of discrimination from society. This caused a direct impact on treatment adherence because some participants were even scared to go to the clinic and be seen outside. The researcher observed how the participants expressed concerns of rejection by close friends and neighbours, and for some even by their own family members.

MDR-TB has a huge adverse economic impact on patients due to the long duration and complexity of treatment. The socioeconomic barriers include inaccessibility of treatment, distance, transport costs incurred during hospitalisation and reduction in salary due to absenteeism (Thomas et al, 2016).

Participants in this study expressed the frustrations of losing the income because of having to leave work after having started MDR-TB treatment. Most of them are bread winners at home; the reduction in the source of income impacts negatively on the family at large.

The participants also mentioned that their relationships with their significant others had also been affected a great deal, to such an extent that some had to break up with their partners. The study revealed that it is a challenge for a number of people to be intimate during their treatment therapy, at least for the first six months of the 22 months period of treatment. This seemed to be a very challenging effect for all the participants who were in relationships.

Adverse-Effects

MDR-TB treatment is reported to having one of the worst adverse-effects. Numerous studies have been done which revealed the different types of adverse-effects experienced by patients on MDR-TB treatment. These included ototoxicity, tinnitus, hearing loss, gastro intestinal effects, swelling in the joints and presence of depression (Awad, Atef & Mahmaoud, 2015).

Second line drugs are frequently associated with very high rates of unacceptable adverse-drug reactions, needing frequent interruption and change of regimen. Close monitoring of the patient is necessary to ensure that adverse-effects of second line drugs are recognised quickly. The physician should be trained to screen patients regularly for symptoms of common adverse-effects: rashes, gastrointestinal (nausea, vomiting and diarrhoea), symptoms, psychiatric symptoms (psychosis, anxiety and depression), jaundice, ototoxicity and peripheral neuropathy (Verma & Mahajan, 2007).

The participants shared their adverse-drug effects. The adverse effects that were mentioned by all participants were nausea and vomiting, dizziness and lumps on injection site.

The findings of the study revealed that the MDR-TB treatment has very toxic effects that are deteriorating to the mind and body of the individual. The researcher observed how the participants struggled to remain focused during their interviews and how long it took for them to respond to questions. Most of the participants displayed signs of fatigue throughout. The researcher observed that the struggle with MDR-TB lies so much in the adverse-drug effects, that this is the number one deterrent when it comes to the success rate of treatment.

Little time for doctor consultation

The study revealed that the public health care facilities are still faced with a big shortage of medical staff. The participants reported that there wasn't enough time to consult with the doctor and often missed the opportunity to ask important questions from the medical officer. Participants also raised concerns about the quality of care this implies. They also described long queues that they encounter in clinics.

Shortage of staff is a very common problem in the medical field due to a number of factors such as high staff turn-over, lack of resources, over-populated medical facilities. However; the

literature that is available does not specifically focus on the shortage of medical officers treating MDR-TB patients, rather on the scarcity of medical facilities in some rural areas and the shortage of MDR-TB drugs.

4.5 Conclusion

This chapter focused on the findings of this research study. A detailed description of participants was given, themes, codes and description of codes was addressed with relevant direct quotes from the participants and lastly was the discussion.

CHAPTER FIVE

Conclusions and Recommendations

5.1 Conclusions

The aim of this research was to explore the experiences of patients with the adverse-effects of MDR-TB treatment in a primary health care facility in the Western Cape.

This study revealed that patients who are on MDR-TB treatment are faced with a lot of challenges when it comes to coping with the adverse-drug effects of MDR-TB treatment. In their discussion, they each highlighted how the adverse-drug effects of MDR-TB treatment have affected their lives. One participant mentioned that after she started the treatment, her life changed for the worst. The study also revealed that, the challenges expressed by the participants were quite similar. All the participants who were working at time they had to start MDR-TB treatment later had to stop working because of the adverse-effects of treatment. Based on the findings of the study, it is clear that the battle against the adverse-effects of MDR-TB treatment goes far beyond the physical struggle; the participants shared the emotional, social and financial struggles that they have endured. The study further revealed that there is a need for more resourceful health care workers who need to assist and support patients on MDR-TB. One of the participants expressed his disappointment with the lack of support from the health care professionals, he said that there is not enough time for the patients to consult with the doctor and they often have a lot of questions to ask the doctors regarding their illness but never gets the chance to do so.

This study had significant value in generating more understanding of how patients experience the adverse-drug effects, by recording in their own words. This could also help to strengthen the support system for patients, and assist managers of tuberculosis programs and clinicians in making evidence based decisions with regard to patient management, particularly with regards to nurses. Nurses play a very big role in the management and treatment journey of patients with MDR-TB at both tertiary and primary level. There thus needs to be a great amount of understanding and skill from the nurse's side and a great deal of trust and responsibility from the patient's side. This study shed light on the relationships between the two.

5.2 Limitations

- The research study was conducted at one primary health care facility only; the findings therefore cannot be generalized and is only applicable to this study setting.
- Some participants were aware that the researcher is a professional nurse and previously employed at the same facility. That might have influenced their response in some instances, reveal information that they wanted me to be aware of hoping that i will be able to do something about it or vice versa.

