

**Health Information and Its Influence On The perception Of
Tuberculosis (TB) Patients: Current Policies and Practices at
Brooklyn Chest Hospital.**

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The logo of the University of the Western Cape, featuring a classical building facade with columns and a pediment, overlaid with the university's name in a serif font.

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Abstract

HIV and TB are major problems in the South African context and the burden of these diseases is proving detrimental to the development of the country. These diseases have been evident in the country for many years and in recent times the infection rates of TB and HIV has been alarming. The World Health Organization (WHO) classified TB as a problem and the world was to actively implement strategies to combat this epidemic.

The issue with TB control strategies is the emergence of HIV which has been the largest contributing factor to the increase in the TB burden in South Africa and many countries like it. South Africa has made great strides in the control of HIV in areas such as mother to child transmission, awareness programs, initiation of ARVs and medical male circumcision which have proven to be successful. In contrast, the TB burden does not share the same fate. The number of deaths caused by TB is continuously rising, as well as the number of new Multi-drug resistant TB cases. Furthermore the emergence of Extreme –drug resistant TB is seen as a sign of a failing health system. Policy makers are now faced with fact that the Directly Observed Therapy Short course (DOTS) program for the prevention of TB is inadequate in an area with a high HIV prevalence, which is what South Africa is faced with.

The research objectives are therefore to identify if knowledge from South African TB policies are being disseminated to people who suffer from TB, also to measure if a lack of knowledge may have an impact on treatment success.

A policy analysis was done of 5 South African TB policies to identify areas of the policies which are patient specific. The TB policies emphasized a patient-centred approach and the researcher used this concept to motivate that patient-specific areas must be known by the

patients. The specific areas identified were: TB specific areas, Treatment specific areas, Adherence specific areas and information/education specific areas. Based on the policy analysis a case study was conducted at Brooklyn Chest Hospital to measure implementation of the policies on the ground.

The study found that education was adequate in areas around TB diagnosis, treatment length, signs and symptoms, and family education. The participants lacked knowledge in areas such as TB contacts, monitoring of TB disease, education of TB prior to diagnosis and a high prevalence of non-adherence and multiple cases of TB were found among the participants. Also, the Chi-Square test found no statistical significance between the length of admission to hospital and treatment outcome. The result also shows that of the participants studied, over 30% of the study had not adhered to TB treatment after discharge.

The study finds that there are significant shortfalls in the knowledge of participants based on South African TB policies, with a high non-adherence rate before and after discharge. The study shows a lack in the implementation of policy directives on education, following a patient-centred approach, which is evident in the lack of knowledge found in the participants in many facets of the TB disease and the processes to control TB.

Key Words:

Tuberculosis, South African TB policy, Patient Perceptions, Policy Impact, Experiences, Public Health, TB Knowledge

Declaration

I Mubashir Goolam Nabie, declare that “*Health information and its influence on the perception of Tuberculosis (TB) patients: current policies and practices at Brooklyn Chest Hospital*” is my own work, that it has not been submitted before for any degree or examination in any other university, and that all the sources I have used or quoted have been indicated and acknowledged as complete references.

Mubashir Goolam Nabie

November 2018

Signed: *MGNABIE*



Dedications

This thesis is dedicated to my loving family who have sacrificed time and effort to allow me to produce this thesis.



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Table of Contents

Abstract	ii
key words:	iii
Declaration	iv
Dedications	v
Acknowledgements	vi
Table of Contents	vii
List of Tables	ix
List of Figures	xi
List of Abbreviations and Acronyms	xii
Chapter One: Introduction: Health Information and Its influence on the Perception of <i>Tuberculosis</i> (TB) Patient	1
1.1 Rationale for this study	Error! Bookmark not defined.
1.2 What is TB?	Error! Bookmark not defined.
2. Framing the study	Error! Bookmark not defined.
2.1 Problem statement.....	Error! Bookmark not defined.
2.2 Aims	Error! Bookmark not defined.
2.3 Objectives	Error! Bookmark not defined.
2.4 Research Questions	Error! Bookmark not defined.
2.5 Significance of study.....	7
Chapter 2: Literature Review: HIV AIDS Health Information and Its Influence on the Perception of <i>Tuberculosis</i> (TB) Patients: Current Policies and Practices	8
2.1 Introduction	8
2.2 The impact of TB on South Africa.....	8
2.3 Effects of HIV on TB.....	10
2.4 DOTS strategy to combat TB	12
2.5 Role of Community Healthcare Workers in DOTS program	14
2.6 Containment of TB patients as a strategy for control.....	16
2.7 Health Policy objectives	18

2.8 Policy analysis of TB policies in South Africa	18
2.8.1 Policies being used.....	19
2.8.2 Reasons for the emergence of TB policies in South Africa.....	19
2.8.3 Aims and objectives of the policies	21
2.8.4 Patient centred care	25
2.8.5 Education.....	29
2.9 Patient specific aspects of TB policies	30
2.9.1 Patient specific areas of the policy	31
2.10 Research design best used for measuring behaviour of TB patients.....	41
Research Hypothesis	Error! Bookmark not defined.
Summary	43
Chapter Three: Research Methodology: To Study Health Information and its Influence on the Perception of TB patients at Brooklyn Chest Hospital.....	44
3.1 Research setting.....	44
3.2 Research approach.....	44
3.3 Research design	45
3.4 Study population and sample	46
3.5 Inclusion Criteria	47
3.6 Exclusion criteria.....	48
3.7 Data collection and instrumentation	48
3.8 Ethical Considerations.....	56
Chapter Four: Results: The Influence of Health Information on the Perceptions of TB Patients at Brooklyn Chest Hospital.	58
4.1 Introduction	58
4.2 Section A: Demographic Information	58
4.3 Section B: Medical Information.....	59
4.4 Section C: Social History	65
4.5 Section D: Participant’s Knowledge on TB Policies	67
4.6 Cross tabulations	75
4.7 Patient outcomes.....	81

Chapter Five: Discussion: Understanding the Impact of Health Information on the Perception of TB Patients: Current Policies and Practices at BCH	85
5.1 Introduction	85
5.2 Demographic Information	85
5.3 TB Specific Areas	87
5.4 Treatment Specific Areas	92
5.5 Adherence Specific Areas	94
5.6 Education/Information Specific Areas	96
5.7 Length of stay versus treatment outcome	101
5.8 Discussion overview.....	104
Chapter Six: Conclusions: Health Information and the Relation to TB Patient Perceptions at Brooklyn Chest Hospital.....	107
6.1 Introduction	107
6.2 Significance of the study	110
Impact for policy	110
Impact for health care providers	111
6.3 Study Limitations	112
6.4 Recommendations	113
References	115
Appendices	124
Appendix I: Data gathering instrument	1234
Appendix II: Informed consent form.....	1237
Appendix III: Participant Information Sheet	12328
Appendix IV: Map of Brooklyn Chest Hospital.....	131
Appendix V: Ethical Clearance	132

List of Tables

Table 2.1: Summary of Patient specific areas	41
Table 3.1: Patient specific themes.....	50
Table 4.1: Substance and alcohol use vs Strain of TB	75
Table 4.2: Living conditions vs Drug and Alcohol use	76
Table 4.3: Employment status vs Alcohol and Substance abuse	77
Table 4.4: The relationship between adherence and employment status	77
Table 4.5: Relationship between type of living structures and exposure to information	78
Table 4.6: HIV dispersion among racial groups in the study	79
Table 4.7: Relationship between the HIV statuses of the participants versus the non-adherence history	79
Table 4.9: Treatment Outcome and Length of Admission Cross tabulation	83
Table 4.10 Results of Chi-Square Test.....	83
Table 4.11: Treatment outcome versus HIV status	84
Table 5.1: Outcomes overview	105

List of Figures

Figure 4.1: Profile of study participants.....	59
Figure 4.2: TB diagnosis of participants.....	60
Figure 4.3: Strain of TB of participants.....	61
Figure 4.4: Episodes of TB of participants	62
Figure 4.5: Episodes of TB among Males and Females	63
Figure 4.6: Current length of treatment of the participants.....	64
Figure 4.7: Number of participants using Alcohol, Substances, both or none.....	65
Figure 4.8: Number of children of participants	66
Figure 4.9: How TB was contracted by participants	67
Figure 4.10: Participants perception of monitoring TB	68
Figure 4.11: Reasons for admission to BCH of participants.....	69
Figure 4.12: Knowledge of signs and symptoms	70
Figure 4.13: Reasons for TB testing of participants	71
Figure 4.14: Reasons for non-adherence to TB treatment of participants.....	72
Figure 4.15: Exposure to TB related information prior to diagnosis	73
Figure 4.16: Exposure to TB related information versus non-adherence	80
Figure 4.17 Treatment outcomes of participants	81
Figure 4.18: Length of admission at BCH	82

