Faculty of Community and Health Sciences

Timely initiation of MDR-TB treatment: A descriptive qualitative study at primary health care facilities in a district of the Cape Metropole

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A mini-thesis submitted in partial fulfilment of the requirement of the Degree of Master of Public Health, in the School of Public Health, Faculty of Community and Health Sciences, University of the Western Cape

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KEYWORDS

Tuberculosis

Drug resistant TB

Rifampicin resistant TB

Rifampicin-mono resistant TB

Multi-drug resistant TB

Extensively-drug resistant TB (XDR-TB)

Delayed initiation

Initial default

Health system

Primary Health Care Facility

Community
ABBREVIATIONS

AIDS Acquired Immune Deficiency Syndrome
ART Antiretroviral Therapy
DoH Department of Health
DR-TB Drug resistant TB
DST Drug Susceptibility Testing
XDR-TB Extensively-drug resistant TB
HIV Human Immunodeficiency Virus
LPA Line Probe Assay
MDR-TB Multi-drug resistant TB
MTB Mycobacterium tuberculosis
NDoH National Department of Health
NHLS National Health Laboratory Service
PHC Primary Health Care
RR-TB Rifampicin resistant TB
TCA Thematic Coding Analysis
TB Tuberculosis
ZN Zeil Niehlsen
DEFINITIONS OF TERMS

**Tuberculosis (TB):** Tuberculosis or TB is an infectious disease that is spread through airborne bacteria in the respiratory fluids of people with active TB.

**Drug susceptible TB (DS-TB):** Drug susceptible TB or DS-TB is regular TB that is not resistant to any of the main medicines used to treat TB. DS-TB is treated with a combination of medicines - comprising of rifampicin, isoniazid, ethambutol and pyrazinamide - that are taken daily for a period of 6 months.

**Drug resistant TB (DR-TB):** For the purposes of this study, drug resistant TB or DR-TB is used to talk about all types of drug resistance, including rifampicin mono-resistant TB, multi-drug resistant TB and extensively-drug resistant TB.

**Rifampicin resistant TB (RR-TB):** For this study rifampicin resistant TB or RR-TB is used to indicate that a patient has been diagnosed with rifampicin resistant TB and should be started on a standard MDR-TB regimen while awaiting the results of further resistance testing. Further resistance testing should be performed on patients diagnosed with RR-TB to ascertain whether the patient has rifampicin mono-resistant TB, MDR-TB or XDR-TB.

**Rifampicin-mono resistant TB:** Patients that are resistant to rifampicin, while remaining susceptible to isoniazid, are categorised as rifampicin-mono resistant. While these patients are not categorised as multi-drug resistant, they should be treated with standard MDR-TB treatment regimens, in combination with isoniazid.

**Multi-drug resistant TB (MDR-TB):** Patients that are resistant to both rifampicin and isoniazid are categorised as multi-drug resistant. These patients should be treated with standard MDR-TB regimens. Depending on the time of a patient’s culture conversion, this regimen should be taken for 18 months to 2 years.

**Extensively-drug resistant TB (XDR-TB):** Patients that are resistant to rifampicin and isoniazid, plus at least one fluoroquinolone (moxifloxacin, levofloxacin, ofloxacin) and one injectable (kanamycin, amikacin, capreomycin) are categorised as extensively-drug resistant. Patients with XDR-TB should be treated with South Africa’s standard XDR-TB regimens or, preferably, with individualised regimens that reflect patients’ drug susceptibility profiles.

**Non defaulter:** Non defaulter is defined a patient who initiated an appropriate DR-TB regimen (according to available resistance results) following diagnosis of RR-TB within five days of specimen collection at a health facility. Patients are defined as ‘non defaulters’ if they initiated drug resistant TB treatment within five days of sputum collection for the episode of DR-TB under investigation, regardless of whether or not treatment was completed.

**Initial defaulter:** Initial defaulter is defined as a patient who initiated an appropriate DR-TB regimen (according to available resistance results) following diagnosis of RR-TB after five days of sputum collection at a health facility. Patients are defined as ‘initial defaulters’ if they initiated drug resistant TB treatment after five days of specimen collection for the episode of DR-TB under investigation, regardless of whether or not treatment was completed.
Abstract
Timely initiation of Drug Resistant Tuberculosis (DR-TB) treatment is essential for an effective TB control programme. Delays in initiating DR-TB treatment increase the risk of death and transmission of DR-TB within communities. DR-TB is diagnosed using GeneXpert testing, results are available to the local clinics within twenty four hours and DR-TB services have been decentralised to Primary Health Care Facilities to potentially reduce the length of time taken to initiate DR-TB treatment. However, it has been reported that despite these efforts, a large number of patients fail to initiate DR-TB treatment. Direct transmission is becoming the main driver of new DR-TB infections in the Western Cape and late initiation of treatment contributes to the spread of DR-TB within the community.

The aim of the study is to explore the factors influencing whether newly diagnosed DR-TB patients initiate treatment on time at Primary Health Care facilities within the Mitchell’s Plain sub-district.

A descriptive qualitative research design was used. Semi-structured interviews were conducted in English with 16 purposefully sampled patients from two facilities in the Mitchell’s Plain sub district were diagnosed with DR-TB. The patient sample consists of some patients who initiated treatment within five days from the date of sputum collection and some patients who initiated treatment more than five days from the date of sputum collection. Interviews were also conducted with health care workers from the health facilities. Data was collected using a digital recorder and field notes. The data was analysed using Thematic Coding Analysis and emerging themes were obtained.

Ethical approval was sought from the University of the Western Cape Senate Research Committee and permission to conduct studies at the facilities was sought from the City of Cape Town. Informed consent was sought from participants.

Based on the research findings, three main themes were identified: Patient Factors, Health System Factors and Factors Relating to Inadequate Patient Analysis. The subsequent sub-themes that were identified under patient factors that affect the timely initiation of DR-TB treatment are as follows: 1) Factors relating to patients’ personal characteristics and perceptions which include: The health status of the patient; social contact with a TB patient and previous TB; the role of knowledge and understanding; the potential role of patients’ beliefs and attitude. 2) Financial considerations which include: employment as a barrier and social grant; subsistence needs and access to health facilities. 3) Society’s views on health,
and their influences on timely initiation of DR-TB treatment which include: stigma and the effect of a supportive environment on the initiation of DR-TB treatment. In this study, these patient factors acted as barriers or enablers for the initiation of DR-TB treatment. The subsequent sub-themes that were identified under health system factors which contribute to timely initiation are as follows: 1) Patients’ sentiments on the health care system which include - waiting time, clinic times and the environment at health facilities; procedures to recall patients; and the availability of resources. Health system factors either act as barriers or enablers for the initiation of DR-TB treatment. Factors relating to inadequate patient analysis included 1) substance misuse and 2) visiting private doctors and were identified as both patient and health system factors which contribute to the initiation of DR-TB treatment. Substance misuse acted as a barrier for some patients in this study and resulted in delayed diagnosis and initiation of DR-TB treatment. Visiting private doctors was an enabler for some patients and a barrier to initiate DR-TB treatment for some patients.

Within the Mitchell’s Plain sub district there is significant opportunity to improve the DR-TB programme through strengthening health system mechanisms in order to improve the time taken to initiate DR-TB treatment following DR-TB diagnosis.
DECLARATION

I, Shaakira Ariefdien, declare that *Timely initiation of MDR-TB treatment: A descriptive qualitative study at primary health care facilities in a district of the Cape Metropole* is my own work, that it has not been submitted before for any degree or examination at any other university, and that all the sources I have used or quoted have been indicated and acknowledged by means of complete references.

Shaakira Ariefdien

Signature: .......................................................... Date: ...08 March 2018
ACKNOWLEDGEMENTS

In the name of Allah, Most Beneficent, Most Merciful. All praise belongs to Allah, the Most High, the Greatest, and peace and blessings on our Master, Muhammad, his noble and illustrious companions. My sincere and greatest appreciation and thanks to the Allah (God Almighty) for the guidance, good health, strength and wisdom throughout my research endeavour.

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Special thanks to Gakeema Karlie for your assistance and the study participants for their willingness to participate in this study, and for providing me with valuable information.
DEDICATION

This thesis is dedicated to my beloved parents, Madeniyah and Gasant Ariefdien for their hard work in raising me, providing me with the best that they were able to give and for their inspiration that motivated me to work hard to reach this far. May the Almighty preserve them.

I also wish to dedicate this work to my children. Let this accomplishment be a source of inspiration to motivate you for future studies.
## TABLE OF CONTENTS

### Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>KEYWORDS</td>
<td>II</td>
</tr>
<tr>
<td>ABBREVIATIONS</td>
<td>III</td>
</tr>
<tr>
<td>DEFINITIONS OF TERMS</td>
<td>IV</td>
</tr>
<tr>
<td>Abstract</td>
<td>V</td>
</tr>
<tr>
<td>DECLARATION</td>
<td>VII</td>
</tr>
<tr>
<td>ACKNOWLEDGEMENTS</td>
<td>VIII</td>
</tr>
<tr>
<td>DEDICATION</td>
<td>IX</td>
</tr>
<tr>
<td>TABLE OF CONTENTS</td>
<td>X</td>
</tr>
</tbody>
</table>

1. **CHAPTER 1 - INTRODUCTION** .......................................................... 1
   - 1.1 Background Information .......................................................... 1
   - 1.1.1 Diagnosing DR-TB using GeneXpert ........................................... 2
   - 1.1.2 Decentralisation ................................................................. 3
   - 1.2 Context ......................................................................................... 4
   - 1.3 Problem Statement ....................................................................... 4
   - 1.4 Outline of thesis .......................................................................... 5

2. **Chapter 2 - Literature Review** ....................................................... 6
   - 2.1 Introduction .................................................................................. 6
   - 2.2 Prevalence of DR-TB ...................................................................... 6
   - 2.3 Initiation of DR-TB treatment in South Africa and the Western Cape .. 7
   - 2.4 Initial Default of DR-TB Treatment Initiation ............................. 8
   - 2.5 Interventions ................................................................................ 9
   - 2.6 Factors Affecting the Timely Initiation of DR-TB treatment .......... 13
     - 2.6.1 Factors relating to Site of TB ............................................... 13
     - 2.6.2 Factors relating to Patients’ Demographics and Perceptions ....... 14
     - 2.6.2.1 Sex and Age ..................................................................... 14
     - 2.6.2.2 Nationality and Education ................................................. 14
     - 2.6.2.3 Financial Considerations .................................................. 15
     - 2.6.2.4 Societies Views on Health, and their Influences on Patients’ Reactions ..... 16
     - 2.6.2.5 Patients’ Sentiments on the health care system ................. 16
     - 2.6.3 Factors relating to the Health System ................................... 17

http://etd.uwc.ac.za
CHAPTER 1 - INTRODUCTION

1.1 Background Information

Globally, tuberculosis (TB) is a significant cause of illness and death, accounting for an estimated 9.27 million incident cases in 2007. South Africa has the third highest incidence of TB cases, and the fourth highest number of multidrug-resistant (MDR) TB in the world. At 1000 per 100 000 cases per population, the Western Cape Province has the highest recorded TB incidence in South Africa (WHO, 2009). The increase of the TB pandemic in South Africa is closely related to the human immunodeficiency virus (HIV) pandemic in the country with people living with HIV more likely to develop active TB illness than HIV-negative people, even when they are stable on antiretroviral therapy (Gupta et al., 2012). Between 2004 and 2012 in South Africa the number of extensively drug-resistant (XDR) TB cases increased from 85 to 1,545 (Ndjeka, 2013). Laboratory confirmed MDR-TB increased from 7.386 in 2010 to 14.161 in 2012 (WHO & NDoH, 2014).

The Department of Health (DoH) recommends that MDR-TB treatment should be initiated within five days, from the time of sputum collection. An initial defaulter for MDR-TB treatment is therefore a MDR-TB case who is not initiated on MDR-TB treatment within five days, from the time of sputum collection (DoH, 2014). In this study, the term drug resistant (DR-TB) is used to refer to rifampicin resistant (RR) TB and MDR-TB. The initiation of an appropriate DR-TB treatment regimen (according to available resistance results) following the detection of RR-TB within five days from the time of sputum collection will be considered as timeous initiation of DR- TB treatment.

_Mycobacterium tuberculosis_ (TB) is an opportunistic infection of Acquired Immune Deficiency Syndrome (AIDS) in Human Immune Virus (HIV)-infected persons (WHO, 2009). There are five closely related mycobacteria responsible for tuberculosis of which mycobacterium tuberculosis (MTB) is the most common. TB is spread from person to person through droplet infection. Transmission generally occurs indoors, in dark, poorly ventilated spaces where droplet nuclei stay airborne for a long time (DoH, 2014). Rifampicin and isoniazid are drugs that are used to treat all people infected with TB. Multi drug resistant-tuberculosis (MDR-TB) is defined as TB that is resistant to at least isoniazid and rifampicin.
Extensively drug resistant-TB (XDR-TB) is DR-TB that is resistant to these drugs as well as several second-line drugs normally used (DoH, 2014).

1.1.1 Diagnosing DR-TB using GeneXpert

Endeavours to control DR-TB in South Africa are beset with challenges due to poor case detection as well as delayed diagnosis and initiation of treatment (Streicher et al., 2012). Prior to the use of GeneXpert diagnostics, health facilities in South Africa relied on the Zeil Niehlsen (ZN) smear test as the initial TB test and line probe assay (LPA) or culture drug susceptibility testing (DST) in order to detect resistance. A culture was done when the TB patient had a positive smear after two months of TB treatment or the patient was a contact of a known DR-TB patient. It takes six to eight weeks to make a diagnosis when using a culture test. Patients were therefore misdiagnosed when using these conventional methods of testing and it took weeks to months to diagnose DR-TB. The use of incorrect medication leads to further drug resistance which causes first time TB patients to have DR-TB and spread DR-TB within the community.

In 2011, a plan for a phased roll-out of GeneXpert to detect TB and DR-TB cases was announced. The GeneXpert MTB/ RIF is an automated nucleic acid test for the detection of TB and rifampicin resistance (RR) (Osman et al., 2014). The GeneXpert reduces the time of DR-TB diagnosis and the results are available within two hours without the requirement of highly trained personnel (Boehme et al., 2011). Results are faxed to facilities within 24 hours of sputum collection.

In the Western Cape, South Africa, a TB suspect (people with TB symptoms, TB contacts and HIV positive patients with pneumonia) produces two sputum specimens, one hour apart at the health care facilities and is asked to return to the facility after forty eight hours for results. Suspects are required to provide their contact details and the contact details of a next of kin as well as their residential addresses for tracing in the event that the results are positive and the suspect does not return for the results. Sputum specimens are submitted to the National Health Laboratory Service (NHLS) via a courier for each TB suspect. For HIV negative TB suspects, one sputum specimen is tested with GeneXpert. For HIV infected patients, if the GeneXpert is negative the second specimen sample is tested by culture. If the GeneXpert result is “positive, rifampicin susceptible”, a second specimen sample is tested by smear microscopy for programmatic monitoring and evaluation. If the GeneXpert result is “positive, rifampicin resistant,” the second specimen sample is tested by (LPA) for
confirmatory drug susceptibility testing for isoniazid and rifampicin. The specificity of the GeneXpert is considerably high, which supports the decision of the South African TB Control Programme to recommend initiation and treatment of MDR-TB on receipt of a GeneXpert result indicating resistance, while waiting for confirmatory testing (Osman et al, 2014). GeneXpert test results are available to Primary Health Care (PHC) facilities within 24 hours.

1.1.2 Decentralisation
Initially, the treatment of MDR-TB patients involved hospitalization during the intensive phase of their treatment (6–8 months), to ensure proper administration and adherence to treatment and to limit transmission. However, this model often results in bed shortages; delays in treatment initiation for MDR-TB patients; an increase in the high likelihood of transmission of MDR/XDR-TB at health facilities; and lack of social support for patients, who are isolated from their families during treatment and who may face financial burdens due to the lengthy hospital stays (DOH, 2014). MDR-TB treatment initiation and continuation of treatment has therefore since been decentralised and treatment is provided at PHC facilities to smear-negative MDR-TB patients and patients that refuse hospitalisation (NDoH, 2011).