5.3 Recommendations

Recommendations for health care providers

- More support structures need to be made available for patients who are being treated for MDR-TB e.g. psychosocial support, therapeutic support, counselling which includes health education for family members or care providers at home.
- Provisions need to be made to accommodate patients who are still on the daily injection; receiving it at their homes for those who literally struggle to make their way to clinic on daily basis.
- All health care providers treating MDR-TB patient need to be equipped with the necessary information so that they can render comprehensive care. For example: training of all community health care workers who provide home visits to patients and do adherence support.
- Frequent health awareness on MDR-TB needs to be done in communities to help combat the stigma attached to MDR-TB and to equip communities members with the necessary information about TB.
- There should be an accuracy/verification checking of sputum results before initiation of treatment.

Recommendations for Stakeholders

- The government needs to create new criteria for social grant application of patients who are on TB treatment which will be accessible to all and aligned with the start of treatment

- Medical staff availability needs to be a priority in primary health care facilities with a high prevalence of MDR-TB.
- There should be more facilities treating MDR-TB in communities so that patients don't have to travel to other facilities to receive treatment.

Recommendations for further research

The researcher recommends that further research be done on:

- The new MDR-TB drug regimen to minimize the amount of tablets and reduce the long duration of treatment.
- Experiences of MDR-TB patients with regards to the kanamycin injection.

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Appendix A: Ethics Clearance Form

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DEPARTMENT OF RESEARCH DEVELOPMENT

10 December 2015

To Whom It May Concern

I hereby certify that the Senate Research Committee of the University of the Western Cape approved the methodology and ethics of the following research project by:
Ms S Tinzi (School of Nursing)

Research Project:	Exploration of experiences of patients with the adverse-drug effects of multidrug-resistant tuberculosis treatment in a primary health care facility in the Western Cape.
Registration no:	15/7/270

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

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

Appendix B: Editing Certificate

Certificate of Proofreading

This is to certify that the thesis of

Siphokuhle Tinzi

has been proofread, corrections made and feedback given.

Editor/Proof reader: Jenny Birkett
M.Ed. (Applied Language Studies), UCT.
Member Professional Editors Group (PEG)

Contact: 072 6887954 (sms)
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Appendix C: Interview Questions

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WESTERN CAPE

Interview guide

Researcher: Introduction of the study and interview location, date and time.

Research Questions

1. What are your experiences with the adverse drug effects of MDR-TB treatment? (How does the treatment make you feel?)

2. How long have you been on the treatment?

3. What are the challenges you have with MDR-TB and its treatment

4. How has the treatment affected your life? (work, family, friends)

5. What do you think can make things better with MDR-TB treatment?

……....

S. Tinzi

2855281

Appendix D: Participant Consent Form

UNIVERSITY OF THE WESTERN CAPE

School of Nursing
Faculty of Health Sciences
Bellville 7535
Email: 2855281@myuwc.ac.za

CONSENT FORM

Title of Research Project: Exploration of experiences of patients with the adverse-drug effects of multidrug-resistant tuberculosis treatment in a primary health care facility in the Western Cape.

The study has been described to me in a language that I understand**.** My questions about the study have been answered. I understand what my participation will involve and I agree to participate of my own choice and free will. I understand that my identity will not be disclosed to anyone. I understand that I may withdraw from the study at any time without giving a reason and without fear of negative consequences or loss of benefits.

Participant's name…….

Participant's signature……

Date……

Appendix E: 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

Email: chs-deansoffice@uwc.ac.za

INFORMATION SHEET

Project Title: Exploration of experiences of patients with the adverse drug effects of MDR-TB treatment in a primary health care setting in the Western Cape.

What is this study about?

This is a research project being conducted by student **S. Tinzi** at the University of the Western Cape, School of Nursing. You are invited to participate in this research project because you are a patient who is diagnosed with multidrug-resistant tuberculosis and is now on treatment at one of the facilities treating tuberculosis in the Western Cape (weltevreden valley clinic). The purpose of this research project is to explore (1) the experiences of patients with the adverse effects of MDR-TB treatment (2) the challenges faced by patients who are on MDR-TB treatment and the social impact thereof. This research will be conducted in the Western Cape, South Africa. Additionally, this research is conducted for the purpose of the Masters study. This study will be conducted in the Western Cape, South Africa.

The research projects aims to find out (1) the experiences of MDR patients with regards to the adverse effect of MDR- TB treatment in a primary health care facility in the Western Cape.

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

If you agree to participate in this research study, you will be expected to take part in an interview session with the researcher, the duration of the interview will be approximately 45 minutes to 1 hour. You will be guided through a few set of questions that you will be expected to answer in your own words, these questions will be stated on the interview guide. Note that during the interview, you are free to stop it at any time and if there are any questions you do not want to answer, we can skip them.

Would my participation in this study be kept confidential?

The researchers commit themselves to protect your identity and the nature of your contribution. To ensure your anonymity, only a code will be linked to your answers. This code is called a study ID, so all your answers will be kept confidential. This means that no one else, except the researcher and Investigators of this study, will have access to your answers; furthermore, they will be kept in a safe locked.

If we write a report or article about this research project, your identity will remain unrevealed.

What are the risks of this research?

All human interactions and talking about self or others carry some amount of risks. We will nevertheless minimize such risks and will act promptly to assist you if you experience any of them during the process of your participation in this study. Where necessary, an appropriate referral will be made to a suitable professional for further assistance or intervention.

What are the benefits of this research?

Research is designed to benefit society by gaining new knowledge. You may not benefit personally from being in this research study. Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you decide not to participate in this study or if you stop participating at any time, you will not be penalized.

What if I have questions?

If you have any questions about the research study itself, please contact Siphokuhle Tinzi at: 0715983888, email address: 2855281@myuwc.ac.za

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