List of Abbreviations and Acronyms

ARVs/ARTs – Antiretroviral treatment

BCH – Brooklyn Chest Hospital

CD4 Lymphocytes – Cluster Differentiation 4 Lymphocytes

CEO – Chief Executive Officer

CHWs – Community Health Workers

DISS-TB – Disseminated *Tuberculosis*

DOTS – Directly Observed Therapy Short Course

DR-TB – Drug Resistant *Tuberculosis*

DS-TB – Drug Sensitive *Tuberculosis*

GCS – Glasgow Coma Scale

HIV – Human Immunodeficiency Virus

MDR – Multi- Drug Resistant *Tuberculosis*

NDoH – National Department of Health

NHLS – National Health Laboratory Services

PTB – Pulmonary *Tuberculosis*

SOB – Shortness of Breath

SPSS – Statistical Package for Social Sciences

TB – *Tuberculosis*

TB Joint – *Tuberculosis* of the Joint

TBM – *Tuberculosis* Meningitis

TB Spine – *Tuberculosis* of the spine

WHO – World Health Organization

X-Ray – X-Radiation

XDR-TB – Extensively Drug Resistant TB

(x^2) - Chi- square



Chapter One

Introduction: Health Information and Its influence on the Perception of *Tuberculosis (TB) Patient.*

1.1 Rationale for This Study

Tuberculosis (TB) has been found for many years in South Africa, but recently TB has caused an increase in mortality rates in South Africa due to an increase in HIV prevalence. Since the development of TB treatment, this view has drastically changed as the ability to cure TB had become relatively simplified. The biggest stressor to this TB endemic has been the emergence of HIV, which has placed the strain on most of the control strategies of TB. (Mukadi et al.2001). Africa was seen to be worse off. This has led to the World Health Organization seeing TB as a regional emergency for the African continent, and the introduction of new HIV and TB initiatives had been put in place in Africa and many countries all over the world. (Lawn et al.2006)

The initiative to control TB has shown positive results in many countries. Looking at New York as an example, TB was controlled by strict adherence to protocols, as well as strong community involvement (De Cock, 1999). However, the same success is not found in Sub-Saharan Africa. This region of the world does not possess adequate time, money and infrastructure in comparison to other countries aiming to accomplish the task of controlling TB. The worsening factor is that the HIV epidemic has been found to be alarmingly high and rising in Africa, and Coetzee et al.(2004), De Cock et al. (1999), Lawn et al. (2006), Dolin et al. (1994) finds that this is the case in relation to Africa, stating that worsening factors to TB

control is the difficulty which has been associated with HIV and TB co-infection. The mortality and morbidity rate for these two conditions simultaneously has increased exponentially and TB has become the highest cause of death in people suffering from HIV (Coetzee et al.2004). With this scenario, the TB burden has been declared an African emergency and more efforts were to be focused on to ensure adequate control.

In the case of South Africa, the high TB rates are often found in informal settlement communities with below standard sanitation and a lack of services like water, electricity and good healthcare systems. (National Department of Health, 2012-2016)

1.2 What Is TB?

A frequently asked question is: What is TB? *Tuberculosis* is a bacterial infection and there are five related strains of this infection which are found. They are *Mycobacterium tuberculosis*, *Mycobacterium canetti*, *Mycobacterium bovis*, *Mycobacterium microti* and *Mycobacterium africanum*. When looking at TB today, the most common form of infection is *Mycobacterium tuberculosis*. (National Department of Health, 2014).

TB is transmitted through inhalation of air droplets infected with *Mycobacterium tuberculosis*, which is spread into the alveolar spaces of the lungs due to its relatively small form. The alveolar spaces serve as a perfect area for growth and replication of the bacteria due to the warm, moist and air filled environment. This process of means of transmission and area of replication causes TB to be a highly infectious disease. Also due to the relatively small size of these TB particles, they can be present in the air of indoor spaces for up to 4 hours. The National Department of Health of South Africa, in the 2014 National Tuberculosis

Management Guidelines found 3 factors which can determine the transmission likelihood of the common strain of TB (*Mycobacterium tuberculosis*), namely:

- The number of organisms expelled into the air
- The concentration of organisms in the air, determined by the volume of the
- Space and its ventilation
- The length of time an exposed person breathes the contaminated air

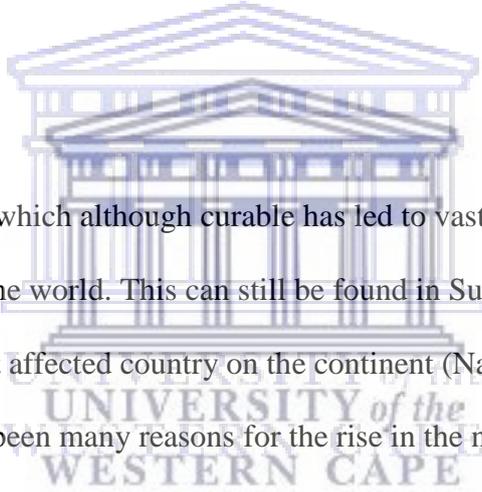
(National Department of Health, 2014)

People exposed to prolonged contact with sufferers of active TB disease have a higher rate of contracting TB bacteria. When infected, the disease may remain dormant or may become active, but this is dependent on the state of the immune system of an infected individual. According to the 2014 National Tuberculosis Management Guidelines, 90% of individuals will manage to suppress the transition of TB infection from becoming an active disease, and only 10% will develop the active disease. This 10% represents the population at risk, which predominantly comprises of the elderly and young children less than 5 years of age, due to lowered immunity. Following this trend, the population suffering from diseases which compromises immunity, or are on treatment which compromises immunity are more likely to develop active TB disease. The guidelines also state that 50-60% of HIV positive persons who are infected with TB will progress to active TB disease. Other conditions which may leave people susceptible to active TB disease are diabetes mellitus; silicosis or people with long-term corticosteroid use, also drug abuse and alcoholism are known to cause the same effect and increases the risk of active TB disease. (National Department of Health, 2014: 8).

The most common site of presentation of TB is the lungs of individuals, more specifically the upper zones of the lungs. This is named Pulmonary TB and this, however, is not the only place TB is found. People may also present with extra-pulmonary TB (TB that has spread to other areas of the body). Areas which are common sites of TB are: the brain, bones and kidneys as these areas provide a suitable environment for the replication and growth of TB bacilli. When TB disease has spread, treatment is prolonged as the target areas must be altered, and extra-pulmonary TB usually occurs in people who present late to health facilities (National Department of Health, 2014).

2. Framing the Study

2.1 Problem Statement



Tuberculosis is a condition which although curable has led to vast amounts of morbidity and mortality in many parts of the world. This can still be found in Sub-Saharan Africa with South Africa being the most affected country on the continent (National Department of Health, 2009). There have been many reasons for the rise in the number of TB cases and the rise of new MDR and XDR TB cases. The South African TB epidemic is growing with more cases being detected and an increase in the number of drug resistant TB cases. To add to this the rates of non-adherence is equally high and places a strain on government TB policy success. (National Department of Health, 2009)

Literature has identified many reasons for this rise, however, this is largely related to the HIV prevalence found in South Africa, and the impact HIV has on TB. (Coetzee et al.2004, De Cock et al.: 1999, Lawn et al.: 2006, Dolin et al.: 1994). South Africa is still divided post-democracy with large pockets of people who live in poverty and do not have access to

adequate services. Many social ills are found among these communities and TB is affecting these people. (National Department of Health, 2012-2016)

The South African Government has persevered to follow WHO guidelines to combat TB through well-written policy directives and ensuring that life-saving medication and services are available. The results have shown that the success rate of TB control is still low in South Africa despite sound policies on TB.

Whitehead, (2001) finds that for behavioural change to occur education needs to be carried out on a large scale to improve knowledge for the most vulnerable groups who pose the greatest risk of contracting TB. It is also found that changing behaviour is important and a successful TB control program must aim to achieve behavioural change to eliminate the disease (National Department of Health, 2012-2016). The high incidence of non-adherence and late presentation to healthcare institutions are a clear way of identifying the lack of knowledge among the participants regarding TB.

This study will examine the relationship between knowledge of TB and the pre-requisites prescribed by South African TB policies, to identify the knowledge of patient-specific aspects of TB policies, patients have at BCH. This will be achieved by understanding the perceptions that TB patients have about their disease and measuring this based on what South African TB policies state should be disseminated to patients.

Previous research has identified barriers to accessing of TB treatment and reasons for non-adherence; however, a gap exists when analysing perceptions of patients with TB, based on South African TB policies.