Accessibility of information and care would also be a crucial factor in managing this disease: decentralisation and integration of MDR-TB treatment at the Primary Health Care (PHC) facilities and the use of GeneXpert should reduce the time in which treatment is initiated and allow for patients with MDR-TB to receive treatment at a community health centre in their communities. According to the Department of Health (DOH) 2014 National TB guidelines, diagnosed rifampicin resistant TB (RR-TB) patients must be started on treatment within five days from date of sputum specimen collection for testing. If this fails to happen, the patient is defined as an initial defaulter. Early diagnosis of RR-TB by GeneXpert MTB/RIF and decentralisation has the potential to reduce mortality associated with delayed diagnosis, as well as decrease the spread of MDR-TB. However, this will only be obtained if appropriate treatment for DR-TB is given timeously following diagnosis. There is an obvious need to maximize the benefits associated with the use of GeneXpert and decentralisation of MDR-TB treatment within the community. Importantly, within high burden communities, direct transmission, rather than acquired resistance, is becoming the main driver of new DR-TB infections in the Western Cape and late initiation of treatment contributes to the spread of DR-TB within the community (Cox et al., 2010).
1.2 Context

According to Western Cape Government, (2012) incidence of DR-TB in the Western Cape is amongst the highest incidence of DR-TB in the world. Mitchell’s Plain is an urban area in the Western Cape that consists of townships with informal housing, formal housing and backyard dwellers. People in poorer communities have an increased risk of TB infection. Dynamics such as poverty, overcrowding, inequity and malnutrition present in this community lead to the population being at particular risk of TB (Zumla et al., 1999). The population of Mitchells Plain was 310 485 in 2011 (Census, 2011) and is well known for gangsterism, taxi violence, poverty, alcohol and drug misuse, and the highest crime reported in South Africa (Crime SA, 2014).

The reasons for initial defaulting of DR-TB treatment within the Mitchell’s Plain sub district have not yet been explored and therefore the purpose of this study is to explore the reasons why patients diagnosed with DR-TB initiate DR-TB treatment within the recommended time or not.

1.3 Problem Statement

Early diagnosis and initiation of treatment for DR-TB are essential for an effective TB control programme, delays in diagnosis and treatment increase the risk of death and transmission of DR-TB, and contribute to the increase of extensively drug-resistant (XDR) TB (Botha et al., 2008). DR and XDR-TB have the potential for huge cost implications to the health system (Pooran et al., 2013). In 2011, a plan for a phased roll-out of GeneXpert to detect TB and DR-TB cases was announced. The GeneXpert MTB/ RIF is an automated nucleic acid test for the detection of TB and Rifampicin resistance (RR) (Osman et al., 2014). The GeneXpert reduces the time of DR-TB diagnosis and the results are available within two hours without the requirement of highly trained personnel (Boehme et al., 2011). Results are faxed to facilities within 24 hours of sputum collection.

The roll-out of GeneXpert testing was teamed with decentralisation guidelines recommending that MDR-TB patients with sputum smear-negative and patients that refuse hospitalisation are initiated onto out-patient treatment - with traditional, centralised hospitals increasingly unable to accommodate the increasing number of MDR-TB patients. Patients diagnosed with RR-TB should be started on a standard MDR-TB regimen while awaiting the results of further resistance testing. Further resistance testing should be performed on patients diagnosed with RR-TB to determine whether the patient has rifampicin-mono resistant TB,
MDR-TB or XDR-TB (NDoH, 2011). RR-TB is an indicator of multi drug resistance as around 90% of patients that are resistant to rifampicin are also resistant to isoniazid and are therefore categorised as MDR (Coovadia et al., 2013).

Despite these efforts the National Department of Health (NDoH) estimated that fewer than half of the cases diagnosed with MDR-TB initiated treatment during 2012 in the Western Cape and nationally (Ndjeka, 2013), posing an increased risk to communities. According to the Global Report, only 41% of patients who were diagnosed with RR-TB during 2013 initiated treatment in South Africa (WHO, 2014). Early diagnosis of DR-TB coupled with early initiation of DR-TB treatment is crucial to reduce the period which DR-TB patients remain infectious and ultimately to reduce DR-TB incidence (NDoH, 2011).

1.4 Outline of thesis

Chapter 1 is an introduction to the study and it includes the formulation of the problem statement and rationale of the research.

Chapter 2 is a literature review, which focuses on reviewing the relevant literature on initiation of TB treatment.

Chapter 3 provides the aim and objectives of the study and explains the research design and methodology that was used to investigate the timely initiation of DR-TB treatment.

Chapter 4 presents the findings of the study.

Chapter 5 discusses and interprets the findings of the study.

Chapter 6 draws conclusions and makes recommendations for improvements in timely initiation of DR-TB treatment.
Chapter 2 - Literature Review

2.1 Introduction
The pre-determined hypothesis of this review is that there are factors that indeed prevent, hinder, or just make it plain difficult to improve incidence of workable timeframes between diagnosis to treatment of Drug Resistant Tuberculosis (DR-TB) (in an attempt to manage the disease to the most optimal levels of health possible), and that this timeframe (the ever increasing and persistent lag between diagnosis and treatment) has in some ways, been highlighted as a culprit of healthcare at worst, or perhaps a stumbling block, red herring even (at best), to improving healthcare statistics in South Africa over the long-term. The results will show that intervening processes were indeed needed and established in order to improve the lag between diagnosis and treatment of DR-TB. This literature review in particular focuses on health provider and patient factors that contribute to the failure of timely initiation of DR-TB treatment as well as the interventions that have taken place around these precise factors to combat the issue.

Limited academic research is however currently available about delayed initiation of DR-TB in South Africa, therefore the researcher has included government documents, presentations and reports as these provide recent information about the research topic. What follows is a high-level discussion of the prevalence of DR-TB in South Africa and the Western Cape, followed by a summation of the initiation of DR-TB treatment and subsequent or apparent statistics on the initial default of DR-TB Treatment Initiation. The patient and health system factors surrounding the default are further explored as part of the evidence of poor diagnosis to treatment links in place, where after the interventions are considered to combat the reasons around the failure around treatment linkage.

2.2 Prevalence of DR-TB
Globally, TB is a significant cause of illness and death, accounting for an estimated 9.27 million incident cases in 2007 (WHO, 2009). DR-TB remains an important medical and public health challenge as it affects approximately 500 000 new patients globally each year (Boehme et al., 2010).

The severe epidemic of TB in South Africa is well documented, and TB prevention and control is a top priority for public health (Goodchild et al., 2011), however, despite efforts to control the severe epidemic situation, TB still remains the leading cause of death in South
Africa. In 2011 it was reported that 10.7% of deaths in South Africa are due to TB. A major challenge to South Africa’s TB response is the growing epidemic of DR-TB and Human Immunodeficiency Virus (HIV). The increase of the TB epidemic in South Africa is closely related to the HIV pandemic in the country due to people living with HIV being more likely to develop active TB illness than HIV-negative people, even when they are stable on antiretroviral therapy (ART) (Gupta et al., 2012). South Africa had the second largest number of diagnosed Multiple Drug-resistant Tuberculosis (MDR-TB) cases globally during 2013, falling only behind India and the highest number of HIV-positive incident TB cases globally (WHO, 2014).

South Africa has recently experienced a drastic increase in DR-TB cases due to a combination of an increasing incidence of DR-TB, as well as improved case detection and diagnosis (WHO, 2014). Between 2004 and 2012 in South Africa the number of extensively drug-resistant tuberculosis (XDR-TB) cases increased from 85 to 1,545 (Ndjeka, 2013). Laboratory confirmed MDR-TB increased from 7,386 in 2010 to 14,161 in 2012 and it increased to 26,023 in 2013 (WHO & NDoH, 2014).

Importantly, within high burden communities, direct transmission, rather than acquired resistance, is becoming the main driver of new DR-TB infections in the Western Cape and late initiation of treatment contributes to the spread of DR-TB within the community (Cox et al., 2010).

2.3 Initiation of DR-TB treatment in South Africa and the Western Cape

It is important to note that according to Dickson-Hall & Nicol, 2014, the initiation of DR-TB treatment in South Africa and specifically in the Western Cape has been recorded as inadequate. What is of greater consequence though, is that the numbers of diagnosed DR-TB cases and patients started on treatment are subject to reporting errors though the number of annually diagnosed DR-TB cases is reported by the South African National Health Laboratory Services (NHLS), however, currently the NDoH and NHLS do not use unique patient identifiers, for example patients’ identification numbers to recognise patients. What this effectively means is that duplicate specimens from the same patient are sometimes reported as being different cases or specimens. It is therefore expected that the NHLS’s reported number of annually diagnosed cases is an overestimate of the actual number of diagnosed DR-TB cases in the country. As a result of reporting errors then, it is predicted that
more patients are initiated on DR-TB treatment than reflected by the electronic register for DR-TB patients (commonly known as the “EDR” registry) (Dickson-Hall & Nicol, 2014).

Notwithstanding the above disclosure then, according to South Africa’s National Department of Health (NDoH), only 45.9% of patients who were diagnosed with DR-TB in South Africa, and 48.6% in the Western Cape, were initiated on treatment in 2012 (Ndjeka, 2013). An observational study was conducted at 10 high burden clinics in the City of Cape Town and the report concluded that between 6 and 9% of patients did not initiate treatment within six months of diagnosis (Naidoo et al., 2014). This result is encouraging for the City of Cape Town, because the result on treatment initiation was better in the Western Cape than in any other province that was previously reported, however, this begs the question as to what the reasons are behind patients not initiating treatment within five days from the day sputum was collected at the health facility.

2.4 Initial Default of DR-TB Treatment Initiation

The findings of the research cited here are not based on the new definitions and current diagnostic measures, therefore the results do not necessarily accurately reflect the current situation. However, the studies reviewed in this literature review do reveal how complex it is to define the concept of what constitutes a positive TB result, and what an initial defaulter is. When examining the delays in initiation of treatment for TB and DR-TB or MDR-TB, the very definition of the disease and defaulter, can actually sketch an either very grim or reasonably stable picture of healthcare.

The Department of Health (DoH) for instance recommends that DR-TB treatment should be initiated within five days, from the time of sputum collection. An initial defaulter for DR-TB treatment is therefore a DR-TB case who is not initiated on DR-TB treatment within five days, from the time of sputum collection (DoH, 2014). There are many other definitions around what an initial defaulter purports to represent, and it is clear that because there is a vast difference in the definitions used across the studies, it results in a vast difference in the findings of the studies.

As a case in point, a prospective study was conducted in 13 Primary Health Care (PHC) facilities in the Stellenbosch district, South Africa. Of the 367 TB cases identified between April 2004 and March 2005, 17% were initial defaulters and up to 26% did not start treatment. In this study, an initial defaulter was defined as a TB case who was not recorded as having started TB treatment within three months of diagnosis, either at the same or at another
PHC facility in the district. For the purpose of the study, a TB case was defined as a TB suspect who had two positive smear results and the study concluded that an unacceptably high proportion of diagnosed TB cases were initial defaulters (Botha et al., 2008).

With the use of GeneXpert testing introduced in South Africa in 2011, a TB case is defined as a TB suspect with one positive GeneXpert sputum result. When using the DoH definition of initial defaulter and the GeneXpert for diagnosing, it is obvious that many TB cases were missed, and the results for initial defaulters would have been much higher if the DoH definition was applied (Ndjeka, 2013). Not only was the definition a definitive criterion in the statistics, but lack of information was another factor, where a patient’s details were not adequate at inception (incomplete information was either collected, or incorrect information was provided) (Botha et al., 2008; Buu et al., 2003).

As result of the above, the statistics around defaulters of initial treatment are not reliable: It can be argued that it is not good enough to merely go on statistical analysis and draw conclusions, as the data is not accurate and complete. Also, rather than excluding the studies that failed to use the current DoH definition, one could argue that it is best to look at all data and studies and begin to understand the trends and themes. The theme and trend we identify then, is that there are issues in determining numbers (who are the patients we are seeing), how a case is defined as being a TB suspect at diagnosis (one or two positive smears), and there are issues in determining the default period that we need to address (is it five days or more before we recognise a defaulter). Timing of data input, analysis, and come-backs is definitely an underlying theme to getting it right it seems. What follows is a look at two of the plans that were implemented in order to right some of the wrongs plaguing the healthcare community when it comes to effective and timeous treatment of TB, seemingly interventions implemented to look at how to improve the time spent. By looking at the plans then, we may come to a more global understanding of initial defaulters of TB treatment or delays in the initiation of TB treatment.

2.5 Interventions

What we understand thus far then, is that there are issues in determining whether a patient has DR-TB, and the time it takes to do this (data, timing and testing issues), so in 2011, two interventions were implemented to reduce the diagnostic delays and delays in initiating DR-TB treatment in South Africa, which in light of the issues faced, makes sense to have pursued as improvements to the issues faced. The interventions included the rollout of GeneXpert
diagnostic tools with the adoption of updated diagnostic and treatment guidelines, and the decentralisation of DR-TB care. The effects of these interventions are discussed below.

Considerable progress has been made in diagnosing and detecting DR-TB since the rollout of GeneXpert: By way of explanation, rifampicin resistance is a reliable marker of multi drug resistance, as around 90% of patients that are resistant to rifampicin are also resistant to isoniazid, and are therefore categorised as MDR. GeneXpert testing is able to detect rifampicin resistance without additional testing such as using drug susceptibility testing or line probe assay, as required on sputum smear and culture tests (Coovadia et al., 2013).

Increasing rifampicin-mono resistance has been recently documented in the Western Cape and KwaZulu-Natal provinces (Coovadia et al., 2013). Before the use of GeneXpert, it was estimated that 63% of DR-TB cases in South Africa were diagnosed, which increased onward transmission of DR-TB (Streicher et al., 2012). A large increase in the number of laboratory confirmed DR-TB cases has been observed since the rollout of GeneXpert. According to NDoH, the number of laboratory confirmed DR-TB cases increased from 7,386 in 2010 to 14,161 in 2012, indicating an increase of 91.7% over two years (Ndjeka, 2013). Simultaneously, the number of laboratory confirmed XDR-TB cases increased from 741 to 1,545 – indicating an increase of 108% over two years (Ndjeka, 2013).

The GeneXpert has not only improved rates of diagnosis and therefore increased incidence but has reduced the time of DR-TB diagnosis and the results are available within two hours without the requirement of highly trained personnel (Boehme et al., 2011). Results are faxed to facilities within 24 hours of sputum collection. Lab diagnostic turnaround time has been reduced from six weeks using a culture (FIND, 2006) to two hours using GeneXpert testing (Menzies et al., 2012). As a result of the updated algorithm and GeneXpert rollout, all TB suspects should now also be screened for rifampicin resistance. This capitalises on the time at initial diagnosis, to try and establish the type of TB we are dealing with, and also to try and address it much quicker than we normally would. This is a major win for improving lag times between diagnosis and treatment (get it all done in one go if you can and win on statistics and treatment initiation – thereby improving treatment initiation).

Prior to the introduction of GeneXpert, a retrospective cohort study was conducted at a Western Cape Hospital and the mean delay was 80 days (11.4 weeks) between the dates of sputum collection to treatment initiation (Jacobson et al., 2013). Similarly, a prospective cohort study in KwaZulu-Natal found average delays between 72 and 93 days from the date
of sputum collection to treatment initiation (Loveday et al., 2012). After the introduction of GeneXpert, an observational cohort study was conducted in 10 high burden clinics in Cape Town. The study found a 26 day reduction in the time to treatment following sputum collection. The study authors also reported that 80% of the reduction in time to treatment was due to reduced laboratory turn-around times, as there were ongoing delays to treatment initiation following diagnosis: As an overall result then, the time taken from diagnosis to treatment initiation was approximately 10 days when using the GeneXpert (Naidoo et al., 2014).

Given the above, one can argue that GeneXpert is beneficial in reducing the time to diagnose DR-TB, as well as playing a role in reducing the length of time to initiate DR-TB treatment, the reason being that GeneXpert testing was rolled out in conjunction with decentralisation guidelines.

The guidelines for decentralised DR-TB care were actually implemented because of evidence that decentralised community-level care could be implemented without compromising treatment outcomes (Cox, 2010). The NDoH 2011 guidelines stated that the waiting lists for patients who need to be admitted to centralised units are long, delaying the initiation of treatment in some provinces for three or four months and several patients die before starting treatment (NDoH, 2011). Patient factors also contribute to this delay and it will be discussed in the section of patient factors). Furthermore, a cost analysis was done to compare the costs of DR-TB treatment between inpatient and outpatient health facilities. Diagnostic and monitoring tests must be performed on DR-TB patients and decentralized DR-TB management is a cost effective option in resource-poor settings (Pooran et al., 2013; Botha et al., 2008).

The guidelines that were eventually implemented started to adopt a more integrated and manageable, repeatable, and dependable process of DR-TB management, patient management and record management – effectively improving time management of DR-TB over the longer-term. Standardising treatment across facilities as a key to improving access to patients and treatment that goes along with positive diagnosis of DR-TB. The standardised decentralisation guidelines therefore aimed at accessing patients much quicker, making it easier for them to come back and start treatment, access treatment and stay in contact – removing barriers to entry as it were. Thus, the guidelines to decentralisation recommended that DR-TB patients with sputum negative smears and patients that refuse hospitalisation are initiated onto out-patient treatment at primary health care clinics (NDoH, 2011). The
guidelines also advise that clinics should also provide daily injections to the patients with smear negative results and ongoing treatment to DR-TB patients who were discharged from hospital or to initiate DR-TB treatment when patients are referred from private health facilities because traditional, centralised hospitals are increasingly unable to accommodate the increasing number of DR-TB patients. Patients diagnosed with RR-TB should be started on a standard MDR-TB regimen while awaiting the results of further resistance testing (NDoH, 2011). Patients who were diagnosed with MDR-TB that is too complicated to treat at primary level facilities and XDR-TB should still be referred to centralised and decentralised DR-TB units for hospitalisation and for treatment to be initiated (NDoH, 2011).