2.2 Aims

The aim of the study is to:

- Investigate the implementation of patient-specific aspects of South African TB policies, through patient perceptions at Brooklyn Chest Hospital.

2.3 Objectives

- Measure the implementation of patient-specific aspects of TB policy in South Africa based on patient perceptions
- Identify policy information dissemination from healthcare personnel to patients with TB
- Identify if a link exists between lack of patient-specific policy knowledge, non-adherence and TB treatment outcomes.
- Measure if admission to a TB hospital has an impact on treatment outcomes and adherence to TB treatment.

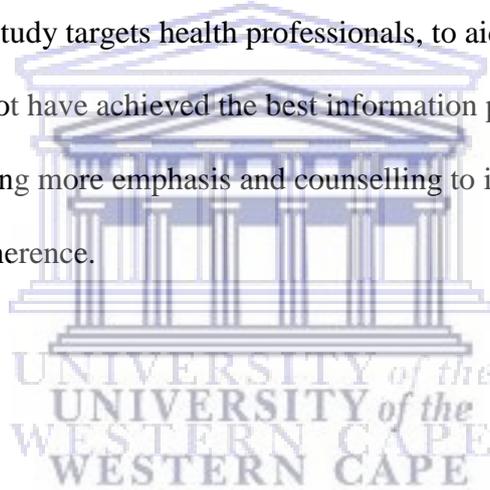
2.4 Research Questions

1. Are patient-specific areas of TB policies being disseminated to TB patients?
2. Are healthcare personnel providing relevant information on all areas required by TB policies in South Africa?
3. Do patients with TB understand their condition and the process required for cure of TB?
4. Does a lack of knowledge on TB impact on non-adherence?

5. Do hospitalization and the length thereof have an impact on TB treatment outcomes?

2.5 Significance of the Study

This study aids in identifying areas in South African TB policies, which could be lacking in dissemination to people who suffer from TB. The study is significant as it provides an understanding from a patient perception of shortfalls in the knowledge of patient-specific aspects of TB policies in South Africa. The information found in this study will target policymakers. This is to ensure more effort is placed in areas which are lacking in patient knowledge, providing guidance on areas most important for further resources to be allocated towards. Furthermore, the study targets health professionals, to aid in the understanding of areas which patients may not have achieved the best information packages. This will guide clinical staff on areas needing more emphasis and counselling to improve outcomes of treatment and limit non-adherence.



Chapter Two

Literature Review: HIV AIDS Health Information and Its Influence on the Perception of Tuberculosis (TB) Patients: Current Policies and Practices

2.1 Introduction

This section identifies the review of relevant information and literature for this study. The chapter focuses on the impact of TB in South Africa. The next area reviewed is the impact HIV has on TB, also the Dots strategy to combat TB in South Africa and the role community healthcare workers play in the DOTS strategy, followed by a review of existing policies and practices to contain TB patients as a method of TB control. Following that, the policy analysis will be shown and patient-specific areas will be found to form a basic theoretical framework for the design of a questionnaire used for structured interviews.

2.2 The Impact of TB on South Africa

According to Schneider (2002), the South African government was late to react to the HIV burden and this has shown in the direct impact it has had on TB in South Africa. The National Department of Health (2011) finds that we live in a country which holds the 3rd highest TB infected population in the world only second to China and India which shows much larger population sizes.

It can be seen that South Africa has worked hard and smart in the fight against HIV and improvement is noticeable in many areas. According to Statistics South Africa in the mid-year population estimates, in 2005, 133000 adults (15+years) have been estimated to have received ARTs, whereas, in 2009, 920000 adults (15+years) have been estimated to have

received ARTs, clearly showing an improvement in the detection and treatment of HIV/AIDS. (Statistics South Africa, 2010).

Also in 2010 the rate of mother to child transmission of HIV at six weeks after birth had dropped to 3, 5 percent, and South Africa's National Strategic Plan, aims to drop this to 2 percent by 2016 (South African National AIDS Council, 2011). In 2008 a survey was conducted to assess how the population of South Africa received campaigns of awareness with regards to HIV. It was found that over four-fifths of South Africans had experienced an aspect of the campaign compared to less than three-quarters in 2005 (Human Sciences Research Council, 2009). The problem is by no means under control but steps have been put in place and some results of a positive nature are visible, and the possibility for future improvement is high.

However, the TB burden does not share the same fate, as all statistics for this condition in South Africa does not seem to be following the same path as the fight against HIV. These statistics show some improvement in HIV with the success of campaigns and protocols. TB does not seem to share the same successes, as the numbers of TB cases are on the rise and default rates and new drug-resistant TB cases are also increasing in South Africa. Africa is the only region in the world showing an increase in TB with a rise from 162 per 100,000 in 1990 to 363 per 100,000 of the population in 2006. South Africa has the highest rate of TB in Africa with 940 per 100,000 populations (National Tuberculosis Management Guidelines, 2009: 9). An increase in drug-resistant TB is also on the rise. In 2004, 3219 people were diagnosed with Multi-drug resistant TB. The figures have increased to 7386 people in 2010. In 2004 South Africa had 85 extensively-drug resistant TB cases and that has also increased to 741 in 2010. This increase shows a challenge in the primary treatment of initial TB which

is shown in the 10, 4% default from medication rate and the 1, 7% failed treatment statistics in 2005. (Department of Health, 2011: 5).

TB in South Africa is currently the highest in Africa, which seems adverse judging by the rate of development shown in comparison to other African countries. TB is also seen as the leading cause of death in HIV infected people in South Africa. All the hard work done to remedy the HIV endemic in this country can be overshadowed if the TB scenario is not improved. Another area which clearly shows a national failure in TB control strategies is the emergence of drug resistant cases of TB. In South Africa, we currently are witnessing an increase in the number of multi drug resistant TB cases and an alarming increase in extensively drug resistant TB. According to Sing et al. (2007), in 2006 an outbreak of Extreme drug resistant TB was found in a rural township in Kwa-Zulu Natal in South Africa. A total of 53 XDR-TB cases were identified and all were tested and found to be HIV positive. The alarming incident though, was that 52 of the 53 infected with this TB strain had died within 16 days after sputum microscopy had identified the strain. (Singh et al.2007).

2.3 Effects of HIV on TB

HIV is known to be a compounding factor to the presentation and evolution of the TB disease. Due to the nature of HIV, the immune system function is significantly compromised. This increases the risks of opportunistic infections including TB, in people with HIV/AIDS. When the HIV infection becomes more severe the CD4 Lymphocytes which are the cells responsible for immunity, are decreased, leading to suppression in the immune function, therefore, causing increases in the opportunistic infections among the HIV positive population.

Lawn et al. (2006) show that the prevalence of TB increases in areas with a high HIV positive population, which is the case of Sub-Saharan Africa and South Africa (Lawn et al.2006). In a study conducted in a peri-urban community in the Western Cape Province of South Africa, it was found that HIV prevalence has increased by more than double in people with TB. The study also found that when the HIV prevalence had become more controlled, this did not have an effect on the TB rate as the numbers of individuals presenting with TB continued to rise. Alarmingly the study also found that the people most affected were between the ages of 20-39 which is the most productive age group in a society (Lawn et al.2006).

The National Tuberculosis Management Guidelines (2009) shows the impact HIV has on TB control. It is found that in a population of HIV negative people only 10% of individuals will progress to active disease. However when the HIV infection is present the numbers increase largely, showing an increase of 50% of HIV positive people will develop active TB. To compound this, the National Department of Health (2009) finds that around 55 % of people diagnosed with active disease are HIV positive. (National Department of Health, 2009).

Not only does the presence of HIV impact on the increase in new TB diagnosis, but it also plays a significant role in changing the clinical picture of the TB disease. Due to the lack of immunity the TB disease is not being halted and is allowed to spread. In the National Tuberculosis Management Guidelines (2009), it is stated: “as HIV related immunosuppression increases, there are increasing numbers of smear-negative pulmonary TB, extra-pulmonary TB, and cases of Disseminated TB” (National Department of Health, 2009: 73). This means that TB is now more easily spread to areas outside of the lungs of infected individuals, and is affecting more organs and spaces of the infected people due to progressive immunosuppression. This also leads to a slow presentation to health care

facilities which ultimately increases mortality, due to the increasing presence of opportunistic infections and delayed diagnosis. (National Department of Health, 2009)

With this information, the literature clearly identifies the impact HIV has on TB which adds to the difficulty of managing TB in South Africa. The spread of HIV in communities have allowed perfect areas for TB to thrive due to immunosuppression and has therefore increased the burden of TB in communities. It is therefore important to manage both conditions simultaneously to ensure the success of both TB and HIV programs.

2.4 DOTS Strategy to Combat TB

The rising TB statistics in South Africa and the problem of co-infection with HIV has led to an increase in the attempts of the World Health Organization (WHO) to control TB. The initiative the WHO implemented for its TB control strategy is called Directly Observed Therapy Short Course strategy (DOTS). In 1993 the WHO had labelled TB as a 'global emergency' and seeing the possible burden TB could have on the world, a new public health strategy was designed.

With regards to the DOTS program, it is important to note that this process had occurred before the rapid increase in numbers of HIV infected individuals. The DOTS strategy required strong government support. Implementation of a TB programme (with a strong reporting system), a steady and constant supply of drugs, a move to diagnose based on sputum samples and supervision of the initial (intensive) phase of treatment (especially with rifampicin). All these strategies are needed to limit defaulting of treatment and resistance (De Cock et al.1999). It is therefore easy to see that the DOTS strategy, although a good initiative, requires many components for success. This may prove difficult for developing countries to implement.

Looking at the Dots program, one of the fundamental areas of the program is the direct observation of patients taking medication. The national department of health finds that a well-functioning DOTS program is an essential strategy for the improvement of TB treatment adherence, in patients with TB in South Africa. The National Tuberculosis Management Guidelines (National Department of Health, 2014), finds that directly observing patients taking medication is fundamental to the target of preventing non-adherence, by ensuring visual confirmation of treatment being consumed. However, this should be done in a manner that is sensitive and caters to the needs of the patients. Some of the benefits found for the program are that the patient can be assisted by Community Health Workers or treatment supporters, therefore bringing the DOTS program to the communities or even within workplaces of the patients requiring treatment. This also limits barriers such as distances to the clinic which prevent patients from receiving life-saving medication. Other benefits to the DOTS program are that not only is adherence improved but early detection of possible side-effects may be identified and managed, limiting ill health as a barrier to accessing treatment. The Directly Observed Therapy Strategy also provides opportunities for constant education and motivation of patients to remain on treatment. (National Department of Health, 2014)

The major factor here is that the DOTS strategy does not take into account areas with high HIV prevalence, which makes the treatment of TB more difficult. This also places large workloads on health staff, but the success of the program is evident all over the world. South Africa has implemented this program, but when looking at the current state of TB in South Africa, it is clear that this is not enough. In an article by De Cock (1999) it was found that although DOTS has many positives, the program alone is not conducive to combat TB in an HIV prevalent society (as in South Africa). Therefore, it is evident that more should be done to try to achieve the necessary goals.

2.5 Role of Community Healthcare Workers in the DOTS Program

When looking at Community Health Workers or Treatment Supporters and the role they play in the success of the DOTS program there are many areas to consider. Community Health Workers are helpers based in the community to assist with health programs on the ground, and they are trained and carefully selected from within the community they serve to provide a service. The idea of this is based on the fact people within the community are more inclined to understand the community beliefs and cultural nuances based in the society they are selected to serve. CHWs based on literature have differing tasks however these tasks are most often based on prevention and development and can be broad-based or specific program orientated as in the case of TB and HIV.

In an article by Lehmann & Sanders (2007), there are positives and negatives identified for CHWs.

Positives

- They improve the basic health services on the ground by providing an improvement in areas of access to health facilities especially in areas of the peripheral geographical location.
- It eases the burden on overpopulated health facilities.
- Provides relief for professional health staff.
- Provides access to service within the community of patients.

Negatives

- This article finds that they do not provide noticeable health improvement.

- In some cases the overall quality of the care is sub-standard.
- They can be swayed by political tensions or instabilities.
- Ensuring prolonged commitment from CHWs is difficult as most are unemployed prior to initiation and seek adequate compensation for the task, which could make the service costly. (Lehmann & Sanders, 2007).

Lehmann & Sanders, (2007) also find, for the success of the programs the CHWs must be adequately trained on all relevant information by trained professionals. CHWs must also be carefully chosen for the task to limit dropouts from identified programs. The CHWs should be given support in all forms like educational etc. and they must be well supervised and guided to ensure all program objectives are met. It is important to note that all CHW programs have not always shown success however it is better than no program at all. (Lehmann & Sanders, 2007)

The Management of Drug Resistance Tuberculosis Policy Guidelines (2011) reiterates the importance of education and goes further to describe the basic knowledge that these DOTS Supporters should have. Emphasis is placed on education around the TB disease, HIV, infection prevention and control methods, common side effects of medications and the interaction of TB and HIV. The aim should be on monitoring and observing the consumption of treatment, early detection of side-effects and motivation and support for people suffering from TB. The policy also mentions that these treatment supporters should be compensated as the DOTS strategy is a government initiative. (National Department of Health, 2011)

Although negative aspects of Community Health Worker initiatives do exist, the Department of Health has seen the benefit of this program and have chosen to implement this as one of

the plans to assist the DOTS strategy, and assist with monitoring treatment, but also as a tool for limiting non-adherence to treatment.

2.6 Containment of TB Patients as a Strategy for Control

Since the emergence of the extensively-drug resistant strains of TB, another highly contested argument has occurred, the first of which is what can be done to contain this strain. The WHO has added quarantine for these types of patients, and patients who show signs of poor compliance on MDR treatment, and who could potentially become XDR-TB patients (Singh et al.: 2007, Koenig: 2008). This has led to many arguments of the restrictions of rights of TB patients versus the safety of the public.

With regards to the isolation of patients with TB, the National Department of Health validates the ethics of quarantine for the benefit of public health by incorporating the Siracusa Principles. In the Management of Drug Resistant Tuberculosis Policy Guidelines it is stated:

“The Siracusa Principles on the limitations and interrogation of provisions in the international covenant on civil and political rights state, public health may be invoked as grounds for limiting certain rights in order to allow a state to take measures dealing with a serious threat to the health of a population or individual members of the population. These measures must be specifically aimed at preventing disease or injury or providing care for the sick or injured and that due regard shall be had to the international health regulations of the World Health Organization”. (National Department of Health, 2011: 22)

Based on the Siracusa Principles the Department of Health has adopted the isolation of drug resistant TB patients who do not adhere to treatment or are at high risk of non- adherence.

(National Department of Health, 2011)

It is important to remember that people with these strains of TB are not prisoners and have not committed any crimes. If detention is for the good of the public and is forced when implemented, ‘detainees’ need to be in an environment that is conducive with dignity and allows the right to live a life which corresponds to a life in the areas they are from. However, despite South Africa following this control strategy, it has proven difficult to maintain.

Firstly, the possibility of forced isolation could act as a deterrent for the initial presentation of patients for TB testing. Social grants are another area which needs to be revised. South Africa is known to have a high unemployment rate, which in turn has led to a dependence on social grants. This has not only become a temporary aid but for many South African this has become the only source of income. The policy in South Africa is that if a person who is on a social grant has to be hospitalized, the person will not receive this grant for the duration of the hospitalization, as the state will support the admitted person in the hospital setting. This proves a problem as people suffering from TB who must be hospitalized will be admitted for long periods of time. This means a loss of income for that period which many patients’ families require for survival. This also leads to the late presentation of TB patients to health care facilities. An article by Singh et al. (2007) suggests that the government should rethink this policy to ensure that this should not be a deterring factor to hospitalization for people with TB.

The next issue to be addressed is the maintenance of patient hospitalization. In 2007 a case was found where 28 MDR TB patients and 20 XDR- TB patients had absconded from a

South African TB hospital by cutting a hole in a fence (Koenig, 2008). This poses a great threat to public health as many of these people will potentially be carrying an untreatable strain of TB. Given the mode of transmission, it would therefore only be a matter of time before many more become infected with this potentially incurable strain in local communities.

The problem many people also face is co-infection with HIV. If we as a nation are focused on reducing the burden of HIV in the country and/or continent without addressing the burden of TB, it would be impossible to achieve. Attempts to improve and prolong lives of people affected by HIV are not ideal without the control of TB.

2.7 Health Policy Objectives

When considering policy, especially in health, it is important to note that the Ottawa Charter sees health public policy as one of the five most key areas for health promotion programs (Kemmer, 2001). Kemmer (2001: 79) finds that “a healthy public policy is a policy that increases the health and well-being of those individuals and communities that it affects”. He also finds that health public policy should look to manage current and future issues. It should be unbiased and be based on sound evidence (Kemmer, 2001). Policy should also aim to reach all stakeholders involved for best implementation. This is what has been found to be lacking with regards to the TB policy and knowledge filtration to patients with TB.

2.8 Policy Analysis of TB Policies in South Africa

In this section all the policies used will be identified, the reasons for the emergence of TB policies will be explored and a policy analysis will be done. The aims and objectives will be looked at of the TB policies and the patient-centred care approach mentioned in the policies will be focused on. Then patient-specific areas of the policies will be identified and based on

this a theoretical framework will be found and a questionnaire will be designed and developed for structured interviews to be used.