In further studies in Khayelitsha, a township in Cape Town, 85% of patients diagnosed with DR-TB in the area initiated treatment after the implementation of decentralisation. This is significantly greater than the national average of 42%. This achievement was also due to shortened time to diagnosis, better tracing systems and improved access to treatment (Cox et al., 2014).

In summary then, there are many that attest the fact that decentralisation was quite effective as an intervention and solution to manage DR-TB – specifically reducing times to treatment initiation (Cox, 2014; Heller et al., 2010; Loveday et al., 2012). Sadly, despite the great departmental efforts to achieve the goals put in place, including an observed improvement in the statistical data, studies show that there is still a delay in initiating DR-TB treatment. A cross-sectional study was conducted in Gauteng after the decentralisation of MDR-TB treatment and it included all newly diagnosed DR-TB patients in 2011. (Ebonwu et al., 2011). Of the newly diagnosed MDR-TB patients, only 63% were initiated on treatment - which is not ideal at all, as delay and non-initiation of MDR-TB potentially increases morbidity and mortality of MDR-TB in the community. Of those who died prior to initiation of treatment, 79.8% were referred for laboratory diagnosis from hospitals, which indicate delays in follow-up of newly diagnosed patients (Ebonwu et al., 2011).

It was subsequently identified that there are weaknesses in both centralised and decentralised care for patients with MDR-TB, however, one of the strengths this particular study found was that there are health system factors that are common obstacles to initiation of treatment and optimal continuation of treatment (Loveday et al., 2013). It is purported that patient costs also influence timely diagnosis and initiation of treatment in both centralised and decentralised health facilities. As a result, it is important to explore the factors that affect the timely initiation of treatment.
2.6 Factors Affecting the Timely Initiation of DR-TB treatment

In this section the researcher will discuss patient factors associated with initial default of DR-TB treatment, as patients and their beliefs, life stories/history and current circumstances have the potential to affect the time between diagnosis and initiation of DR-TB treatment. Most of the literature that exists on this subject does however talk about TB in general, not specifically DR-TB. For the purpose of this review, the researcher will still use the body of work on the subject, as the researcher believes strongly in the seriousness of undiagnosed DR-TB cases, some of which are simply classified as TB cases because of how TB is defined, inter alia. One such body of work is a systematic review of 58 studies worldwide found that the main reasons for delay in initiating TB treatment is rural residence; low access due to geographical barriers due to informal settlements; initial visitation to private practitioners, or traditional healers; old age; poverty; female sex; alcoholism and substance abuse; history of immigration; low education level; low awareness of TB; incomprehensive beliefs; self-treatment and stigma (Dag et al., 2008). Substance abuse has also been shown to increase treatment delays amongst drug susceptible TB patients (Storla et al., 2008). Some of these factors are discussed in more detail below.

2.6.1 Factors relating to Site of TB

A study conducted in Norway found that the site of TB was a significant predictor in delay of diagnosis and treatment initiation: The delay of patients with extra-pulmonary TB was two to three times more than the delay of patients with pulmonary TB (Farah et al., 2005); and a systematic review of studies of patients with drug susceptible TB also reported that patients with extra-pulmonary TB have longer delays to diagnosis than patients with pulmonary TB (Storla et al., 2008). Despite having longer delays in diagnosing extra-pulmonary TB, a study conducted in the Western Cape reported that patients with extra-pulmonary MDR-TB had shorter delays to treatment initiation than patients with pulmonary MDR-TB. This could possibly be because the patients with extra-pulmonary MDR-TB are more ill and already admitted to hospital, making initiation of treatment easier upon diagnosis (Jacobson et al., 2013). In fact, Haemoptysis may be the most characteristic and severe TB symptom, therefore it causes the patient to hasten for clinical assistance and leads to timely diagnosis and treatment initiation (Cai et al., 2015). Notwithstanding the above, according to Farah et al. (2005), the median and mean period between hospital admission and initiation of TB treatment for patients hospitalised before treatment initiation was 4 (1-18) and 18 days, thus indicating that hospitalisation can cause delays.
2.6.2 Factors relating to Patients’ Demographics and Perceptions

The section that follows purports to touch on various patient demographics, that is derived from the patients natural being and make-up (sex and age), upbringing (nationality and education), economic status (living conditions and monetary considerations), societal dispositions on diseases, and the role this plays in the consequential natural susceptibility to dealing with DR-TB diagnosis and treatment.

2.6.2.1 Sex and Age

Due to the higher prevalence, TB is more likely suspected and definitely investigated more readily in males. In a systematic literature review of factors associated with patient and provider delays for TB conducted in Asia, results showed that in seven of 33 studies showed a negative correlation between male sex and delay in seeking diagnosis and treatment (Cai et al., 2015). The same studies also found that males are more likely to seek health care earlier when symptoms appeared. A community survey conducted in India reported that the initial default was 24.4% among males and 17.6% among females – more males that females were unwilling (refused or not interested) to initiate treatment and the default rate was similar in the 15-44 and 45 and over age groups (Gopi et al., 2005).

Despite the above, a study conducted in KwaZulu-Natal and a study conducted in Gauteng did not observe any differences in rates of treatment initiation between age or gender groups (Naidoo et al., 2014; Ebonwu et al., 2013). The Gauteng study did however still conclude that patients over the age of 65 years had an increased risk of not initiating DR-TB treatment (Ebonwu et al., 2013).

2.6.2.2 Nationality and Education

On top of being male and over 65years, a Voss De Lima et al.’s (2013) study in Johannesburg related that patients’ who were not South Africa citizens, and demonstrated that they were lacking in formal education, whilst also exhibiting low CD4 counts, were more likely to be at risk of failure to initiate treatment. The reasons behind this were that they were not traceable by phone and provided incorrect addresses: Foreign-born individuals and individuals who lack formal education may find it challenging to interpret the information provided at the time of referral and may be less empowered to seek continuation of care. This is supported by a systematic review that showed patients who immigrated and have an illegal residence are more likely to have delayed diagnosis and initiation of treatment (Storla et al., 2008), compounded by the fact that there are language barriers, fear of being deported, cultural
differences in the interpretation of signs and symptoms and stigma in patients from high prevalence TB countries (Farah et al., 2006).

A systematic review of factors that impede DR-TB treatment linkage, showed that living in a rural area increases one’s risk of diagnostic and treatment delays (Storla et al., 2008; Cai et al., 2015), whereas the Gauteng study showed that patients living in Gauteng’s central business districts were less likely to initiate treatment than people living in the suburbs or informal settlements (Ebonwu et al., 2013).

A cross-sectional study conducted in Gauteng in 2011 found that people residing in townships were less likely to initiate MDR-TB treatment compared to patients residing in prisons, informal settlements and in suburbs (Ebonwu, 2011). Patients in prisons were more likely to initiate and comply with treatment due to the strict rules in prisons. Social grants was an incentive that contributed to the initiation of treatment in the informal settlements and better access to care was the reason for people living in the suburbs to initiate treatment (Ebonwu et al., 2011). Health facilities are not always easily accessible without transport and patients often use public transport to attend health facilities. According to Cai et al. (2015) the use of public transport for the first visit causes a delay in the diagnosis and treatment. The time taken to take public transport back and forth has to be a great consideration (we need to fit healthcare into our daily routines). It is no wonder then that long travel time or distance from the patient’s home to the health facility was reported to be negatively correlated with provider and patient delays and consulting a public hospital was associated with delay in ten studies (Cai et al., 2015). In fact, a study conducted in rural Ethiopia agreed that difficulty of geographic access to health facilities was identified as one of the primary reasons for patient delay (Tadesse et al., 2013); this indicates that geographic location of health facilities can influence the timeliness of diagnosing and initiating DR-TB treatment, particularly in remote and low-income areas, which brings me to the next factor to consider: Money needed or spent in order to see to health care needs.

2.6.2.3 Financial Considerations

The cost involved in attending health facilities places a financial burden on patients therefore poverty may discourage patients from seeking health care in a timely manner and therefore affect the initiation of treatment amongst DR-TB patients (Cia et al., 2015). The cost includes transport costs, money lost for being absent from work (loss of wages) in order to attend the health facility, payment for consultation, tests and medication at private health facilities and
traditional healers. Work related problems have also been identified as a reason for initial default (Gopi et al., 2005). Loss of money due to absence from work causes patients to seek help from traditional healers for the first consultations, and thus cause a further delay in diagnosis (Storla et al., 2008) because traditional healers do not have the equipment to diagnose DR-TB however patients seek help from traditional healers or private health facilities due to convenient operating hours, distance from home and shorter waiting times. Furthermore, two Cape Town studies reported that patients sometimes miss appointments or delay initiating treatment due to family, financial and employment responsibilities (Naidoo et al., 2014; Niekerk et al., 2013).

2.6.2.4 Societies Views on Health, and their Influences on Patients’ Reactions

A participatory research study in Cape Town found that people with TB may avoid or delay TB diagnosis due to fears around anticipated HIV-stigma (Murray et al., 2013). A study conducted in the Eastern Cape South Africa found that 95% of people tend to hide their TB status because of stigma (Cramm et al., 2010). Cape Town there is a common misconception that TB is a disease that people who live in poverty contract because of filth (Murray et al., 2012). TB is considered to be an African disease and there is a misconception that TB patients will develop HIV (Cramm et al., 2010). The anticipation of HIV-stigma and the feeling of lack of control discourage people from seeking TB diagnosis and treatment and therefore may cause a delay in diagnosis and consequently delays between diagnosis and treatment (Murray et al., 2012). The study found that people delay going to the clinic out of fear that they will be told they are HIV-positive and because they fear that people will talk about their visit to the clinic (Cramm et al., 2010).

2.6.2.5 Patients’ Sentiments on the health care system

Patients’ experiences at facilities affect the time taken to initiate DR-TB treatment. A study conducted in Gauteng found that patients who previously reported having negative experiences at primary clinics were less likely to link to care following diagnosis of TB (Edginton et al., 2005). Similar challenges have been identified in Vietnam (Buu et al., 2003). Patients’ negative perceptions of health care worker attitudes also contribute to default following DR-TB treatment initiation in South Africa (MRC, 2009). Dissatisfaction with health services as a result of the perceptions of the bad staff attitudes, have been reported to be a reason for delayed diagnosis and initiation of DR-TB treatment. Previous negative
experiences at health facilities may cause patients to delay returning to the facilities and therefore contributes to failed linkage of diagnosis to treatment (Gopi et al., 2005). Unfortunately, if you don’t enjoy being at a place, you don’t go, and if being at the health care facilities negatively affects your mental well-being, then time spent at the hospitals or clinics can also become an issue, as evidenced by a study that found that the higher educated people mentioned that there are long queues at the clinic, therefore they delay going to the clinic (Cramm et al., 2010). The above then, would point to it worth doing some analysis on what is happening in the health system that could potentially affect (delay or negate) initiation to treatment of DR-TB.

2.6.3 Factors relating to the Health System

Whilst there are many more factors on patient-related studies that point to failure to initiate treatment in and of themselves, there are other factors contributing to the linkage to treatment problem being discussed in this review, factors that relate specifically to the health system. It is purported above that health system factors have the potential to either delay or reduce the length of time taken to initiate DR-TB treatment. These factors are considered next, and as you will note, administrative issues are at the heart of many of the health system issues we are facing today.

2.6.3.1 Referral Issues between Health Facilities

In KwaZulu-Natal the integration of TB and HIV services has been reported to improve the outcomes of DR-TB (Loveday et al., 2014) and a study conducted in Gauteng found that HIV-positive patients were more likely to initiate DR-TB treatment after diagnosis than patients who were not infected with HIV (Ebonwu et al., 2013). The integration of services is beneficial to patients as it provides a holistic care approach and patients can be initiated on treatment without being referred to another department or facility. Referring patients to another facility contributes to the delay in initiation of treatment because there is often a gap in the communication process.

A cohort study of TB patients diagnosed at an urban hospital, to assess the outcomes of linkage to TB and HIV care and identify risk factors for poor referral outcomes was done (Voss De Lima et al., 2013). The study was aimed to determine the proportion of people who fail to link to care for TB and HIV treatment following a TB diagnosis at an inner city hospital in Johannesburg, South Africa, and assess risk factors for delayed or failed linkage to TB and HIV care. Linkage to care was determined by review of clinic files, national death
register, and telephone contact, and classified as linked to care, delayed linkage to care (>7
days for TB treatment, >30 days for HIV care), or failed linkage to care. Among 593 TB
patients, 23% failed linkage to TB treatment and 30.3% of the 77.0% who linked to care
arrived late. Among 486 (86.9%) HIV-infected TB patients, 38.3% failed linkage to HIV
care, and 32% of the 61.7% who linked to care presented late. One in six HIV-infected
patients failed linkage to both TB and HIV care. Only 20.2% of HIV-infected patients were
referred to a single clinic for integrated care. A referral letter was present in 90.3%, but only
23.7% included HIV status and 18.8% CD4 cell count (insufficient information in the referral
letter). This particular study indicates that there is a gap in communication within the health
system. Patients are either referred for care to another facility without a referral letter, or with
an incomplete referral letter, and no direct follow-up between the referring hospital, the clinic
that the patient is referred to and the patient. It is important to deduce reasons for this. Thus,
the study also reported that staff may not spend enough time on patient education and may
not be able to communicate in the native language of the patient (Voss De Lima et al., 2013),
which is a contributing factor to the gap in communication discussed above. Moreover,
Loveday et al. (2013) reported that 15% of the patients reviewed in the study had missing
notes: missing clinic records causes a delay in referral of patients, initiating and continuation
of treatment. However, problems with the computer system were also reported as a reason for
delay – and therefore administratively, the issue was purported to be systematic and not really
staff related. One should however argue that in the absence of working systems and
electricity etc., there should always be a manual process to follow. The computer and
computer record may be just as good as the user or recorder. It’s not good enough to use this
as an excuse, but unfortunately, the efficacy of a health care professional is of vital
importance, which the next section explores.

2.6.3.2 Factors Relating to Inadequate Patient Analysis

Poor history taking causes delay in diagnosing TB. The shame is that practitioners prescribe
several courses of antibiotics before investigating for TB, despite the patient having family
members with a history of TB (Farah et al., 2005). A recent Gauteng study reported that 84%
of patients that did not initiate MDR-TB treatment were previously treated for TB and these
patients faced a greater risk of death (Ebonwu et al., 2013). Furthermore, substance misuse
was reported to increase the delays in diagnosing and treatment amongst drug susceptible TB
patients (Storla et al., 2008). In fact, in the Western Cape, smoking currently, or in the past,
was reported to be associated with delays to treatment initiation (Jacobson et al., 2013).
Moreover, the presence of chronic cough or lung disease negatively affects diagnosis and treatment initiation time (Storla et al., 2008). As substance misuse and smoking is typically understood to cause chronic coughs, it is no surprise then that patients will delay seeking medical assistance, which ultimately increases the delay of diagnosing and initiating DR-TB. Thus, the presence of chronic cough or lung disease negatively affects diagnosis and treatment initiation time (Storla et al., 2008), and failure to record and link this to possible TB checks is key in delaying diagnosis and treatment of TB.

2.6.3.3 Procedures to Recall Patients

Unfortunately, there is often a domino effect in most things, and if there is inadequate analysis of patients, balls may be dropped in various other record taking procedures: In fact, procedures to track and recall patients who have been diagnosed as having DR-TB, influence the initiation of treatment. Hospitals are more inclined to rely on phone calls to contact patients as a means of follow up, compared to primary level clinics who perform home visits for patients that cannot be contacted telephonically (Nkosi et al., 2013). Depending exclusively on phone calls is potentially challenging because patients in rural areas, do not have phones (Jacobson et al., 2013) and cell phones are not always reliable as people change numbers, phones are stolen or patients may not own cell phones because they do not have electricity in the area or cannot afford it.

A study conducted in Gauteng reported that tracing procedures could be improved at clinics by increasing staffing levels and clarifying the roles and responsibilities of staff (Nkosi et al., 2013). In Cape Town, the employment of nurses at a sub-district level to trace patients contributed to timely initiation (Naidoo et al., 2014). Given that tracing procedures are now in place at clinics, clinics are more effective in tracing patients to initiate treatment.