2.8.1 Policies Selected for the Study

The researcher has identified five TB policies drawn up by the National Department of the health of South Africa. The policies were chosen because they were developed in different time frames and show a clear progression of the plan to control and combat TB in South Africa. The policies identified by the researcher are:

- South African National Tuberculosis Control Program Practical Guidelines (2004)
- National Tuberculosis Management Guidelines (2009)
- Management of Drug Resistant Tuberculosis Policy Guidelines (2011)
- National Strategic Plan on HIV, STI's and TB (2012-2016)
- National Tuberculosis Management Guidelines (2014)

These policies form the basis for the management of TB in the country of South Africa and all health establishments must adhere to the guidelines presented in these policies to combat the TB epidemic.

2.8.2 Reasons for the Emergence of TB Policies in South Africa

TB has been around for many years; however, an increase in the case detection in industrialized countries, and the formation of Multi- Drug Resistant TB in bigger cities had re-energized the focus of global health role players to re-assess the effects of TB as a global health emergency. Although many of the larger cities were reporting this new trend, less

developed countries especially Sub-Saharan Africa including South Africa was fast becoming uncontrollable. (Raviglione, 2003)

The World Health Organization had aimed to address this issue by developing the ‘five-element DOTS strategy’ as a means to measure and control the TB burden. This was developed in 1994-1995. The roll-out of this program to TB afflicted regions was good and by the year 2000, 148 regions or countries had adopted and committed to the implementation of the DOTS strategy. (Raviglione, 2003)

South Africa had also adopted the DOTS strategy of the World Health Organization as the TB epidemic was on the rise. South Africa being previously run by a government which implemented the apartheid system, which oppressed the rights of the vast majority of the population, had neglected the TB epidemic in the country. Under the apartheid government, the majority of healthcare resources were reserved for the White minority, while the Black majority received inadequate health services (Van Rensburg & Benatar, 1993). TB affecting mostly the poor and therefore the Black population was not prioritized in the health system, which contributed to the exponential increase of TB in the country. (Compion, 2008).

However since democracy more had been done by the South African government to combat TB. The way forward was for policies to be developed that was grounded in the framework of the WHO’s DOTS strategy. This led to the development of the South African National *Tuberculosis* Control Program in 1996. Some of the aspects the policy included were standardized treatment protocols, a move to diagnose with bacteriological confirmation and electronic standardized reporting systems, which are all in line with the DOTS strategy. By 2003 all the provinces in South Africa were reached with the DOTS strategy and the National policy for MDR-TB was rolled out by the year 2000. (Weyer, 2007)

Weyer (2007) finds however that although so much has been achieved in South Africa to control TB, the rate of new cases and deaths due to TB had continuously increased. The research found that the fundamental mistake made by the South African government was that resources had been focused on the identification of new TB cases but lacked in the areas of ensuring treatment of TB was completed. Another problematic area was the emergence of Drug-Resistant TB which was seen as a failure and inadequacy of the control strategies and programs. It was also found the many factors which are well documented in low socio-economic areas compounded the failures, and the emergence of HIV played a large role in the TB program difficulties. (Weyer, 2007)

The South African government continued to learn from the mistakes and developed new or made editions to the TB policies in attempts to control the TB epidemic. Many policy adjustments had been made over the years, adjusting areas of treatment and focusing on identification of TB patients, the completion of TB treatment and a large focus on behavioural change and community education on TB. This will ensure that people are tested earlier and are well educated on the importance of remaining on treatment.

2.8.3 Aims and Objectives of the Policies

The policy used was the South African National *Tuberculosis* Control Program Practical Guidelines (2004). The main aims and objectives identified were based on the enhancement of public healthcare services to ensure that the DOTS strategy could be implemented in South Africa. Next, the policy aimed at improving the involvement of communities to assist in the care of TB patients and to ensure stigma was removed. The policy aimed to ensure a patient-centred approach to reach as many people and communities to improve health seeking behaviour and access to treatment of people with TB. Another objective was to promote

collaboration between different sectors and stakeholders to improve quality, but this was to be run by the provincial health departments to ensure the objectives of the program remain clear. The next mentioned area was to improve synergy between TB and HIV programs and lastly to improve the implementation of the DOTS strategy to manage and avoid the MDR-TB rise.

The second policy identified was the National *Tuberculosis* Management Guidelines (2009).

The strategic objectives of this policy were initially focused on the improvement of new detection of TB cases, the improvement of the cure of patients with TB and improving new detection of TB cases, the improvement of the cure of patients with TB and improving the rate of successful treatment. Furthermore the policy focuses on the strengthened implementation of the DOTS strategy with emphasis placed on achieving the five-elements of the DOTS strategy (political commitment, case detection based on sputum microscopy, standard treatment protocols with the direct observation of this, a steady supply of drugs and a system to monitor and evaluate the TB control strategy).

The policy then aims to promote collaboration with TB and HIV programs and looks to improve measures for MDR and XDR TB control. A focus is placed on the improvement of the healthcare system to ensure TB services are adequate and accessible in all parts of South Africa while ensuring a high standard of care for people with TB regardless of their geographical region. The importance of the collaboration between different sectors and stakeholders are also mentioned, which is aimed at improving the quality and the reach of TB programs.

Lastly, the policy aims to ‘empower people with TB as well as communities’ (national department of health, 2009: 12). This will be achieved in three ways. Firstly, this will be

achieved through community communication and social interaction or mobilization. This will ensure that information and recommendations are from the ground up. This involvement will improve knowledge, health-seeking behaviour and decrease stigma attached to TB and HIV. Secondly, empowerment will occur by encouraging community involvement in TB programs and packages of care. This allows roles to be provided for community members to allow involvements in programs, in DOTS, and as treatment supporters. This is important as these people will best understand the cultural and community ideals which may improve the motivation and support to people suffering from TB.

Lastly, the policy identifies the importance of the respect of rights of people with TB disease. This will be achieved by providing education on all aspects of the disease from diagnosis to treatment etc. while respects the fears or misnomers of people which will improve relationships with healthcare providers and ultimately lead to improvement in adherence.

The third policy identified was the Management of Drug Resistance *Tuberculosis* Policy Guidelines (2011). This policy was more focused on the guidelines for the clinical management and treatment of drug resistant TB. The target audience for this policy was mainly medical and clinical healthcare practitioners who deal with the medical aspects of TB control. The main aims were to provide guidelines for the treatment regimens for patients and educate on the mechanisms put in place for diagnosing, monitoring and referring of TB patients. The policy also aims to ensure comprehensive psychosocial support is provided and educates on the protocols for infection control and health services for healthcare providers in the advent of occupational infections with TB.

The next policy analysed was the National *Tuberculosis* Management Guidelines (2014). Much like the policy above, a majority of the focuses of the aims was based on clinical

management of TB patients; however, this policy also included the management of drug sensitive cases as well as drug resistant TB scenarios. The aims of these policies were to:

1. Reduce transmission of infection in the community
2. Diagnose drug sensitive and drug resistant TB early
3. Initiate treatment in all patients diagnosed with TB early
4. Retain patients in treatment and care until completion of treatment and
5. Prevent TB in people living with HIV by initiating all eligible HIV positive people on ART and Isoniazid Preventative therapy. (National Department of Health, 2014:3)

The last policy identified was the national strategic plan on HIV, STI's and TB (2012-2016).

The basis of this policy is based on four objectives which drive the policy. Firstly the barriers of social and structures which hamper the achievement of the goals of prevention and cure are targeted. This is an important area as most studies have shown societal and behavioural constructs are key drivers to TB increases. The policy looks to tackle areas such as inadequate living conditions, access to healthcare in peripheral areas as well as the impact of alcohol and substance abuse in TB. Secondly, the objective of this policy moves away from just the cure of TB patients but emphasizes a strong focus on the prevention of TB, HIV, and STIs. Regarding TB control the policy aims to achieve this by ensuring maximal opportunities for screening and testing of people in the community and also enforces the collaboration of TB and HIV services to identify people affected with either TB or HIV in this highly affected group.

The third objective is to improve the wellness and health of people with TB and HIV by reducing and limiting the impact these diseases have on individuals and families. The aim is to reduce morbidity and mortality by ensuring quality services is available for the treatment and diagnosis of people with TB and HIV. One of the methods identified to achieve this is strong communication through all possible mediums and media. If successful the message will be far-reaching leading to improvement in knowledge which could improve health-seeking behaviour, early detecting of TB cases, leading to an increase in success rates of treatment and improved adherence to TB treatment. The last objective is the protection of the rights of people with TB and HIV and the main goal of this objective is to eliminate the stigma attached to these conditions. The stigma and discrimination have an impact on health-seeking behaviours and treatment compliance as people fear telling friends and family which ultimately leads to them not presenting to healthcare facilities.

2.8.4 Patient Centred Care

When analysing the TB policies one of the standout frameworks being used as a strategy for good adherence to medication and TB control is the patient-centred approach. The National *Tuberculosis* Management Guidelines 2014 states

“Promoting adherence through a patient-centred approach that includes facilitating access to treatment, choosing with the patient the most convenient time and place for direct observation of treatment and, when possible, providing other social and medical services, is much more effective than spending resources on default tracing.”(National Department of Health, 2014: 52)

With this in mind, it is important to understand what patient-centred care is and how National policies aim to use this approach in the promotion of good adherence. Patient-centred care does not have one definition but is widely regarded by many countries as a package of care that is based on the interaction between the healthcare provider and the person seeking care, with family involvement. An article by Luxford et al.. (2010) defines patient-centred care as:

“An innovative approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families. Patient- and family-centred care applies to patients of all ages, and it may be practiced in any health care setting”.(Luxford. et al., 2010: 13)

Kitson et al.. (2013) found when analysing papers which looked at patient-centred care, three common themes appeared. Namely “patient participation and involvement, the relationship between the patient and the healthcare professional, and the context where care is delivered”. (Kitson et al., 2013: 6). Therefore there are benefits to this approach and this is an indication of why the Department of health has chosen this as a strategy for the improvement of non-adherence. The benefits of this approach are that the treatment and planning of treatment are more holistic in nature, and focuses not only on the knowledge of the treating healthcare provider but also a consideration is made to the belief system of the patient. Other benefits include an increase in respect which leads to a cohesive decision-making environment where education would be more effectively understood. In addition, the patient-centred care approach also focuses on the inclusion of family in the planning process which ensures a support structure. This would aid in the improvement of adherence to medication of people suffering from TB and many other conditions. The greatest benefit for patients is that a rapport can be established with their healthcare professional which would lead to greater

access and understanding of information and education. Also, care may become more continuous and coordinated and a sense of emotional support can be found in a patient-centred care approach. (Luxford et al., 2010)

Interestingly, Luxford et al. (2010) also make mentions of the benefit for the healthcare professionals. Staff experiences a greater sense of purpose and involvement in the holistic outcome of patient care which allows a more in-depth form of medical care. The experiences of staff, however, must be improved as the effectiveness of patient-centred care requires large staff involvement.

When adding this to the South African context, it is clear to see why the Department of Health has chosen to use this approach in the fight against TB and HIV. South Africa uses the Primary Health Care system which emphasizes care at the grassroots level making access to health care a primary objective. The idea is to increase the number of clinics in communities to ensure that all members of communities have healthcare services on their doorstep.

TB and HIV are also seen to be managed at this level of care to ensure that patients are able to access lifesaving medication in their communities, limiting distance as a factor for medication non-adherence. This is the perfect environment for patient-centred care to take place with regards to the management of TB and HIV. Treatments of these two conditions are medium to long-term and a strong monitoring system is a requirement of the DOTS strategy. Patient-centred care would play a central role in this process as education on the importance of DOTS will be more effective in this approach. When asking patients to receive treatment on a daily bases, while being monitored to ensure compliance, it is important to ensure they are well informed of the importance of this.

Another positive factor is that the patient-centred approach has a strong emphasis on family involvement in the care of a patient. When looking at TB and HIV, this approach will aid in the identification of a treatment supporter for the convenience of the patient. In the National *Tuberculosis* Management Guidelines (2014) the importance of treatment supporters are encouraged. This is an alternative to overburden clinic systems and also forms part of a strategy to limit traveling distance as a reason for treatment non-adherence. The policy, however, emphasizes the adequate assessment of possible treatment supporters and nominated candidates to require mandatory training (National Department of Health, 2014). Another reason the patient-centred approach could prove vital to adopt in the South African context, is the natural diverse cultures and backgrounds of people in the country. One of the positives earlier mentioned was that this approach helps to understand cultural differences, and this should be incorporated into the design of a treatment program to ensure adequate adherence. The National *Tuberculosis* Management Guidelines (2014) highlights the impact of cultural differences which may affect treatment and identifies a patient-centred approach as the best way forward. This allows a trusting environment where differences may be discussed and an education process may be adequate to help the patient understand the importance of treatment.

Alternatively, arrangements may be made to ensure treatment may be taken without any interruption at places or time which may be more convenient for the patient. A major South African contextual problem is achieving changes in behaviour which is required for the achievement of treatment goals. (National Department of Health, 2014)

The patient-centred approach also aims to not only attend to the medical nature of a patient but also the physical, the social and mental state of patients. This lends itself to the move

towards a prevention ethos as well as a treatment focus. When attaching this idea to TB and HIV, it is clearly evident that education on these conditions will lead to prevention, early detection and commencement of treatment and ultimately good adherence which in the case of TB could lead to a cure.

2.8.5 Education

Based on the information gathered from the analysis of the 5 policies mentioned above, one of the key patient-specific areas of the policies is education. The policies emphasize the importance of education in the prevention of TB and see education as an integral part of the TB control programs. Education is mentioned in many areas and is encouraged in aspects of the TB policies which will form the basis of information. With sticking to the patient-centred approach it is important to ensure constant education on all aspects of the treatment program to ensure adherence. Education is emphasized in areas on the identification of signs and symptoms of TB, to ensure early presentation to health care facilities which increase the chances of successful treatment.

It is also encouraged in the areas of post-diagnosis, where knowledge of the TB disease is important. Education in areas of treatment and the importance of adhering to treatment is needed, also the length of treatment and infection control strategies are all shown in the policy as a vital aspect for the control of TB. Education is also encouraged on TB contacts to ensure identification of people in the community who are affected, are found and can be treated. Education on the DOTS strategy is highlighted in the policies to ensure that participants understand the reason for the direct observation of treatment and see the bigger picture of the impact TB has on the community.

The knowledge of the effects, TB has on high risks groups like young children, can help to ensure that infected individuals pay special attention to practice infection prevention etiquette around these people. Not only is education of people with TB important, but the policies also identifies the importance of mass education on communities and high risks groups or occupations, as a fundamental strategy for the reduction in negative stigma and discrimination of people with TB and HIV, and allows for communities to buy-in and assist with TB control strategies, like becoming treatment supporters etc. Mass education will also assist with providing motivation and support in communities, and improve family support if the conditions are understood. Therefore it is important to ensure education is a well-functioning mechanism in the control strategy for TB and HIV.

2.9 Patient Specific Aspects of TB Policies

Introduction

By understanding the importance given by the South African TB policies on the above-mentioned sections on patient-centred care and education, the researcher aims to use this as a basis for the design of a theoretical framework. By government policy stating that a patient-centred approach is to be used, and identifying the education of patients and communities as a fundamental aspect of the TB control program, this allows the researcher to believe that the information found in areas of policies on TB and HIV, which is patient-specific, should be disseminated to patients. Therefore all areas which are explicitly mentioned as patient-specific interventions may be assessed as a yardstick for the measurement of implementation of the patient-specific information found in the policies. With this in mind, questions measuring patient perceptions on areas which the policies say should form part of the education process to ensure adherence will be identified and analysed.

The areas found for analysis will be identified by the researcher and the perceptions of patients will be assessed to measure dissemination of information, from the policy to people with TB at Brooklyn Chest Hospital. The information gathered will allow me to measure the implementation of patient-specific areas of the policy, based on their perceptions and knowledge of the TB policies which affect the population being studied.

2.9.1 Patient Specific Areas of the Policy

In this section, the policy analysis takes place identifying patient-specific areas of the TB policies in South Africa for the design of a theoretical framework, from which a questionnaire will be designed. The questionnaire will measure the implementation of patient-specific areas of the policy, based on the dissemination of this information to people with TB, following the patient-centred approach mentioned in the policies.

The areas identified for the design of the questionnaire have been divided into four areas/categories, which are:

1. TB specific areas
2. Treatment specific areas
3. Adherence specific areas
4. Education specific areas

1. TB Specific Areas

1.1 Diagnosis of TB

knowledge of the diagnosis of TB is important for all people living with TB to have, and the South African National *Tuberculosis* Control Program Practical Guidelines (2004), points out the various types of TB diagnosis that are commonly found. When describing the site of TB the policy divides this into pulmonary TB and extra-pulmonary TB. Pulmonary TB is TB which is found in the lung tissue (lung parenchyma) and is usually the initial site of TB disease or the origin of the infection due to TB's mode of transmission, being inhalation of airborne infected droplets.