The use of community health workers is a cost effective way to increase staffing at health facilities. To improve follow up on diagnostic results, a cell phone system was piloted by TB/HIV Care in KwaZulu-Natal, which used text messages to inform community health care workers of new TB diagnoses. After receiving text messages, community health care workers were responsible for contacting patients to inform them of their results and to refer them to clinics for treatment. The project reported initiating 89% of patients onto treatment within five days of diagnosis (TB/HIV Care, n.d.). This is all good and well, however, we need consistent staffing and availability of staff to actually make a dent in improving the negative linkage to treatment issues, and this is what our next health system factor relates to.
2.6.3.4 Staff Turnover

Whilst the above a KwaZulu-Natal study reported that high staff turnover weakens the consistency and quality of MDR-TB care. Facilities with more consistent staffing were more likely to notice missed appointments and follow up with patients when necessary (Loveday et al., 2014). Staff turnover has the very real result of leaving health care facilities with untrained staff in charge (in some instances), which results in health workers not being aware of policy and guideline changes and this contributes to delayed initiation of DR-TB treatment. Many health care workers have reported being unaware of or not having seen updated guidelines. In a Gauteng study, 86% and 64% of staff who were interviewed at primary care clinics and hospitals respectively, reported being unaware of the MDR-TB guidelines (Nkosi et al., 2013).

2.7 Conclusion

Previous studies have identified factors that influence the initiation of DR-TB treatment and they have also highlighted research gaps. To date, there has been little exploration of patient and health worker perspectives regarding factors that impact on the initiation of DR-TB treatment and there is limited understanding of how patient and health system factors impact on the initiation of DR-TB treatment. This study aims to explore these factors. The next chapter discusses the methodology that is used in this study.
Chapter 3 - Methodology

3.1 Introduction
The third chapter of this study outlines the methodology used in this study. The study methodology includes the following: aims and objectives; study design; study setting; research population; sample and sampling procedure; data collection and analysis; ethical considerations and study limitations.

3.2 Aim
The aim of the study is to explore the factors influencing whether newly diagnosed drug resistant tuberculosis (DR-TB) patients initiate treatment on time at Primary Health Care facilities within the Mitchell’s Plain sub-district.

3.3 Objectives
The objectives of the study are:

- To explore the experiences and perspectives of health providers about the factors that influence the time of initiation in newly diagnosed DR-TB patients
- To explore the experiences and perspectives about treatment initiation of newly diagnosed DR-TB patients who initiated treatment within five days of sputum collection
- To explore the experiences and perspectives about treatment initiation of newly diagnosed DR-TB patients who initiated treatment after five days of sputum collection.

3.4 Study design
To achieve the aim and objectives of this study a qualitative approach was utilised. Qualitative research focuses on the study of people in their natural environment and attempts to understand the meaning of people’s words and behaviour. It aims to obtain rich descriptions of people’s social worlds (Lambert et al., 2012). Qualitative research allowed the researcher to explore the experiences and perceptions of health providers and patients about the timely initiation of newly diagnosed DR-TB patients by giving the participants voices of their own in an environment that they are comfortable in.

Qualitative research requires more in-depth and open ended questions (Baum, 1995). The qualitative method allowed the researcher to conduct semi-structured interviews with
participants to explore their perceptions, experiences and roles in timeous treatment initiation. The qualitative method permits the researcher to explore further by adding questions and by asking clarifying questions while conducting the interviews or later in the study if the researcher required further clarification.

### 3.5 Selection of the study setting
Mitchell’s Plain was selected as the setting for this study in order to explore the experiences and perspectives of health provider and patients about the factors that influence the time of initiation in newly diagnosed DR-TB patients. The Mitchells Plain sub-district is relatively large and it includes the areas of Mitchells Plain, Crossroads, Philippi and Weltevrede (CoCT, 2012). The researcher has decided to choose part of a sub-section of the Mitchells Plain area within which to conduct this study. In order to determine in which sub-section of Mitchells Plain the research would be conducted, convenience sampling was used to select the sub-section. Eastridge clinic and Lenteguer clinic was selected for their central location, for ease of access via public transport and because the researcher resides in the area.

### 3.6 Study population
The study population refers to individuals from whom the sample was selected to participate in this study because they meet the inclusion criteria as stipulated in this study (Burns et al., 2003). The study population consists of individuals who receive DR-TB treatment at the City of Cape Town health facilities in the Mitchells Plain sub district that has been selected for the purpose of this study.

### 3.7 Sampling
The study sample chosen for the purpose of this study provided an in-depth understanding of the phenomenon by sharing their experiences (Sandelowski, 1995). The sample consists of two categories of people (the patient population consisting of 15 participants and the health care worker population that consist of three participants). The patient population reflects different contextual factors as these factors may have influenced how the phenomenon was experienced (Kuper et al., 2008). The first group are patients who demonstrate rifampicin resistance (RR) identified by any laboratory test, diagnosed for the first time during the study sample period (and for whom this was the first test result in the six month period prior to the study). Some of the patients in the study sample initiated DR-TB treatment within five days from the date of sputum collection and some patients initiated treatment after five days of sputum collection.
3.7.1 Inclusion Criteria

- All patients over the age of 18 years with a RR result.
- All patients regardless of co-morbidity because the MDR-TB treatment timing guidelines apply to all.
- Patients with private sector laboratory results will be eligible for inclusion.

3.7.2 Exclusion Criteria

- Patients with an additional or first previous RR result within the preceding 6 months because they are not considered newly diagnosed.

The second group sample consisted of health care workers (TB nurses or TB assistants allocated to work in the TB room and the MDR-TB coordinator). The sub district MDR-TB coordinator and one health care worker from each of the two facilities who were allocated to work in the TB room was interviewed to explore health system barriers that contribute to the delay in initiating MDR-TB treatment.

This study used the purposive sampling technique by purposefully recruiting participants who met the inclusion criteria to participate in this study. The researcher made an effort to select a similar proportion of male and female participants in order to explore the impact that gender has on timely initiation of DR-TB treatment. Within each gender group, effort has also been made to select patients with a wide age range in order to explore how age influences timely initiation of DR-TB treatment. Patients under the age of 18 years were excluded given the complexity involved in securing their informed consent to participate in the study.

The MDR-TB patients were selected from an electronic drug register that the MDR-TB coordinator has access to - this register has the details of patients who test positive for DR-TB within the Mitchell’s Plain sub district. Once the researcher arrived at the relevant facilities, the list of patients selected from the electronic register was compared to the MDR-TB register at the facility and the list of patients to be interviewed was then finalised by the researcher. Those who were eligible for the study were contacted by a health care worker from the relevant facility who informed them about the study and the interviews that took place on the day of their clinic appointment. The sub district manager informed facility managers about the study and that the researcher will be visiting the facilities to interview health care workers and patients.
3.8 Data collection

Semi-structured interviews were used to collect data. An interview guide was used as designed for each group (Appendices 3 & 4) (Robson, 2011). The semi-structured interview was used to potentially co-create meaning of health-related experiences with patients by allowing them to share their experiences (DiCicco-Bloom et al., 2006). Semi-structured, open-ended interview guides were used to guide the interviews. Open-ended questions were used to draw out the participants perceptions regarding why DR-TB treatment was or was not timeously initiated. However, as the study is exploratory, the researcher was not limited to questions in the guides and probes were also used in order to get more details from the responses given by the participants.

3.9 Data analysis

Data was analysed and coded manually, using Thematic Coding Analysis (TCA). The tape recorded interviews were transcribed by the researcher. TCA was informed by the research question and codes that emerge from the data. The themes functioned as a basis for further data analysis and interpretation (Robson, 2011). TCA consists of five phases (Gibbs, 2007):

Phase 1: Familiarisation – the researcher became familiar with the data by interviewing the participants, listening to the audiotapes, transcribing the recordings and reading the transcripts. The researcher made notes of key impressions.

Phase 2: Coding - The researcher grouped together conceptually similar data by examining the data for similarities and differences.

Phase 3: Identifying Themes – The codes were examined, sorted and clustered together into common themes.

Phase 4: Reviewing Themes – this process may involve two levels; level 1: The themes are placed on charts or a thematic map and the researcher scrutinized it. Level 2: The researcher studied the individual themes to ensure validity and the correctness of the meanings reflected in the data set.

Phase 5: Integrating and Interpreting – The analysed data was interpreted and the researcher has drawn conclusions from the themes and organisation of the data to develop an explanation.
3.10 Rigour

For the purpose of this study, the researcher discusses the application of triangulation, researcher reflexivity and transferability to ensure rigour in this study. Triangulation ensures the validity of results, by using the information received from various sources to create common themes or categories in a study (Creswell & Miller, 2000). Triangulation of data sources was done in this study by conducting semi-structured interviews with health care providers and patients. The data was compared and personal experiences, perceptions and views were considered in terms of similarity, consistency and differences. By using the information received from various sources to create common themes or categories in the study, the researcher also ensured validity through triangulation (Creswell & Miller, 2000).

Researcher reflexivity is a method of ensuring validity in the study, by self-disclosing their assumptions, beliefs, and biases, the researcher acknowledged, described and reflected on the social, cultural and historical forces that may influence the interpretation of the data (Creswell & Miller, 2000).

Transferability was established by providing a detailed description of the study context (Creswell & Miller, 2000). In addition to providing thick description of the study context, inclusion and exclusion criteria of participants, number of participants, data collection tools and methods used for this study and factors that influence the delay of initiating MDR-TB treatment is included in the study to establish credibility. The results could therefore possibly be transferred to similar study contexts (Creswell & Miller, 2000).

3.11 Ethical consideration

Ethical approval was sought from the University of the Western Cape Senate Research Committee and permission was granted from the City of Cape Town (City Health) to conduct the study at their facilities. Participants were given an information sheet (Appendix 1). Participants were required to provide specific written informed consent in order to be included in the study and were informed that they could withdraw from the study at any time during the study (Appendix 2). Participants were enrolled into the study once they have provided informed consent.

The researcher has conformed to the organisations code of conduct which ensures confidentiality of client information. Confidentiality was further assured by assigning clients unique identifying (ID) numbers so that all their data could be coded with this number and not their details.
While there were no specific risks associated with participating in this study the fact that people were unwell and the nature of the questions about failure to follow procedure may be sensitive and cause people to feel persecuted. The questions were very sensitively phrased and the risk associated with the sensitive nature of the discussions was acknowledged. Questions about failing to initiate treatment on time may offend participants (they might feel that they are being blamed) or cause discomfort (psychological or otherwise) and elicit negative reactions. The researcher minimised such risks by acting promptly if discomfort was noticed and reassured participants. In the unlikely circumstance that this may further intervention was required, participants were referred to a suitable professional for further assistance. Participants were reassured that they will not be reported or victimised in any way and that their names will not be used.

Visits from the researcher could be a potential risk to health care workers and to patients as it could potentially disrupt services, therefore the researcher communicated with facilities prior to visits in order to identify the most convenient and least disruptive times to visit the facilities.
Chapter 4 – Findings

4.1 Introduction

This chapter presents the findings of this study about the timely initiation of DR-TB treatment of patients who were tested for TB at two primary health care (PHC) clinics in the Mitchell’s Plain sub-district. Thematic coding analysis was used in the data analysis process as discussed in Chapter 3. The main factors were first identified as being patient and health care factors. The data was then grouped together into main and sub-themes that were relevant to the two factors. The key themes are presented below in Table 1 and the results will be presented as per the key factors and themes in this chapter.

Table 1: Themes and Sub-Themes of the Study Findings

<table>
<thead>
<tr>
<th>Themes</th>
<th>Sub-Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>4.3 Patient Factors</td>
<td>4.3.1 Factors relating to Patients’ Personal Characteristics and Perceptions</td>
</tr>
<tr>
<td></td>
<td>4.3.1.1 Health Status of Patient</td>
</tr>
<tr>
<td></td>
<td>4.3.1.2 Social Contact with a TB Patient and Previous TB</td>
</tr>
<tr>
<td></td>
<td>4.3.1.3 The Role of Knowledge and Understanding</td>
</tr>
<tr>
<td></td>
<td>4.3.1.4 The Potential Role of Patients’ Beliefs and Attitude</td>
</tr>
<tr>
<td>4.3.2 Financial</td>
<td>4.3.2 Financial Considerations</td>
</tr>
<tr>
<td></td>
<td>4.3.2.1 Employment as a Barrier and Social Grant</td>
</tr>
<tr>
<td></td>
<td>4.3.2.2 Subsistence Needs and Access to Health Facilities</td>
</tr>
<tr>
<td>4.3.3 Societies Views on Health, and their Influences on timely initiation of DR-TB treatment</td>
<td>4.3.3.1 Stigma</td>
</tr>
<tr>
<td></td>
<td>4.3.3.2 The Effect of a Supportive Environment on the Initiation of DR-TB treatment</td>
</tr>
<tr>
<td>4.4 Factors relating to the Health System</td>
<td>4.4.1 Waiting time and clinic times</td>
</tr>
<tr>
<td></td>
<td>4.4.2 The Environment at Health Facilities</td>
</tr>
<tr>
<td></td>
<td>4.4.3 Procedures to Recall Patients</td>
</tr>
<tr>
<td></td>
<td>4.4.4 The Availability of Resources</td>
</tr>
</tbody>
</table>
4.5 Factors Relating to Inadequate Patient Analysis

4.5.1 Substance Misuse

4.5.2 Visiting Private Doctors

The participants’ comments are presented in italics within each theme or sub-theme, as further evidence of the particular barrier or enabling factor.

4.2 Demographics of the Study Population

Male and female patients who met the inclusion criteria for this study were interviewed. The age of the patients’ ranged between 18 and 73 years. Most of the patients were over the age of 45 years. Most of the patients were unemployed at the time of the interview and one patient was a university student. Most of the patients lacked formal education and did not complete primary school education. Of the 13 patients who were interviewed only three patients initiated treatment within the recommended time as per guidelines, only four potential patients were identified as eligible for this category, but one patient was not able to attend the interview due to work commitments. The study was conducted at two health facilities within the Mitchell’s Plain sub-district. All three patients who initiated DR-TB treatment within the recommended time were attending one health facility. None of the patients at the second facility initiated treatment within the recommended time.

4.3 Patient Factors

In this section we discuss patient factors that were identified as either barriers which contributed to the delay in the initiation of DR-TB treatment or as facilitators which contributed to the timely initiation of DR-TB treatment. Patient factors are discussed below under the following main headings: factors relating to patients’ personal characteristics and perceptions; financial considerations; society’s views on health, and their influences on timely initiation of DR-TB treatment.

4.3.1 Factors relating to Patients’ Personal Characteristics and Perceptions

The section that follows examines various personal patient characteristics or issues that respondents felt affected the time to DR-TB diagnosis and treatment. In particular, we will discuss patients’ health status; social contact with a TB patient and previous TB; the potential role of knowledge and understanding and the role of patients’ beliefs and attitudes. We will explore the potential role that patient characteristics play in the time DR-TB treatment is diagnosed and DR-TB treatment is initiated. These factors were described by participants of
this study as either a barrier or facilitator in the diagnosing of DR-TB and the initiation of DR-TB treatment.

### 4.3.1.1 Health Status of Patient

The health status of patients in the sample seemed to influence whether or not DR-TB treatment is initiated, as well as whether the patient is treated in a centralised or decentralised DR-TB facility. The initiation of DR-TB treatment may be delayed based on the medical condition of the patient and can be the result of the patient being an initial defaulter. For example, the patient may not be able to initiate treatment due to the effect of the treatment on the organs in a condition such as renal impairment. The key informant as well as the other nurses who were interviewed highlighted that the health status of the patient is the reason for DR-TB treatment initiation being delayed.

*Especially elderly clients like maybe with renal impairment or uhm... potassium problems, if they have creatinine problems and potassium problems then they can’t be started [on DR-TB treatment].* (Nurse 2)

The nurse below also describes that the health status of a patient has the potential to delay the initiation of DR-TB treatment.

*Creatinine, magnesium, potassium levels has to be within the normal range before patients can start treatment. If patients are too sick or have renal impairment and if they are HIV co-infected then [DR-TB] treatment cannot be started immediately.*

(Nurse 3)

The health status noted above may be affected by the impact of DR-TB treatment on the renal system of such patients. Patients’ medical status also seems to possibly determine whether the patient will return to the facility to collect their sputum results. The intensity of DR-TB and the physical effect that the symptoms may have on the patient was a barrier for some participants. In some cases DR-TB left patients in severe pain which they felt made it difficult for them to return to the facility for their sputum results as well as to initiate treatment. The symptoms made it difficult for the patients to execute tasks that they were usually comfortable doing – such as walking.