Next, extra-pulmonary TB is TB which is found not only in the lung tissue but has disseminated to other organs or sites in the body. The National *Tuberculosis* Management Guidelines (2009) finds that the impact of HIV has increased the severity of the progression and has led to the dissemination of TB to other organs, or extra-pulmonary TB. Forms of extrapulmonary TB are described in the South African National *Tuberculosis* Control Program Practical Guidelines (2004), as:

- TB meningitis: which is TB affecting the meninges of the brain
- TB lymphadenopathy: which is TB affecting the lymph nodes commonly around the clavicle (collarbone) or axilla (under the arm??)
- Miliary TB: which is TB found in the blood
- *Tuberculosis* Serous Effusion: which is TB in spaces where there is serious fluid present like the pleura and pericardium
- *Tuberculosis* of the spine: which is TB affecting the spine etc. (National Department of Health, 2004)

TB is also diagnosed based on the sensitivity profile/ strains, of TB bacteria in relation to standard treatment regimens. The National *Tuberculosis* Management Guidelines (2009) describes this and divides the sensitivity profile into three strains namely:

1. Drug sensitive TB: *Tuberculosis Mycobacterium* which is sensitive to all medication.
2. Multidrug-resistant TB (MDR-TB): *Tuberculosis* which is resistant to both Rifampicin and Isoniazid, or more of the first line regimen.
3. Extensively Drug resistant TB: *Tuberculosis* which is resistant to Rifampicin and Isoniazid from the first line regimen and fluoroquinolones and an injectable drug. (National Department of Health, 2009)

It is also important to note that the emergence of MDR and XDR TB is seen as a failure on the TB control strategies on the part of all role players and as mentioned before is seen as being driven by the HIV epidemic in South Africa.

1.2 TB Contacts

TB contacts are people who come in contact or live in close proximity to people with active *Mycobacterium Tuberculosis*, who are coughing infected droplets into the air for prolonged periods. This is an important area of any control program for TB, as the focus on early identification of patients with TB is found to be beneficial and is a priority of TB policies. The National *Tuberculosis* Management Guidelines (2009) finds that people who are in close proximity of people with active pulmonary TB have an increased risk of contracting active TB disease which also increases the chance of spreading it to the community. If Tb contact investigation is done adequately and early, the chances of spreading TB in the household and communities decrease. (National Department of health, 2014)

By identifying TB contacts early, prophylactic treatment can be started for high-risk groups like young children and people living with HIV etc. Also if people are able to identify possible TB contacts or who the person is they have contracted TB from, the strain of TB can be identified. This will allow clinicians to administer the appropriate medication initially instead of waiting for culture microscopy to return results. Therefore it is important to have a well-functioning TB contact investigation process to ensure people are started on the best treatment plan early. This, in turn, allows for prompt initiation of prophylaxis in high-risk groups to avoid getting active TB and to limit the spread of TB in the household and community.

1.3 Knowledge of Signs and Symptoms of TB

One of the focus areas for the control of TB in South Africa is an early diagnosis of TB. This ensures people are treated before having severe morbidity and eventual mortality, but also to limit the spread of TB in the community. One of the important ways to achieve this is to increase education of signs and symptoms of TB to encourage early screening and presentation to healthcare facilities. With this said it is important for the public to have knowledge of the signs and symptoms of TB. All the policies identified the signs and symptoms clearly which are:

- A persistent cough for more than two weeks
- Loss of weight
- Loss of appetite
- Prolonged fever for more than two weeks

- Night sweats
- Chest pain and shortness of breath
- The general feeling of weakness and ill health (National Department of Health,2009)

The signs and symptoms should be known by the public and especially high-risk groups for contracting TB e.g. HIV positive people, to ensure early diagnosis and management. Health education programs should be rolled out and must include the signs and symptoms of TB and screening for TB must be offered at all primary healthcare facilities.

2. Treatment Specific Areas

2.1 Length of Treatment

The National *Tuberculosis* Management Guidelines (2014) highlights the importance of TB treatment. All participants should be started on the appropriate treatment as early as possible to prevent morbidity and mortality and should be treated for the appropriate time periods to avoid drug resistance and ensure best outcomes. Therefore the length of treatment is emphasized in all TB policies.

Based on the principles of patient-centred care, to achieve this all patients should be well informed and educated on the length of time treatment is indicated for, to promote treatment completion and avoid non-adherence and drug resistance.

Looking at the length of treatment for drug sensitive TB treatment, it is divided into two phases. Initially, an intensive phase which consists of two months is followed by a continuation phase of four months. This means that patients will be required to remain on treatment for a period of no less than six months. When looking at extra-pulmonary TB,

especially TB of the spine, joints, and meninges, treatment may be extended to a nine-month period based on the clinical judgment of the clinician. With this regimen, the intensive phase remains two months while the continuation phase is extended to seven months. It is important for all participants to be educated on this and understand this, as patient's clinical condition may improve and symptoms may dissipate, leaving patients with the perception of cure. This could lead to the incompleteness of treatment, which causes flare-ups in the condition of the patient leading to preventable morbidity, new drug resistant strains of TB and also mortality. (National Department of Health, 2014)

When looking at drug resistant TB (MDR-TB and XDR-TB), the treatment length significantly increases. This is due to the resistance of medication which is used to decrease the length of treatment to six months. People with drug resistant TB must be treated for 18-24 months without interruption, and drug resistant TB is expensive to treat, making prevention vitally important. XDR-TB provides great difficulty in treatment and the cure rate is low. It is important to complete treatment before drug resistant strains emerge. The greater the resistance of TB *Mycobacterium* the more difficult cure becomes. (National Department of Health, 2014)

2.2 Types of Treatment

The type of TB treatment is important and is standardized in TB policies to ensure clinicians are treating all people with TB appropriately. It is vital for people with TB to understand the treatment regimen, as well as the prescribed dosage and time frames medication, should be consumed. If this is achieved, the correct medication will be taken ensuring high-quality treatment, also limiting non-adherence to treatment, and the conversion to drug resistant strains of TB.

TB treatment is specified and has different functions tailored to combat specific areas of the TB disease. TB treatment may be bactericidal meaning acting against active TB disease or bacteriostatic meaning acting to sterilize TB bacteria. Some drugs function to prevent resistance to the drugs used for long periods of time. For first-line treatment for drug sensitive TB, the drugs used are called: Rifampicin, Isoniazid, Pyrazinamide, ethambutol, and streptomycin may be used. (National Department of Health, 2014) when there is resistance to the first line regimen which is the case with MDR-TB and XDR-TB an injectable like Kanamycin or Capriomycin is used, also a fluoroquinolone like ofloxacin and moxyfloxacin is added with other drugs to strengthen the regimen (National Department of Health, 2009). This should be known by all patients to improve chances of adherence.

2.3 Monitoring of TB

Treatment must be monitored appropriately to ensure patients are receiving the most adequate medication, also to ensure that treatment is not being failed, and to ensure the correct length of treatment is given. By monitoring TB efficiently drug resistant strains of TB can be identified early and treated.

The two most widely used methods of monitoring TB treatment based on the policies analysed are bacteriological monitoring and clinical monitoring. Bacteriological monitoring is done mostly through sputum specimen evaluation to identify if TB is still present and active in the sputum of individuals with TB. The National *Tuberculosis* Management Guidelines (2014) clearly lays out the periods of when sputum specimens must be collected and analysed by the laboratory services and the reasons for this. The next method identified is through clinical monitoring, which is mostly used for people who are diagnosed with TB based on clinical findings. Patients with TB can be monitored clinically especially with extra-

pulmonary TB where symptoms improve. Weight can also be used as a useful tool for clinical monitoring as TB is known to cause unexplained weight loss and therefore weight gain can be seen as a clinical improvement.

However, the Management of Drug-Resistant *Tuberculosis* (2011) policy adds two more areas for monitoring which are: ‘other laboratory tests and Chest X-rays’. Other laboratory tests are mainly used to measure adverse drug reactions, which when done early can avoid serious side-effects to medication. Chest x-rays are used as a monitoring tool whenever a TB patient’s condition worsens or surgery for the patient is considered, which would entail the removal of a section of the lung which is heavily infected increasing the chances of successful treatment outcomes (predominantly used for drug resistant TB cases). Chest x-rays may, however, show limited to no significant improvement and cannot be used in isolation. Chest x-rays also provide a means of comparison with initial x-rays taken before treatment compared to during treatment which can show clinical improvement. All patients should have the insight into monitoring processes to ensure they know when and what to do to allow the TB disease to be adequately monitored.