*It was difficult to go to the clinic again. I knew that I needed to start using the medication, but I couldn’t walk. I was very weak. I really had to struggle to get to the*
clinic and I walked there eventually, albeit very slowly and with difficulty. (Patient 12, initial defaulter)

This patient does not have transport and has to walk to the clinic. The patient experienced pain, shortness of breath and lack of energy, which made walking to and from the clinic very difficult. Patients’ experience various symptoms, however shortness of breath, lack of energy and lethargy were noted as contributing to delays in initiation of DR-TB treatment for several patients.

4.3.1.2 Social Contact with a TB Patient and Previous TB

Being in contact with someone who has TB, who previously had TB, or having had a personal experience of TB previously, served as an enabler for some of the patients who were interviewed in this study. Evidence of this is given below:

*My mommy told me to go for a test. She had TB before but she’s done with the TB.* (Patient 7, non-defaulter)

None of the patients who were interviewed in this study who previously had TB mentioned that previous TB was a barrier for the initiation of DR-TB treatment. None of the patients who were interviewed in this study previously had DR-TB. For the minority of the patients who previously had TB, previous TB was a facilitator to initiate DR-TB treatment, see quote below:

*I previously had TB. Where I live there are two boys who have TB, so I came for a [TB] test. My son died from the same TB [MDR-TB].* (Patient 8, initial defaulter)

Being in contact with someone who has TB and personal previous TB definitely heightened the awareness of TB and was potentially a facilitator for the initiation of DR-TB treatment.

4.3.1.3 The Potential Role of Knowledge and Understanding

Knowledge about and understanding of DR-TB had the potential to either enable patients to initiate treatment on time or to be a barrier and cause delayed initiation of DR-TB treatment. Some of the patients who failed to initiate treatment within five days from the date of sputum collection demonstrated lack of knowledge and inadequate understanding of DR-TB. These patients were not aware that initiation of DR-TB treatment potentially reduces the risk of spreading the disease. One participant in particular felt that if safety measures are in place then it is impossible to spread the disease and despite having DR-TB contacts, the participant was still unsure about how DR-TB was contracted.
I’ve been here for 6 months and I still don’t understand about MDR. There’s a lot of people I know who have it and I don’t understand why I got it because we have safety measures that’s in place at work and all that stuff and still somehow, I got the disease. (Patient 2, initial defaulter)

One of the nurses showed that this perception about the inadequacy of DR-TB knowledge is also noted as a problem within the health sector.

 Clients need to be educated about drug resistant TB and why it is important to start them on treatment as soon as possible – more information will make them start earlier. (Nurse 3)

Where people had access to good information about the disease this was an enabler or it created opportunities for access. Understanding that DR-TB disease is contagious and understanding that the initiation of treatment has the potential to reduce the risk of spreading DR-TB encouraged some of the participants to initiate DR-TB treatment as soon as possible. The concern of spreading the disease to family members and friends contributed positively to timely initiation of DR-TB treatment.

 I was hoping and praying that it wasn’t TB. It was very emotional because at that time I didn’t understand TB. I just thought wow... I was going to be contagious... but I had to adjust. I wept it was like I was dying now... I didn’t want my family and friends to get this [DR-TB], so I just had to start it [DR-TB treatment]. (Patient 13, non-defaulter)

It is interesting to note that knowledge and understanding is influenced by many factors, such as being a foreign-born individual, not having permanent residence as well as not originally being from Cape Town, and these were identified as barriers to initiation of DR-TB treatment by health workers. The reason for this observation comes from one of the health workers: she felt that foreign-born individuals rather than locals find it challenging to interpret the information provided due to language barriers. She also mentioned that many of the patients are originally from the Eastern Cape but come to Cape Town for work, and some of these patients go back to the Eastern Cape after testing for TB without returning for their results - the reason for this was not mentioned. Finally, she also found it challenging to recall patients who do not have permanent residence. Unfortunately, none of the patients who were interviewed are foreign-born, from outside Cape Town or without permanent residence.

See commentary from the said healthcare worker:
You can’t actually communicate with them [foreigners], so they can’t speak English sometimes so we always tell them bring somebody with you that can communicate or speak English... We got street kids also, they move around here on the streets and it’s sometimes very hard to find those patients to give them results and we can’t send anybody if the families said that this patient doesn’t live here anymore and they haven’t got a proper address that is so hard to find the patient. We can’t send anybody to a house if the patient moved to an unknown address or unknown area. (Nurse 1)

Knowledge and understanding is a contributing factor to whether or not DR-TB treatment is initiated within the recommended time.

4.3.1.4 The Potential Role of Patients’ Beliefs and Attitudes

The attitudes and beliefs that patients have regarding DR-TB have the potential to be a barrier or a facilitator for the initiation of DR-TB treatment, this is often closely linked to information too. The following patient comment is from an initial defaulter of DR-TB treatment, false belief acted as an enabler for the patient to start treatment, only due to fear that DR-TB will convert to HIV. HIV appears to carry a higher stigma than DR-TB because there is no cure for HIV and the belief that TB converts to HIV was common amongst some of the participants.

If I don’t start with DR-TB treatment, then the DR-TB will become HIV. (Patient 8, initial defaulter)

Positive patient attitude and wanting to be cured functioned as a support for some patients, and for others a positive attitude along with external support was encouragement to initiate DR-TB treatment.

I wanted to come back. Not just because they told me to come back but because I want to be cured. (Patient 6, initial defaulter)

When asked about what motivated patients to initiate treatment or what caused them to delay the initiation of treatment, a positive attitude and the will power to initiate treatment in order to be cured appeared to be a facilitating factor for most of the patients who were interviewed-to initiate DR-TB treatment.

Fear of the unknown emerged as a barrier for some of the patients and is illustrated in the quote below by one of the initial defaulters who were afraid to initiate DR-TB treatment:
I was confused... I was dead scared... because of the unknown. I didn't know what was waiting for me (Patient 2, initial defaulter)

Health workers mentioned patient attitude and how patients accept their diagnosis as a major contributing factor to whether or not patients will initiate treatment early. Although denial was not a barrier for the patients who participated in this study, it is an existing problem for some patients and it is a concern for the health sector which surfaced from health care workers.

Some patients are in denial and they just point blank refuse to initiate treatment. (Nurse 1)

A positive attitude was an enabler for most of the patients who were interviewed. The minority of the patients were affected by fear of the unknown and none of the patients who were interviewed denied their DR-TB diagnosis.

4.3.2 Financial Considerations

Patients have subsistence needs that cannot be met without having a means of finance – such as employment or a social grant. This section describes the effect of employment, social grant and insufficient financial support on timely initiation of DR-TB treatment.

4.3.2.1 Employment as a Barrier and Social Grant

Employment was a barrier for the initiation of DR-TB treatment for the participants who were employed at privately owned companies, because for some of them initiation of DR-TB treatment meant that they would have to give up their jobs with no guarantee that they would be hired at the company again. This is due to the participants either not being permanently employed at the companies or lack of support at work and lack of benefits such as sick leave and unemployment benefits. Patients who initiate DR-TB treatment qualifies for a social grant of R1500 per month for the first six months of treatment. The decision to give up a job to initiate DR-TB treatment was difficult for patients because they would receive a social grant that is a lot less that what they earn being employed. When a client who is employed is diagnosed with DR-TB, the doctor books the patient off from work for six months due to the contagious nature of DR-TB disease.

The grant stopped after six months, it’s tough [without the grant]. I had to leave my work for the first six months [of DR-TB treatment – after diagnosis], but I am looking for a job now. (Patient 9, initial defaulter)
Patients described the idea that they had to stop working as the most challenging part of initiating DR-TB treatment. Most of those who lost their jobs as a result of DR-TB described that it was difficult for them to initiate treatment because job loss would be the end result for them. The main reasons for this were that they were unsure of whether they would get a job again after the six month period and because the social grant that they would receive is much less than their monthly income and stops after six months. An identity document (ID) is a prerequisite for the application of a social grant and not having an ID caused delays for some patients, therefore causes a financial strain on them and their families as described in the quote below:

*I was working and the doctor put me off for 6 months and said they will organise me the SASSA, but it was a problem because the grant is not enough to cover everything that I must see to... the bills and the family... it wasn’t easy to just leave my job like that. I don’t have an ID because I lost my ID and I’m the only one who was working in the house. Everyone depends on me. The work sometimes phones me to come but I tell them I can’t work now [because of the DR-TB].* (Patient 4, initial defaulter)

The social grant assisted patients with their financial responsibilities but was not always enough to cover all their basic needs such as food. Some participants mentioned that they did not have an ID, and first had to get an ID before they could apply for a social grant, but the idea of receiving a social grant was enough motivation for them to initiate treatment as well as to apply for ID documents.

Patients who were unemployed at the time that they were diagnosed with DR-TB were motivated to initiate treatment because they are informed about the social grant that they will receive when they initiate DR-TB treatment. For those patients who were unemployed at the time of DR-TB diagnosis, the idea of receiving R1500 per month whilst still being unemployed is a bonus and an encouragement to initiate treatment and to be adherent to the treatment. Health workers assist the patient to apply for the grant, but also inform them that they will have the grant stopped if the patient is not compliant to the treatment. The social grant and assistance from health workers was a facilitating factor for some patients to initiate DR-TB treatment as indicated in the quote below:

*The counsellor actually helped me with something also, with the grants and that. The disability grants by SASSA. I didn’t work so the grant is a benefit for me, R1500. I can*
provide for me family, my baby with all the essentials. It helps me big time. (Patient 6, delayed initiator)

This study found that the social grant was a facilitating factor for some patients to initiate DR-TB treatment.

4.3.2.2 Subsistence Needs and Access to Health Facilities

Food insecurity was noted as a potential challenge to the initiation of DR-TB treatment. Participants from all categories mentioned food insecurity as either an enabler or a barrier in the initiation of DR-TB treatment. Food is supplied at one of the health facilities and has been identified as an enabler for patients to initiate DR-TB treatment. Most patients expressed their gratitude for the food that they receive at the facility because they receive one meal for the entire family for the day and it was an encouragement for some patients to return to the facility to initiate treatment. The patient below describes this below:

What more can this clinic do to get people to start treatment [DR-TB treatment]? They’re already giving us food every day and food to take home! Maybe they can add popcorn Friday [laughter]. (Patient 13, non-defaulter)

Food insecurity is a barrier for many patients and it also impacts the ability of patients to access the facilities to initiate DR-TB treatment, especially when money has to be used to travel to and from the facility.

I stay far. Sometimes I didn’t have money to come here [to the clinic]. And it’s far for me to walk here. Sometimes I just want to stay away. There isn’t even bread, how can I take that money for taxi fare [to come to the clinic for DR-TB treatment]. (Patient 3, initial defaulter)

There is no satellite or mobile clinic available in the areas that the two clinics are situated in. Facilities are not within walking distance for all patients. Some patients require public transport to attend facilities and this causes a further financial burden on patients and results in a delay of initiation of DR-TB treatment. The cost to access facilities is a barrier for initiation of DR-TB treatment for some patients as indicated below:

We stay far from the clinic... I had to borrow [money] from people to get here. (Patient 2, initial defaulter)
Being employed was a barrier for some of the patients and caused them to delay the initiation of DR-TB treatment because they had to leave their jobs. Patients receive a social grant but it is not always enough to cover their basic needs, leaving them unable to access health facilities to initiate DR-TB treatment, because the money cannot be stretched to cover transport costs as well. For some patients, receiving food at the health facility acted as an enabler for them to initiate DR-TB treatment.

4.3.3 Societies Views on Health, and their Influences on Timely Initiation of DR-TB Treatment

A society’s view on a health issue can affect patients’ actions and whether or not DR-TB treatment is initiated timeously. In this section we discuss the effect of stigma and a supportive environment on the initiation of DR-TB treatment.

4.3.3.1 Stigma

Although not everyone mentioned it, stigma emerged as something that still seems to affect peoples’ initiation of care.

_Cause I thought what is my friends going to say. Are they still going to be with me? I thought they’d say that I must stay away from them. Otherwise I’m going to give them the sickness? So I didn’t want to come to the clinic to start treatment and be seen here._ (Patient 5, non-defaulter)

Due to stigma patients felt that people would talk about them if they knew that they were diagnosed with DR-TB and therefore they preferred not to disclose their diagnosis.

_When I found out that I have TB I told my children not to tell anyone... I couldn’t take it that everyone will talk about me because I have TB. They can gossip so...”_ (Patient 10, initial defaulter)

Stigma was identified as a barrier which contributed to delays in initiating DR-TB treatment at both facilities.

4.3.3.2 The Effect of a Supportive Environment on the Initiation of DR-TB Treatment

A supportive environment was perceived as an essential factor for the continued effort in managing DR-TB disease. After receiving their results, most patients relied on family, friends, communities or clinic staff to create a supportive environment in order for them to
cope with what they were experiencing emotionally and to encourage them to initiate and continue with DR-TB treatment.

_Yoh these women [the staff working in the TB room at the clinic] are amazing! I haven’t ever received so much love. I sometimes forget I’m sick... we called the MDR family. The support I received here and at home also made it easy for me to start treatment. (Patient 13 non-defaulter)_

Despite the evidence for a supportive environment being an enabler, there was also evidence from the data collected from health workers that suggests that support can have a detrimental effect – not only on the initiation of DR-TB treatment, but also after treatment was initiated.

_Some patients don’t want to start treatment because some of their peers also have MDR-TB then they encourage him or her to not start treatment especially when they belong to gangs. (Nurse 3)_

Health workers also mentioned that lack of a supportive environment due to social issues such as domestic violence, substance abuse and gangsterism prevent patients from returning to the health facility for their results. The following comment is from a nurse:

_Sometimes, females get abused by their husbands or partners or lovers or whatever and they can’t come back to the clinic to start the treatment or get results. And the lovers or partners are involved in substance abuse or gangsterism... all that stuff... [they have] financial problems, unemployment. (Nurse 1)_

Household responsibilities were further identified as a barrier for the initiation of DR-TB treatment. Patients who did not have a supportive environment or assistance with their household responsibilities sometimes delayed the initiation of DR-TB treatment in order to take care of their responsibilities. Health workers also mentioned that some of the patients have dependants that they have to take care of and that they need to take and fetch their children from school, therefore they delay initiating treatment.

_They have problems because sometimes they need to go and fetch the children at school, prep the children for school, but she needs to be here 8 o’clock for doctors session if there’s no one else to do it so they do have some difficulties especially if they have a family then they miss their appointments. (Nurse 2)_

A supportive environment was an enabling factor for most patients which made it easier for them to initiate DR-TB treatment.
In summary, the patient factors that affect the timely initiation of DR-TB treatment are the factors relating to patients’ personal characteristics and perceptions which include: the health status of the patient; social contact with a TB patient and previous TB; the role of knowledge and understanding; the potential role of patients’ beliefs and attitude. Financial considerations which include: employment as a barrier and social grant; subsistence needs and access to health facilities. Society’s views on health, and their influences on timely initiation of DR-TB treatment which include: stigma and the effect of a supportive environment on the initiation of DR-TB treatment. In this study, these patient factors acted as barriers or enablers for the initiation of DR-TB treatment.

4.4 Factors relating to the Health System

In this section we discuss the health system factors that were identified as either barriers which contributed to the delay in the initiation of DR-TB treatment or as facilitators which contributed to the timely initiation of DR-TB treatment. Patient factors are discussed below under the following main headings: waiting time and clinic times; the environment at health facilities; procedures to recall patients; and the availability of resources.

4.4.1 Waiting time and Clinic times

In this section we discuss the patients’ sentiments on the health system regarding waiting time and clinic times. The time that the clinic opens and closes is not convenient for all patients. Despite the clinic times being 7.30 – 16.30, a patient mentioned that the TB services were not available when he arrived on a Friday afternoon. See comment below:

_I had to go to town the Friday morning, so when I came here past three the clinic door was closed and the nurse in the TB room wasn’t available._ (Patient 4, initial defaulter)

Patients who attend the DR-TB clinic for daily treatment are told to be at the clinic at 8am, as that is the time that medication will be dispensed to DR-TB patients. Some patients experienced challenges being at the clinic at 8am daily for various reasons such as having to prepare children for school, take children to school and for some waking up early was a challenge as described below:

_My only challenge… it’s almost like a jail sentence… you must stand up every morning and be here [at the clinic] at 8 o’clock._ (Patient 6, initial defaulter)

Other patients felt that the long waiting time was a barrier for them and they felt frustrated with the amount of time that they spend in the health facility to be tested for TB, when they
Clinic times and long waiting time has been identified as contributing factors to delayed initiation of DR-TB treatment.

4.4.2 The Environment at Health Facilities

In this section we discuss the patients’ sentiments with regard to the environment at health facilities. The safety of patients who are attending health facilities is often compromised either on their way to facilities or when they are at the health facilities – this is largely due to gang activity within the surrounding areas that patients need to get through in order to attend health facilities. A patient was attacked on his way to the clinic and outside the clinic on separate occasions which resulted in the patient not initiating treatment within the recommended time.

They stabbed me in my chest when I was on my way to the clinic. On a separate occasion I was also held at gunpoint in front of the clinic. (Patient 12, initial defaulter)

Patients indicated feeling intimidated by gangsters in the health facility. Patients also mentioned that the health facility does not have enough security guards and that the security guards spent most of their time outside of the facilities. The availability of space and the amount of time patients have to wait in the facilities is also a barrier for patients.

The space is very narrow there [in the clinic] and there’s people sitting there. I had to stand outside, where the people are in and out. So for me it [the experience] wasn’t nice. The people that’s coming out of there is mostly that people that’s on drugs, gangsters that come in to stand there [in the clinic]. (Patient 1, initial defaulter)

Health workers identified gansterism as a barrier for initiation of DR-TB treatment as gansterism made it difficult for community care workers [CCW] to recall patients who are affected by gang violence. This is indicated by the comment below:
We have a client that started late and defaults treatment because of gang rivalry and even the CCW who works in those areas can’t go out because of the shooting. (Nurse 2)

The initiation of DR-TB treatment is largely affected by the environment that patients find themselves in. Gang violence and gangsterism is a barrier for the initiation of DR-TB treatment.

4.4.3 Procedures to Recall Patients

The clinics have procedures in place to recall patients who were tested at the facility. In order for the recall process to be successful, patients need to provide the correct contact information to the health facility and it is the responsibility of health workers to emphasise the importance thereof. Provision of the correct contact details facilitated the initiation of DR-TB treatment for patients when there was a need to recall them to inform them of their DR-TB diagnosis.

The sister phoned me and she phoned my children because she had their numbers also and she said tell ma she must come to the clinic. (Patient 10, initial defaulter)

The response time of the patient plays a vital role in the initiation time of DR-TB treatment and is influenced by various personal factors which cause a delay in initiating DR-TB treatment, as indicated by the nurse below:

You recall the client so it’s either that client is going to come that same day or the client is going to come the next day so if he comes the next day there’s already a delay of one day. (Nurse 2)

The procedures to recall patients are influenced by the cooperation of patients, which ultimately effects the time taken to initiate DR-TB treatment.

4.4.4 The Availability of Resources

In order to have a well-functioning DR-TB programme and to timeously initiate DR-TB patients onto treatment the relevant resources need to be available. The following resources have been identified to act as either an enabler or barrier for the initiation of DR-TB treatment:

Medication is usually ordered on a monthly basis via the sub-district pharmacist. Each facility forwards a list of the required TB medication to the sub-district pharmacist who checks the orders and then sends it to the main stores who delivers the medication to the relevant health
facilities. Health workers and the key informant mentioned that medication is always available, and that the availability of medication facilitates the process of initiating DR-TB treatment as explained by the nurse below:

*Medication is always available we are just waiting for the shortened regime! (Nurse 3)*

None of the patients identified medication stock-outs as a barrier for initiating DR-TB treatment.

X-ray services are not available at the TB clinics, patients are sent to the Community Health Centre (CHC) (also referred to as the day hospital). Patients who are not attending the clinic next to the CHC have to travel to the CHC because there are no mobile x-ray facilities in the sub-district. Health workers identified not having x-ray services available at the facility as a reason for the delay in the initiation of DR-TB treatment, see comment below:

*We need to send the client to the day hospital in order to go and do the x-rays... it is an extra expense for the patient also. (Nurse 2)*

The availability of dedicated TB nurses, DR-TB counsellors and tracers, as well as support staff were highlighted by health workers and the key informant as a vital component of a well-functioning TB program – especially in the timely initiation of DR-TB treatment.

The absence of a medical doctor to initiate treatment at the facilities was identified as a barrier for initiation of DR-TB treatment at both facilities. An initial defaulter below describes that he could not get an appointment to be seen by the doctor within the recommended time to initiate DR-TB treatment:

*I came for a test the Tuesday, my results came the Thursday and then they gave me an appointment to see the doctor the next Wednesday. He was fully booked the Monday so they could only squeeze me in for the next Wednesday. (Patient 9, initial defaulter)*

Another patient was referred to another clinic for a doctors’ appointment, due to the unavailability of a doctor at the facility that he visited initially. See the comment below from the said patient:

*They [DR-TB clinic] phoned me again to say that I must be in Lentegeur [clinic] for that appointment with the doctor because the doctor was already at this clinic the Tuesday before. (Patient 1, initial defaulter)*
Nurses are rotated within the health facility and sometimes between health facilities to ensure better integration of services. Health workers and the key informant mentioned that the rotation of nurses interrupts the consistency within the TB room, but also mentioned that it is sometimes necessary especially if the nurse does not have the skills required to work in the TB room. The key informant also mentioned that the lack of a dedicated person in the TB room for receiving and signing off results and completing the sputum register contributes to missed results and delays in acting on results. The key informant explained that absenteeism of staff and staff shortages result in the TB nurse being removed from the TB room in order to assist in other areas or in the event that the TB nurse is absent, untrained staff or a TB trained staff member is allocated to work in the TB room for that time. The staff member who is temporarily allocated to work in the TB often just does the necessary work for the day – such as providing patients with daily medication and doing new sputum tests. This results in a delay in recalling patients and initiating medication. See comment below:

*High absenteeism rates can also have a negative effect on the initiation of TB and DR-TB initiation. If a nurse is placed in the TB room for a day or a few days just to relieve in the TB room then they don’t always take responsibility of what needs to be done in the TB room and they don’t always have the time or experience to follow up.*

(Nurse 3)

Health workers and the key informant also identified staff turnover and untrained TB staff as a barrier. The key informant explained that when new nurses are appointed they have to wait for TB training to become available before training is done. In many of the facilities there is only one or two trained Tb nurses, due to the high staff turnover the facility is then sometimes left without a trained nurse in the TB area, see comment below:

*High staff turnover has an impact on the TB control program and there isn’t always more than one TB trained staff member in the facility to fill in if the staff member leaves or goes on leave.*

(Nurse 3)

Sputum samples are collected at the health facilities and sent to the lab for GeneXpert testing via courier. The health facilities have received negative GeneXpert results from the lab for patients who were culture positive for TB and sensitivity tests revealed a DR-TB diagnosis, this causes diagnostic delays. Further testing was done due to the patients symptoms. The reason for the false negative result is not known – it could possibly be that the sputum sample was insufficient, but that has not been confirmed. Health workers and the key informant
complained that the GeneXpert test is a resource that is available to them however the results are not always reliable. The nurse explains below:

*The gene expert is negative, but that is not something that we have control over—because we need to wait for the culture results.* (Nurse 2)

Despite GeneXpert being identified as an enabler to initiate DR-TB treatment, it also has the potential to cause delays due to false negative results that have been provided to health facilities.

In summary, the health system factors which contribute to timely initiation are as follows:

Patients’ sentiments on the health care system which include - waiting time, clinic times and the environment at health facilities; Procedures to recall patients; and the availability of resources. Health system factors either act as barriers or enablers for the initiation of DR-TB treatment.

### 4.5 Factors Relating to Inadequate Patient Analysis

The factors that were identified as factors relating to inadequate patient analysis included both patient factors as well as health system factors, therefore this section cannot be placed under one of the two main themes above. In this section we discuss how substance misuse and visiting private doctors potentially relate to inadequate patient analysis.

Inadequate patient analysis transpired in cases of substance misuse. Substance misuse was identified as a patient factor because the patient potentially delays seeking health care due to the nature of withdrawal symptoms. The withdrawal symptoms and effects of substance misuse potentially causes health system delays because patients are inadequately analysed and the possibility of TB as a diagnosis is sometimes overlooked by both the patient and health practitioners – doctors and clinical nurse practitioners at community health care clinics and private doctors, therefore substance misuse was also identified as a factor relating to inadequate patient analysis.

Patients’ also choose to visit private doctors for various reasons such as, long waiting times at clinics or clinic hours. Health system factors coupled with the patient deciding to visit private doctors instead of the TB clinic have resulted in inadequate patient analysis of DR-TB. These are both health system and patient factors which potentially acts as an enabler or a barrier to the initiation of DR-TB treatment.

In this section we discuss how substance misuse and visiting private doctors potentially relate to inadequate patient analysis.
4.5.1 Substance Misuse

Substance abuse is a major problem in the area and most of the male patients who were interviewed admitted to using drugs up until the time of diagnosis and some admitted that they are still using drugs while they are on treatment. On trying to get admitted to a drug rehabilitation centre, a patient was forced to do a TB test at the clinic and was diagnosed with DR-TB, this compulsory TB test facilitated the process of diagnosing and initiation of DR-TB treatment because the patient indicated that he did not recognise that he had TB symptoms.

*When I got to the rehab, the rehab told me no they can’t just take me in because there were patients that they just took in. So, I had to go for a TB and HIV check-up. That’s when I came to the clinic, I took the HIV test and it was negative. And the TB test came out positive and that’s when I found out I had MDR-TB. (Patient 6, initial defaulter)*

Some patients had TB symptoms but did not go for TB testing because they thought that the symptoms was due to the drug use, therefore substance misuse acted as a barrier for these patients and resulted in delayed diagnosis and initiation of DR-TB treatment.

*I thought I just had like a flu and I always used to get like that [flu like symptoms] because of the drugs when it was pulling out [withdrawals]. I didn’t know it could be TB so I just used normal flu tablets. (Patient 6, initial defaulter)*

According to health workers, some of the patients who are involved with substance misuse initiate DR-TB treatment late because they are not eager to start treatment after they are told that they need to stop using drugs. See comment below:

*The clients are not so keen to start treatment because we tell them that they need to stop their habits. (Nurse 2)*

Substance misuse facilitated the diagnoses of DR-TB treatment for one patient and it (substance misuse) was a barrier for some patients.

4.5.2 Visiting Private Doctors

Patients who visited private practitioners received several courses of antibiotics and the like before TB was investigated, despite the patient having TB symptoms. A diabetic patient who visited the private doctor on several occasions received antibiotics and cough mixture when
she visited the private doctor on several occasions and no TB test was done. See comment below:

*She would give me sugar-free cough medicine, because I’m a diabetic and maybe an antibiotic. That’s about it. (Patient 2, initial defaulter)*

Visiting a private doctor resulted in some patients being misdiagnosed and not being tested for TB – which ultimately led to a delay in diagnosing DR-TB as well as a delay in initiation of DR-TB treatment as described by the patient below:

*I was coughing since November the year before. The doctor said he must send me for a scope for my throat cos I was coughing for so long that I had no voice. I only got appointment for August. I went to doctor before May. (Patient 10, delayed initiator)*

Visiting a private doctor was an enabler for some patients who did not recognise the symptoms as TB symptoms. The patient below visited the private doctor and was not aware that the symptoms that the patient was experiencing are TB symptoms. The doctor immediately referred the patient to the day hospital for TB testing. See comment below:

*He referred me here to the day hospital to do the test and I found out here that I have drug resistant TB. (Patient 13, non-defaulter)*

According to health workers, the relationship between private medical doctors and the TB clinics seem to be non-existent, and most of the private doctors that are being visited by undiagnosed TB patients are not following the new TB guidelines and methods of testing, which is the main reason for the delay in initiating DR-TB treatment. The nurse below described this:

*Private GP does TB testing then refers to us [the clinic] if it’s positive but the problem is they do smears at Pathcare [the laboratory private doctors use in the area]. Then because it’s a positive test we have to start TB treatment, but as soon as they arrive here we collect sputum for GeneXpert for sensitivity then we have to wait for results. If it comes back as drug resistant we have to do the bloods and send for x-ray and book for doctor. (Nurse 2)*

Factors relating to inadequate patient analysis that includes substance misuse and visiting private doctors were identified as both patient and health system factors which contribute to the initiation of DR-TB treatment.
4.6 Summary

This study found that timely initiation of DR-TB treatment is influenced by patient factors, health system factors and factors relating to inadequate patient analysis.

The patient factors that affected the timely initiation of DR-TB treatment are the factors relating to patients’ personal characteristics and perceptions which include: the health status of the patient; social contact with a TB patient and previous TB; the role of knowledge and understanding; the potential role of patients’ beliefs and attitude. Financial considerations which include: employment as a barrier and social grant; subsistence needs and access to health facilities. Society’s views on health, and their influences timely initiation of DR-TB treatment which include: stigma and the effect of a supportive environment on the initiation of DR-TB treatment. In this study, these patient factors acted as barriers or enablers for the initiation of DR-TB treatment.

The health system factors which contribute to timely initiation are as follows: patients’ sentiments on the health care system which include - waiting time, clinic times and the environment at health facilities; procedures to recall patients; and the availability of resources. Health system factors either act as barriers or enablers for the initiation of DR-TB treatment.

Lastly, factors relating to inadequate patient analysis that include substance misuse and visiting private doctors were identified as both patient and health system factors which contribute to the initiation of DR-TB treatment.
Chapter 5 – Discussion

5.1 Introduction
This chapter discusses the findings of this study in relation to the literature review. In particular, the discussion focuses on various patient and health system factors that were identified as barriers or facilitators of timely initiation of DR-TB treatment in the study context. Therefore, this study sought to explore the experiences and perspectives of newly diagnosed DR-TB patients who initiated treatment within five days of sputum collection, newly diagnosed DR-TB patients who initiated treatment after five days of sputum collection, and the health provider. The analysis was compiled and the evidence suggested that the influences of timely initiation of DR-TB treatment are directly related to the views of the patient or the society in which they live. These factors are highlighted in this discussion. The study further aims to recognise the challenges that DR-TB patients are faced with in ensuring timely initiation of treatment. The study is therefore identifying priority areas to help improve the timing of DR-TB treatment initiation, and ultimately the DR-TB programme.

5.2 Patient Factors Influencing Timely Initiation of DR-TB Treatment
This study identified several patient-related factors that were observed to function as barriers or enablers to the timely initiation of DR-TB treatment. These factors specifically related to patient’s personal characteristics or their perceptions and attitudes, financial factors that impact their choices or experiences and future prospects, the role of stigma and society’s views on people with DR-TB, and finally the socio-economic conditions affecting a patient and their management of the disease.

In this study, poor health status was a reason that the initiation of DR-TB treatment was delayed. This delay is due to the fact that the initiation of treatment may worsen the condition, for example in patients with renal impairment or chronic liver failure. A record review conducted by Chang et al. (2014) found that renal function impairment is a common complication during anti-TB treatment in an elderly population. Other health conditions may also impact on time to diagnosis and treatment initiation, including the presence of a chronic cough or lung disease (Storla et al. 2008).

This study however also showed that the TB symptoms and related health that patients experience could also act as an enabler for them accessing the health facility to initiate treatment. According to Cai et al. (2015) haemoptysis may be the most characteristic and
severe TB symptom, therefore it causes the patient to hasten for clinical assistance and leads to timely diagnosis and treatment initiation. Unfortunately, our study also found that immobility and severe pain due to TB symptoms was not just an enabler but also a potential barrier to the initiation of DR-TB treatment. Individuals’ symptoms made it more difficult for patients who experience immobility and severe pain to access the health facilities to initiate DR-TB treatment.

In some more cases where patients had a TB contact or personal previous experience with TB before, this seemed to be an enabler to the initiation of DR-TB treatment. Patients who had social contact with a TB patient were advised by their contact to visit the clinic for TB testing and more readily initiated onto DR-TB treatment. Patients’ who previously had TB identified the symptoms and went to the clinic for TB testing. This was also the finding of a similar Cape Town Study (Naidoo et al., 2015). However, a recent Gauteng study reported that 84% of patients who did not initiate MDR-TB treatment were previously treated for TB (Ebonwu et al. 2013).

Patient knowledge and understanding about TB were found to be important facilitating factors in this study and played a role when people presented for treatment once they have been diagnosed with DR-TB. Many of the patients did not have adequate knowledge or understanding of DR-TB and how it is spread. Some patients in this study were not aware that initiating DR-TB and continuing treatment reduces the risk of spreading the DR-TB disease. This study found that some patients had knowledge of TB and understood that TB is contagious, therefore initiated DR-TB treatment out of concern for loved ones. A study similar to this study carried out in Limpopo province, South Africa (Supa, & Peltzer, 2005) reported that the proportion of patient’s delayed among those who knew less about causes of TB was higher than the proportion among those who had high knowledge on causes of TB. The nurses, family members and friends were identified as the main sources of TB information in educating the majority of DR-TB patients. Unfortunately, the majority of the participants were not aware of any health education activities concerning TB in their area.

Understanding of TB was not in agreement with biomedical knowledge among many participants in this study. This study found some misconceptions about the cause of TB, especially regarding signs and symptoms of TB. A few of the respondents believed that TB will convert to HIV. An Ethiopian study of lay beliefs of TB/HIV found a similar result - some patients have the belief that TB could transform to HIV (Mekdes et al., 2011). This false belief was an enabler for a patient in this study. Despite having the belief that TB could
convert to HIV, most patients demonstrated that they had knowledge about HIV transmission. This finding is in concordance with a Thailand study, which found that the community was more aware of HIV than TB (Ngamvithayapong et al., 2000).

Fear of the unknown was a barrier for some patients and health workers mentioned that denial is also a barrier for the initiation of DR-TB treatment. A study conducted in Latin America also found fear to be a barrier to the initiation of DR-TB treatment (Paz-Soldan et al., 2014). Conversely, positive patient attitude and wanting to be cured functioned as a support for some patients. This study found that a positive attitude and the will power to initiate treatment in order to be cured acted as a facilitating factor for most of the patients who were interviewed to initiate DR-TB treatment.

5.2.1 Factors related to the patient’s finances and subsequent financial considerations

The financial situation of patients was identified as either a barrier or enabler to the initiation of DR-TB treatment. This section discusses the effect of employment, social grants and insufficient financial support on timely initiation of DR-TB treatment.

Health workers and the key informant noticed that patients who are employed as informal workers and patients who are self-employed were also facing monetary issues and therefore delays in the initiation of DR-TB treatment. None of the other studies that were reviewed reported that being self-employed or being an informal worker contributed to delayed initiation of DR-TB treatment though.

In a community where dynamics such as poverty, overcrowding, inequity and malnutrition lead to the population being at particular risk of TB (Zumla et al., 1999), an unexpected finding in this study is that employment is a major barrier in the initiation of DR-TB treatment initiation. Nonetheless, Gopi et al. (2005) identified work related problems as a reason for initial default. Similarly, this study found that employment is a barrier to the initiation of DR-TB treatment for some patients, because the patients are booked off on sick leave for the first six months of DR-TB treatment. Loss of money due to absence from work causes a further delay in diagnosis and initiation of treatment (Storla et al., 2008).

Patients reported that the idea that they had to stop working as the most challenging part of initiating DR-TB treatment. Similarly, a previous Cape Town study reported that delays in treatment initiation is because patients are missing appointments, and the underlying reason
for this is often due to financial and employment responsibilities (Naidoo et al., 2014; Niekerk et al., 2013).

Directly linked to concerns of earning money, is providing for basic needs like food. Food insecurity was also noted as a challenge in initiation of DR-TB treatment, despite DR-TB patients receiving a social grant. A study conducted in sub-Saharan Africa found that food insecurity and hunger not only interfere with day-to-day adherence but that fears about hunger and food insecurity may also cause people to delay initiating or to discontinue ART (Weiser et al., 2010). Patients who were interviewed from the health facility that provides food for the patient and the family mentioned the provision of food as a facilitator for the initiation of DR-TB treatment.

This study found that society’s views on health have the potential to influence the timely initiation of DR-TB treatment and that the views that the society holds dictates the associated stigmas attached to TB - this stigma determines how supportive the environment in which a patient lives is. Lack of knowledge about DR-TB has a domino effect and seems to be a major contributor to the stigma that exists in the community, stigma may also be linked to lack of knowledge. Other research suggests that in Cape Town there appears to be a common misconception that TB is a disease that people who live in poverty contract because of filth (Kendall et al., 2013). Several studies in different socio-cultural contexts, such as, Vietnam, have come up with evidence that stigma is closely attached with TB, and results in delay in seeking health care (Meursing, 1997; Liefooghe, 1997).

Household responsibilities were further identified as a potential barrier for the initiation of DR-TB treatment in this context. Patients who did not have a supportive environment or assistance with their household responsibilities sometimes delayed the initiation of DR-TB treatment in order to take care of their responsibilities. This is also supported by Niekerk (2013) who reported that patients contribute to delays to treatment initiation by missing appointments, often due to family responsibilities. Similarly, according to the NDoH, patient’s household responsibilities may contribute to treatment delays amongst patients referred to centralised services (NDoH, 2011).

Participants also mentioned that lack of a supportive environment due to social issues such as domestic violence, substance abuse and gangsterism prevent patients from returning to the health facility for their results and initiating treatment. A sixteen country study that was conducted by the International Committee of the Red Cross (ICRC) in 2011 provided further
proof of the damaging effects of violence on access to and provision of health care. A Canadian study reported that the loss to follow up rate was high in women who are victims of inter partner violence (Harriet et al., 2009). The findings of this study then are that a supportive environment is a much-needed facilitating factor to initiate DR-TB treatment for most patients. In fact, a supportive environment was perceived as an essential factor for the continued effort in managing DR-TB disease. A Vietnamese study indicated that compliant behaviour is associated with social support from the family or other persons (Long et al., 2001). This is also supported by Love (2002) who found that patients who live with supportive family members are more likely to complete treatment.

5.3 Health System Factors

This study found that there are many health system related factors that are shaping the landscape of treatment of DR-TB. In particular, this study identified that these factors are specifically related to waiting and clinic times; the environment at health facilities; procedures to recall patients; and the availability of resources.

This study found that long waiting times were a barrier for the initiation of DR-TB treatment. A study recently conducted in five provinces in South Africa, reported that spending long hours at health facilities is a reason for non-initiation and default of TB treatment (Skinner & Claassens, 2016). According to Skinner and Claassens (2016), the long waiting times are largely due to health facilities being unorganised. Participants in this study mentioned that they also have to remain in the queues while staff members have their tea and lunch breaks. Staff members are without a doubt entitled and deserving of these breaks, but the impact of not having staff members to relieve them in order to have continuity is felt by patients. Patients who were enrolled in this study mentioned that they have work and family responsibilities and cannot always attend the facilities at the time the clinic operates. Due to the long waiting times at health facilities, it almost seems impossible for patients to make any other commitments for the day when they visiting the clinic. Skinner and Claassens (2016) also found that the operating hours of the health facilities were not convenient for all patients and contributed to delayed initiation of DR-TB treatment. Similarly, a study conducted in Latin America about patient delays in seeking TB treatment reported inconvenient clinic hours and long waiting time as a barrier to the initiation of DR-TB treatment (Paz-Soldan et al., 2014).
The safety of patients enrolled in this study who were attending health facilities is often compromised either on their way to facilities or when they are at the health facilities – this is largely due to gang activity within the surrounding areas that patients need to get through in order to attend health facilities. Participants also mentioned not feeling safe in health facilities because the security is not visible and is insufficient. The initiation of DR-TB treatment is largely affected by the environment that patients and health workers find themselves in (ICRC, 2012). Gang violence and gangsterism was found to be a barrier for the initiation of DR-TB treatment in this study, and just like that prevailing insecurity prevented health-care workers from performing their duties (ICRC, 2012).

This study found that the procedure to recall patients is affected by whether or not patients provide accurate contact details. Depending exclusively on phone calls is potentially challenging because patients in rural areas, do not have phones (Jacobson et al., 2013) and cell phones are not always reliable as people change numbers, phones are stolen or patients may not own cell phones because they do not have electricity in the area or cannot afford it. For this reason it is important for health workers to ensure that they update the contact details of patients, especially so when the patient visits the facility to do a sputum test. Health workers mentioned that they sometimes slip up when it comes to updating contact details and they assume that the contact details on the folder is still in use. Procedures to track and recall patients’ who have been diagnosed as having DR-TB, influence the initiation of treatment. Hospitals are more inclined to rely on phone calls to contact patients as a means of follow up, compared to primary level clinics who perform home visits for patients that cannot be contacted telephonically (Nkosi et al., 2013). The response time of patients can contribute as a barrier or enabler to the initiation of DR-TB treatment.

This study found that the initiation of DR-TB treatment is affected by the availability of various resources. Similarly, medication stock outs and lack of equipment have been previously documented as a challenge, negatively impacting on the provision of antiretroviral therapy (Uebel et al., 2011). The availability of medication was an enabler to the initiation of DR-TB treatment, as patients did not have to wait for medication to be ordered in order for them to initiate DR-TB treatment. Drug stock outs could potentially lead to further drug resistance and ultimately increased risk of unsuccessful treatment outcomes for patients (Loveday, 2013). The unavailability of x-ray services at the facilities was identified as a barrier to the initiation of DR-TB treatment. Mobile x-ray services are not available at the health facilities that are not within walking distance from the day hospital, which means that
patients need to travel to the day hospital to have x-rays taken before they are given an appointment to see the TB doctor at the clinic in order to initiate DR-TB treatment.

The availability of dedicated TB nurses, DR-TB counsellors and tracers, as well as support staff were highlighted by health workers and the key informant as a vital component of a well-functioning TB program. Health workers mentioned that continuity of care and follow up of results is difficult to accomplish without dedicated staff in the TB room. Without this consistency, there is a lack of communication, patients’ results end up falling through the cracks and this is a barrier that weakens the TB programme (Gebremariam et al., 2010). Similarly, a KwaZulu-Natal study reported that high staff turnover weakens the consistency and quality of MDR-TB care (Loveday et al., 2014). The rotation of nurses in the facility was identified as a barrier as it interrupts the consistency within the TB room. In Cape Town, the employment of nurses at a sub-district level to trace patients and ensure treatment initiation contributed to the improvement in the time to initiate DR-TB treatment (Naidoo et al., 2014).

Absenteeism of staff and staff shortages result in the TB nurse being removed from the TB room in order to assist in other areas or in the event that the TB nurse is absent, untrained staff or a TB trained staff member is allocated to work in the TB room for that period. In a Gauteng study, majority of the nurses reported that they were unaware of DR-TB guidelines (Nkosi et al., 2013). The staff member who is temporarily allocated to work in the TB often just does the necessary work for the day – such as providing patients with daily medication and doing new sputum tests. Results are sometimes missed and the initiation of DR-TB treatment is delayed. Similarly, Loveday et al. (2014) reported that rotation of staff between services contributes to a loss of skills from the DR-TB programme in South Africa and a breakdown in consistency of services.

The absence of doctors at facilities was identified as a barrier to the initiation of DR-TB treatment in this study. Doctors work according to a roster and do weekly half day sessions at most of the clinics depending on the amount of patients registered for TB at the facility. Clinics with a higher TB case load have more regular doctor sessions or even have one or more permanent doctors at the facilities on a daily basis. Despite having procedures in place to arrange an emergency appointment with the doctor - where the doctor comes to the facility especially to initiate DR-TB treatment of newly diagnosed DR-TB patients or referral of the patient to one of the other facilities for a doctors’ appointment. Shortages of health care workers may further contribute to delays in initiation of DR-TB treatment. To address this,
the NDoH has identified the need for nurse initiated and management of MDR-TB care (NDoH, 2011), although this has not been implemented to date.

Participants from this study mentioned that false negative GeneXpert results contribute to the delay in diagnosing and initiating DR-TB treatment. Similarly, a study conducted in Khayelitsha Township, in the Western Cape, reported that between 2012 and 2013 only half of patients diagnosed with RR-TB were diagnosed using GeneXpert. This was due to the failure of GeneXpert to detect RR-TB (Cox et al., 2014).

5.4 Factors Relating to Inadequate Patient Analysis

The factors that were identified as factors relating to inadequate patient analysis included both patient factors as well as health system factors. Patients’ also choose to visit private doctors for various reasons such as, long waiting times at clinics or clinic hours. These are both health system and patient factors which potentially acts as an enabler or a barrier to the initiation of DR-TB treatment.

Substance misuse has been shown to increase treatment delays amongst drug susceptible TB patients (Storla et al., 2008). Substance misuse acted as a barrier for some patients in this study and resulted in delayed diagnosis and initiation of DR-TB treatment. Substance abuse has repeatedly been highlighted as a major driver of South Africa’s high DR-TB default rates (Holtz et al., 2006; Kendall et al., 2013; MRC, 2009). Health workers who were interviewed in this study mentioned that patients are usually reluctant to initiate DR-TB treatment because they have to quit using drugs which causes them to delay the initiation of DR-TB treatment. Some of the patients who were interviewed mentioned that they had TB symptoms but did not go for TB testing because they thought that the symptoms were due to their drug use.

This study found that for some patients visiting a private doctor resulted in patients being misdiagnosed and not being tested for TB – which ultimately led to a delay in diagnosing DR-TB as well as a delay in initiation of DR-TB treatment. In a study undertaken in Cape Town, South Africa, poor TB screening practices in the private sector was reported as a contributor to delays in diagnosis and initiation of DR-TB for many patients (Naidoo et al., 2015). According to Naidoo et al. (2015) patients first sought care in the private sector, due to perceptions of poor treatment in the public sector, particularly long waiting times and poor staff attitudes. Previous studies from India have reported that two-thirds of the TB patients visit private practitioners when they first develop chest symptoms, and more than half are diagnosed by the private doctors (Hazarika, 2011). In this study, visiting a private doctor was
an enabler for some patients because the doctor suspected TB at the first visit and patients were immediately referred for further management.

5.5 Limitations
The findings of this study give us a view into the life of patients who need care and help us to build the knowledge to improve DR-TB services within the Mitchell’s Plain sub district, these findings however, due to the sample size, cannot be generalised to the Mitchell’s Plain as a whole. A limitation in this study is that the researcher intended to interview eight participants who initiated treatment within five days of sputum (specimen) collection and eight participants who initiated treatment after five days of sputum collection as a sample or until saturation is reached in each group. Unfortunately, only three patients initiated treatment within five days of sputum collection at the first facility and none at the patients at the second facility initiated treatment within five days of sputum collection, therefore only three patients were interviewed in total who initiated treatment within five days of sputum collection. Of the remaining 13 participants one interview was not conducted due to the patient being intoxicated at the time of the interview (the researcher thought it to be unethical to continue the interview knowing that the patient is intoxicated) and a total of 12 patients who initiated treatment after five days of sputum collection were interviewed. Since the study sample was small owing to limits of time and resources for a mini thesis, there was a further limitation for the researcher, as it was not possible to reach the point of data saturation. However, there was a consistency across the interviews, so we feel it is unlikely that we missed major themes.
CHAPTER 6 - CONCLUSIONS AND RECOMMENDATIONS

6.1 Conclusions

The purpose of this study is to explore why patients who are diagnosed with DR-TB in the Mitchell’s Plain sub-district fail to timely initiate DR-TB treatment. Decentralisation and GeneXpert testing were implemented to reduce delays in initiating DR-TB treatment, but delayed initiation of DR-TB treatment remain a problem, identified by the literature and in this context by a folder audit.

Based on the research findings, this study primarily explored the experiences and perspectives of newly diagnosed DR-TB patients, who were divided into two groups: Those who initiated treatment within five days of sputum collection, and those who initiated treatment after five days of sputum collection. It also sampled health providers to assess their opinions about the factors that influence the time of initiation in newly diagnosed DR-TB patients. The overall conclusion of the study was that both the patients and health workers described several interrelated factors that were thought to be barriers or facilitators to the initiation of DR-TB treatment at the selected health facilities within the Mitchell’s Plain sub-district.

The patient factors that affected the timely initiation of DR-TB treatment were the factors relating to a patients’ knowledge around the disease, their image in society that needed to be maintained, the cost issues involved in seeking healthcare on a continuous basis, and finally the measure of support and understanding provided by family, friends and indeed society as a whole. These patient factors ended up acting as barriers and/or enablers for the initiation of DR-TB treatment.

More specifically, the major facilitating factors for the initiation of DR-TB treatment for patients were past experiences of the disease (regardless of whether it was through social contact with a TB patient or the participant previously having TB), and their understanding and knowledge of the severity of the disease and the benefits of initiating DR-TB treatment (which was largely due to knowledge of the contagious nature of TB and not wanting to infect loved ones). Both factors influenced the view that which showed that diagnosis and treatment is necessary. Support, in the form of money (via social grants) and attitude (whether your own or societies) also lent a helpful hand in ensuring treatment was sought and
that the attitude being cultivated was that the future is what we create, not what we have experienced.

A number of barriers to initiation of DR-TB treatment were identified by patients. The health status of the patient was a contributing factor for patients who were not mobile and for those who had underlying medical conditions or blood results that were not within normal range. Lack of knowledge and understanding of TB was a major contributing factor to delayed initiation of DR-TB treatment. Financial issues and subsistence needs affected most of the patients and largely contributed to the delays in initiating DR-TB treatment. The initiation of DR-TB treatment created a financial burden for some of the participants – this is because some of the participants who are employed at the time of DR-TB treatment initiation do not receive any financial benefits from the companies where they are employed during their absence from work due to DR-TB and the social grant of R1500 is much less than the salary that they received. Stigma and the social environment also negatively affected the initiation of DR-TB treatment. The absence of supporting structures from spouses, other members of the family and from social structures outside of the family were also found to be potential barriers to the initiation of DR-TB treatment.

The major health system factors that were enablers to the timely initiation of DR-TB treatment for patients in this study were the procedures to recall patients if accurate contact information is provided. The availability of DR-TB drugs was also an enabler for all patients.

There is a significant opportunity to improve the timely initiation of DR-TB treatment within the Mitchell’s Plain sub district. The availability of DR-TB trained nursing staff and lack of doctors within facilities was identified as a major barrier in this study. Staffing challenges impede timely initiation of DR-TB treatment and increases the waiting time within the facilities. An increase in the amount of staff allocated to the DR-TB area could potentially contribute to the elimination of staffing challenges and ultimately decrease the time taken to initiate DR-TB treatment.

An unsafe environment at the health facility and in the surrounding area was also a potential barrier which hindered access of patients and prevented health workers from doing home visits in order to recall patients who were not contactable telephonically. Procedures to recall patients were also a possible barrier when health workers did not update the contact details of the patients or when patients provided incorrect contact details.
Despite the availability of GeneXpert testing, participants from this study mentioned that false negative GeneXpert results contributed to the delay in diagnosing and initiating DR-TB treatment. The unavailability of resources such as X-ray services at the facility created a financial burden for some of the participants and it increased the time taken to initiate DR-TB treatment. Despite the fact that DR-TB services have been decentralised, facilities are not within walking distance for many of the patients. Patients who experience pain, shortness of breath, lethargy or other symptoms related to DR-TB have difficulty walking to and from the health facilities, with the result that they delay the initiation of DR-TB treatment.

Factors relating to inadequate patient analysis that were identified as barriers are substance abuse and visiting private doctors. Substance misuse acted as a barrier for some patients due to TB symptoms being overlooked because it resembles withdrawal symptoms, therefore substance misuse resulted in delayed diagnosis and initiation of DR-TB treatment. Visiting private doctors was an enabler for some patients and a barrier to initiate DR-TB treatment for some patients.

The findings thus indicate several interrelated factors that were found to contribute to the timely initiation of DR-TB treatment – the patients, the health system and support structures. To summaries the themes of the patient issues, education and support were vital to changes in behaviour. Education was key because knowledge is power and without knowing the cause and effect of TB, people cannot be expected to act in their best interest. Support was identified as being both financial and emotional, however, support was not limited to all things out of the public sectors control. Support at healthcare facilities were needed to ensure accessibility (to get to a clinic nearby, and to be able to still see someone within a quick enough turn-around time that doesn’t impact someone financially due to not being able to work for the entire day), privacy (because TB patients are generally shown to a certain section and discussions with patients can be overhead by everyone else in the waiting room) and affordability (it should not cost an arm and a leg to get basic access to health). This leads to the support structures, which were lacking at the health facilities too, in that healthcare providers (staff) were not always on duty to assist the crowds of people, and society in general has a high crime rate (making safety an issue to come to the clinic), and a low tolerance for people with disease (partly because of a lack of education, and also because time is money, and time therefore cannot be made up when you need to go the clinic for treatment or diagnosis. These are the issues that need to be addressed in order to change the outcomes of the factors influencing the timely initiation of DR-TB treatment. In view of the

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findings from this study then, which it is evident are supported by literature from other studies, the MDR-TB coordinator and management of the Mitchell’s Plain sub-district could utilise these findings to improve the timely initiation of DR-TB treatment within the Mitchell’s Plain sub district. The researcher is of the opinion that active participation by all stakeholders to improve the timely initiation of DR-TB treatment will contribute to the ultimate success of the DR-TB programme within the sub district. Recommendations from this study will be useful to identify gaps within the health system and presented to the sub-district management to improve TB control within this context. Results will also be presented to local ward counsellors and will hopefully influence their health promotion projects to educate the community about DR-TB and infection control. The information may also be useful for health committees, the environmental health department, fire and safety and other organisations within Mitchell’s Plain.

6.2 Recommendations

Based on the above conclusions, the following recommendations are made about mechanisms for improving the timely initiation of DR-TB treatment.

6.2.1 TB Education

This study revealed that there is a gap in knowledge and understanding of TB. There is a need for health facilities to educate the community (including TB cases) on causes, transmission, prevention and recovery in order to improve their knowledge and understanding of TB. According to Republic of South Africa (Act No. 108 of 1996), the Patient’s Rights Charter indicates that patients have the right to knowledge about their health.

It is important to strengthen social mobilization for information dissemination in order to raise awareness about TB. One observation is that health facilities have educational posters on the walls, but the information on the posters is insufficient to educate the community about TB. Various methods are recommended to strengthen the social mobilisation for information dissemination; such as health education sessions at the health facility, community gatherings, relevant posters, flyers and radio announcements should be done continuously throughout the year. A methodological review was conducted about developing health interventions and the results of these articles suggest that successful health education depends on using a few messages, of proven benefit, repeatedly, and in many forums (Loevinson, 1990). Another observation is that on World TB day much effort is put into educating patients about TB – but one day of the year is not sufficient.
6.2.2 Reduce Stigma

The health facilities endeavour to create a discreet environment by attempting to enable patients to collect their medication rapidly which ultimately reduces the potential of the patients being exposed to stigma. On the other hand, health facilities contribute to the stigma by insisting on patients who visit the TB room to wear masks and only the staff members who work with the TB patients wear masks (this was evident when the researcher entered the health facilities). The national TB guidelines and City of Cape Town infection control policy indicate that staff who works directly with TB patients should wear a N95 mask as a protective/preventative measure and that patients who are coughing should be given a paper mask. These policies and guidelines should include all health workers within the facility to wear a mask, as well as all patients as a preventative measure. This could potentially reduce stigma within health facilities as well act as an infection control measure.

Educational programmes focusing on reducing stigma and improving perceptions regarding TB in communities as well as in health institutions. Tackling the problems of misperceptions, as evidenced by the study, would be a strategy to deal with stigma and thus reduce delay.

6.2.3 Financial Considerations

There is a need for public health facilities to increase accessibility, especially targeting patients with high potential for delay in seeking treatment. The provision of food support (in addition to social grants) should be evaluated as a tactic to improve timely initiation of DR-TB programme. In Afghanistan the food assistance has contributed to the success of the DOTS-based programme, and in settings where food security is a barrier to accessing care and adhering to treatment, food supplementation is an obvious enabler for TB patients (Padrozzoli et al., 2016). A shuttle or transport service to collect and drop off patients at pick up points closer to home would be beneficial to reduce the financial burden that patients are experiencing due to money spent on travelling to and from the health facility to initiate and to remain compliant on DR-TB treatment.

6.2.4 Reduce Waiting Times

An appointment system should be implemented for patients so that patients who are recalled are given a time slot to return to the facility instead of having to wait in a queue again. The TB area should have a separate queue for patients who are only coming to collect daily medication and patients who were recalled to initiate treatment - with these patients being fast tracked in order to reduce waiting time and potentially reduce the time taken to initiate DR-
TB treatment. The waiting time was decreased by 40% at an ART clinic in North West Ethiopia after the implementation of an appointment system (Atnafu et al., 2015).

6.2.5 Ensure Patient Safety
The republic of South Africa (Act No. 108 of 1996) indicates that patients have the right to a healthy and safe environment and access to healthcare. In order to ensure the safety of patients and staff within the facilities security guards should be more visible. Metal detectors should be installed and working in order to prevent patients from entering the facilities with weapons.

6.2.6 Staff Availability and Training
Reduce staff absenteeism by providing staff with incentives such as special bonuses or gifts to employees as recognition to employees who are present at work more often than others.
Training of nurses to initiate DR-TB treatment in the absence of doctors could potentially act as a facilitator for the initiation of DR-TB treatment. The introduction of mentors or in-house TB training could be done to decrease the time staff members wait to go for TB training and this should ultimately increase the amount of trained TB staff at facilities.

6.2.7 Communication with the Private Sector
Each health facility should have a list of private doctors and traditional healers within the surrounding area who offer services outside the facility. The facility manager could send TB and other updates to these practitioners, and have an open line of communication and quarterly meetings with them in order to improve communication between the local clinics and the private sector in order to improve the outcomes of the TB programme.

6.2.8 Recommendations for further studies
This study found employment to be a major barrier for some patients. The researcher recommends that further studies be done in this area in order to further investigate the impact of the initiation of DR-TB treatment on employment, as well as the challenges patients who are employed are faced with after being diagnosed with DR-TB treatment.
References


Beijing University, Beijing, PR China
http://journals.plos.org/plosone/article/file?id=10.1371/journal.pone.0120088&


Appendix 1 - Information sheet

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INFORMATION SHEET

Project title: “Timely Initiation of MDR-TB Treatment: A Descriptive Qualitative study at Primary Health Care facilities in a district of the Cape Metropole.”

What is this study about?
This is a research project being conducted by Shaakira Ariefdien at the University of the Western Cape. We would like to invite you to take part in a research study that is investigating why patients that are diagnosed with DR-TB who start treatment do or do not experience a delay in starting treatment.

Why are we doing this study?
Drug-resistant Tuberculosis (TB) is a major health problem in South Africa, but most forms of TB can be cured if treated early and well. In our study we want to find out what factors contribute to when a patient starts treatment after being diagnosed. This study will also be submitted to the University of the Western Cape towards the research’s fulfilment of a Master’s Degree in Public Health.

What will I be asked to do if I agree to participate?
You will be asked to participate in an interview during which you will share information. The interview will be conducted in a private room at the health facility that you are receiving treatment from or employed at, at a time that is convenient to you. The interview will last for approximately 30 minutes. The interview questions will focus on your experience and challenges of starting or not starting treatment with delays and challenges you have faced.

What happens if I do not agree to take part in this study?
You do not have to take part in this study. If you do not take part, this will not affect the medical care that you receive. You can stop taking part in the study at any time, without giving a reason.

What are the risks and benefits of taking part in this study?
This study poses little to no risk to you if you agree to take part. All the information that you give to the researcher will be kept confidential. You will not benefit medically from participating in this study, however you will be able to share your experiences with the researcher and so broaden the
understanding of the challenges faced by patient’s and health care workers following diagnosis. Questions about failing to initiate treatment on time may offend participants (they might feel that they are being blamed) or cause discomfort (psychological or otherwise) and elicit negative reactions. The researcher will minimise such risks by acting promptly if discomfort is noticed and reassure participants. If necessary further intervention is required, participants will be referred to a suitable professional for further assistance.

**How will the information collected during this study be recorded?**

If you take part in the study, your interview will be recorded using an audio recording device and the interviewer may write some notes on paper during the interview.

**How will the information collected during this study be kept confidential?**

Audio recordings and notes from your interview will be kept securely and confidentially in a locked cabinet or digital safe by the researcher. Only restricted University staff members will have access to the cabinet or digital safe. Confidentiality will further be assured by assigning unique identifying (ID) numbers to participants so that all their data will be coded with this number and not their details. If you are quoted in the study report, your name will be replaced by a pseudonym to protect your identity. Your name or any other identifiable information will not be included in any reports about the study or published papers.

**What if I have questions?**

This research is being conducted by Shaakira Ariefdien from the School of Public Health at the University of the Western Cape. If you have any questions about the research study itself, please contact Shaakira Ariefdien at: shaakirah.ariefdien@gmail.com

Should you have any questions regarding this study and your rights as a research participant, if you wish to report any problems you have experienced related to the study or if you have any questions about the ethics or approval of the study, please contact Dr Lucia Knight at: lknight@uwc.ac.za or 021) 959 2243.

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Dean of the Faculty of Community and Health Sciences:

Prof José Frantz
This research has been approved by the University of the Western Cape Senate Research Committee.

**Who can I contact for support and counselling?**

The Depression and Mental Health Helpline 0800 567 567

Lifeline 0861 322 322

The National AIDS Helpline 0800 012 322
(Also provides TB assistance)

The National HIV & TB Health Care Workers Hotline 0800 212 506

The Social Grants Helpline 0800 601 011

You may also contact one of the following NGOs for information and support:

TB/HIV Care 021 425 0050

Treatment Action Campaign 021 422 1700
Appendix 2 – Consent form

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Participant informed consent form  Study ID number: __________

Study title: “Timely Initiation of MDR-TB Treatment: A Descriptive Qualitative study at Primary Health Care facilities in a district of the Cape Metropole.”

Researcher (MPH Student):

University of the Western Cape, South Africa: Shaakira Ariefdien

The participant understands the following:

➢ I understand that my participation is voluntary (Yes/ No)
➢ I understand that I will not be identified by name in the finished study report or in any published papers (Yes/ No)
➢ I understand that the interview will be recorded (Yes/ No)
➢ I acknowledge that the contact information of the researcher and the researching institution have been made available to me (Yes/ No)
➢ I understand that I may withdraw from this study at any time without giving a reason and without affecting my normal care and management (Yes/ No)
➢ I have had the opportunity to ask questions about the study and any questions I have asked have been answered to my satisfaction (Yes/ No)
➢ I agree to take part in the study (Yes/ No)

Study participant name (printed): _________________
Signature/mark/thumbprint: _________________ Date: _________________

Witness name (printed): _________________ Signature/mark/thumbprint: _________________ Date: _________________

Researcher name (printed): _________________ Signature: _________________ Date: _________________

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Appendix 3
Interview guide – Health care worker

- Prompts
- Follow up questions

1. Do you think that the time that patients waited to start Drug Resistant Tuberculosis (DR-TB) treatment after diagnosis was acceptable, good or bad?
   - Why?
2. Is there anything that you can think of that can be done to shorten the length of time taken to start DR-TB treatment after diagnosis?
   - If no, why?
   - If yes, what?
3. What challenges do the patients who attend this facility face when starting treatment?
   - Did the patient have transport
   - Delays in diagnosing
   - Records unavailable
   - Medication stock outs
   - Did challenges affect when treatment was started?
   - How?
4. Do you have insight about personal problems after they are diagnosed that impact starting treatment?
   - Dependents
   - Employment
   - Alcohol or substance abuse
   - Gangsterism
   - Use of traditional or alternative medication
   - Other...
5. Do you know what factors enable patients to start treatment within five days from sputum collection?
6. Do you know what factors prevent patients from starting treatment within five days from the time sputum was collected?
7. Under what circumstances are patients referred to another facility to start treatment after diagnosis at this facility?
   - XDR
   - Children
   - Sputum positive
   - Substance abuse issues
   - Other...
8. Under what circumstances are patients referred to this facility to start treatment?
   - Medication stock out at another facility
   - No doctor at other facility
   - Diagnosed in private
   - Other...
9. Does the referring facility follow up if patients started treatment?
10. Are there systems available to track patients who do not return to the clinic to start treatment after diagnosis?
11. In general, how does referral impact the time taken to start treatment?
12. Do you know if patients experience difficulty reaching referral sites?
   - Financial
   - Transport
   - Dependants need caregiver
   - Other...
13. Are there services available to assist patients to reach the referral sites?
14. What is the average time that patients take to start treatment following DR-TB diagnosis at this facility?
15. Do you face challenges personally in dealing with DR-TB patients and starting them on treatment?
   - Results from lab
   - Contact details of patients
   - Other...
16. What recommendations do you have for this facility or sub district to improve on the time taken to start DR-TB treatment?
Appendix 4
Interview guide – patient

- Prompts
- Follow up questions

1. Where did you first find out that you had Drug Resistant Tuberculosis (DR-TB)?
2. How were you informed of your DR-TB diagnosis?
   - At facility when returning for sputum results
   - Telephone call
   - Home visit
   - Other...
3. What were you told to do after you were given your results?
   - Start treatment at the facility immediately
   - Return to facility to see doctor
   - Referred elsewhere
   - Other...
4. How much time passed between coming to the facility for a TB test, getting results and starting treatment?
5. Can you describe what happened in this time?
6. How did you feel after finding out that you had DR-TB?
7. What did you do after finding out that you have DR-TB?
8. Did you choose to delay starting treatment after finding out your diagnosis & why?
9. How were you treated by health care workers after you were diagnosed with DR-TB?
10. Did you seek help elsewhere after your diagnosis before starting treatment?
    - Traditional healer
    - Private practitioner
11. Where you provided with any counselling or educational materials to explain the importance of DR-TB treatment?
    - If yes, please describe
12. What were the main challenges that you faced in starting treatment?
    - (Personal or related to the facility)
    - Facility operating times
    - Medication shortage
    - Staff shortage
    - Employment
    - Transport
    - Stigma from community
    - Fear of medication side effects
    - Did these challenges impact on when you started treatment
    - If yes, how?
13. Were there factors that helped you to start treatment?
    - Support system at home, work or at facility
    - Able to take time off work
    - Did this impact when you started treatment?
14. Did you have to make any changes in your personal life to start treatment?
   - Quit job
   - Change starting times at work
   - Stop alcohol or drug use
   - Other...

15. Did you face any difficulties getting to the facility to start treatment?
   - If yes, describe

16. Can you describe what the most difficult thing about starting treatment was for you?

17. Do you have any suggestions on how the facility can make it easier for patients to start DR-TB treatment?