3. Adherence Specific Areas

Good adherence to TB treatment is paramount to the success of any TB control program and this is especially important for South Africa. Non-adherence to TB treatment is a major concern as the aim of TB policies is to complete treatment regimens for people suffering from TB disease. TB is a curable condition if the correct treatment is consumed for the correct length of time, therefore making adherence to TB treatment a focal point of the South African policies on TB. Non-adherence has devastating effects on people suffering from TB, their families, and communities at large. Non-adherence is a contributor to a more severe

presentation of the TB disease, prolonged illness, also increases in preventable morbidity and mortality and the possibility of the conversion to drug resistant strains of TB. Non-adherence increases the infectious period of people with TB, increasing the risk placed on family and communities of contracting active TB disease.

The National *Tuberculosis* Management Guidelines (2014) identifies the importance of adherence and aims to target the promotion of good adherence through a patient-centred care approach. The policy shows the importance of discussion based on adherence and designing treatment programs with patient participation. This will ensure the best times and places are explored to assist with adherence to treatment, and also provide a more inclusive patient-healthcare practitioner relationship, leading to better results. The policy also identifies some possible reasons for non-adherence and barriers to adherence, like:

- People who are immigrants to South Africa without the necessary papers could fear being sent back to the countries they come from.
- People may prioritize other life expectations higher than treatment of TB like working for their families.
- Some may not see the public health sector as well functioning and therefore avoid presenting to healthcare facilities.
- People who abuse alcohol or drugs fear the mixing of these substances with TB medication and are not willing or unable to leave the addiction for TB treatment.
- People may fear the stigma attached to TB and may not want to be discriminated against in the community or family structure.
- Attendance to healthcare facilities may require time off from occupations, which could mean a loss of income.

- Patients may fear the side-effects of TB treatment.
- Patient's health belief and cultural belief systems may impede on the TB treatment regimen. (National Department of Health, 2014: 52-53)

There are many other reasons found in the literature for non-adherence but all policies agree that good adherence is vital for the success of TB control in South Africa, and following the patient-centred approach, education must be carried out to ensure patients adhere to treatment.

4. Education/ Information Specific Areas

Education and information form the basis of the patient-centred approach and all policies analysed identify education as a means to aid in the control of TB in South Africa. Policies use education and access to information as a tool to achieve the ultimate goal of the success of the implementation of policies on various levels and areas. Education is encouraged for education on signs and symptoms, to decrease stigma, to ensure treatment compliance, to identify side-effects to treatment early, to understand treatment and monitoring of treatment and many more. Because of the nature of the disease, education is not only directed to the person with TB but also to communities and families with the aim of prevention over cure. Education and information dissemination must be readily available, and must make use of many forms of media and mediums, and must be far-reaching to ensure people living in the geographical peripheries have access to life-saving information on TB, states the policies.

Table 2.1: Tabulation of Patient specific areas

1. TB specific areas	2. Treatment specific areas	3. Adherence Specific areas	4. Education/ Information Specific Areas
1.1 Diagnosis of TB	2.1 Length of treatment	3.1 Reasons for non-adherence	4.1 Access to information
1.2 TB contacts	2.2 Types of treatment		
1.3 knowledge of signs and symptoms of TB	2.3 Monitoring of TB		

(Author's construct, 2018)

Table 2.1 above identifies the four patient-specific areas found in the TB policies in South Africa and the sub-sections identified which will be used to design items for a questionnaire measuring the aims and objectives of the study.

2.10 Research Design Best Used for Measuring Behaviour of TB Patients

Early detection and diagnosis, coupled with strong TB treatment compliance, is the most essential and pivotal aspects needed for TB control programs (Liefogh et al., 1997).

However, a component which must be taken into account is the behaviour of the people who must comply with the policy objectives. In studies measuring health-seeking behaviours and

perceptions of the TB population in many countries, researchers have found that the qualitative method of research is the best form.

Many variations of instruments have been used to conduct this research, such as; surveys, structured interviews, focus groups, and open-ended questionnaires. This has all opened many avenues of understanding behaviours among these patient populations (Liefogh et al.: 1997, Addington: 1979, A Banerj et al.: 2000, Kilale et al.: 2008). In most literature found, perceptions and health-seeking behaviour are well documented. However, a gap has been identified when looking at perceptions of patients with TB, based on policy guidelines and protocols. This, in my opinion, has a direct impact on TB patients. The lack of this information could lead to a lack of understanding of the importance of compliance to treatment. Based on this information, this study will follow the same style of research methodology used, with the added policy analysis as a theoretical basis for the design of the data gathering instrument.

Research Hypothesis

The study hypothesizes that TB is on the rise and patient-specific policy implementation around education could impact the TB burden. I hypothesize that the knowledge of the patient-specific aspects of TB policy in South Africa lacks adequate dissemination which therefore leads to the inadequate implementation of patient-specific areas of these TB policies and may have an impact on treatment outcomes.

Summary

The above-mentioned chapter highlights the current arguments and literature regarding the control of TB. The chapter provides an understanding of the origin of TB in South Africa and highlights the impact TB has had on the population of South Africa. The main strategy for TB control is discussed which is the DOTS strategy, and this forms the basis of the protocol for the South African Health Department in its efforts to control TB in South Africa. The bulk of the section is based on the South African TB policies that were used for the study. The policies were systematically analysed to identify the main aims and objectives of each policy. The South African TB policies were further analysed to identify all patient-specific themes which form part of the patient-centred approach. Based on the highlighted patient-specific areas of the South African TB policies identified (patient-specific areas, treatment specific areas, adherence specific areas and education/information specific areas), a questionnaire was developed. This questionnaire will be used in the next chapter. The best methods identified in the literature were identified and stated to guide the researcher to use the most appropriate research methodology to conduct the study.

Chapter Three

Research Methodology: To Study Health Information and its Influence on the Perception of TB patients at Brooklyn Chest Hospital.

In this chapter, the study setting and the methods used in the study is described. The study design, study population, sampling method, and instrumentation are presented. The data collection procedure and analysis of the data are also explained. The chapter is concluded with the ethical considerations pertaining to the study.

3.1 Research Setting

The study was conducted at Brooklyn Chest Hospital (BCH), which is situated in the Brooklyn/ Milnerton area in Cape Town (see Appendix IV). The hospital is classified as a specialist TB hospital and has a bed capacity of 320. BCH provides an in-patient service for people infected with TB and with the co-infection of TB and HIV and has patients admitted from all parts of the Western Cape. The hospital has wards which are specified per type of TB strain and is divided into wards which separate Drug sensitive TB patients, Multi Drug Resistant TB patients and Extensively Drug Resistant patients. The hospital has a full complement of staff including medical doctors, nursing staff, physiotherapists, occupational therapists, counsellors, social workers, audiologists, pharmacists, a psychologist, dietician, and a radiographer.

3.2 Research Approach

The study consists of two components. Initially, a policy analysis is done of five South African TB policies, to identify patient-specific areas. These areas will be used as the basis of the design of a questionnaire which will be used to conduct one-on-one structured interviews

with the participants selected for the study. The second component of the study is the use of the questionnaire and structured interviews to understand patient perceptions at BCH, to identify the dissemination of knowledge from policies to patients and therefore measure the implementation of patient-specific areas of the policies. The study consists of a qualitative and quantitative design to understand trends and identify reasons for these trends amongst the patient population at BCH.

3.3 Research Design

The study will consist of two components, initially a policy analysis based on five South African TB policies namely:

- South African National *Tuberculosis* Control Program Practical Guidelines (2004)
- National *Tuberculosis* Management Guidelines (2009)
- Management of Drug Resistant *Tuberculosis* Policy Guidelines (2011)
- National Strategic Plan on HIV, STI's and TB (2012-2016)
- National *Tuberculosis* Management Guidelines (2014)

The aim of the policy analysis was to identify patient-specific areas of the policy. Based on the emphasis placed on the patient-centred approach in the South African TB Policies, I will use the identified patient-specific areas of the policy as a theoretical framework for the design of a data gathering questionnaire providing the structure for face-to-face interviews, which is used for the second section of the study. The second section is a cross-sectional approach which uses the questionnaire to identify patient's perceptions of the patient-specific areas of the policies at BCH. This will allow me to understand the implementation of the patient

specific aspects of the TB policies, and measure dissemination of these areas to patients at BCH. This aims to bring forth quantitative and qualitative data. The quantitative data provides the trends of the patients at BCH while the qualitative data provides explanations of these trends and allows patients to explore the reasons, attitudes, and knowledge of areas of the TB policies.

3.4 Study Population and Sample

The hospital being used, Brooklyn Chest Hospital consists of approximately 320 patients with the capacity not always achieved due to waiting times for admissions or sudden deaths. The study population was sampled based on the Yamane formula $n = \frac{N}{1 + N(e)^2}$ where n = sample size, N = population size and e = level of precision (Israel, 1992). The size of the sample was defined and random selection or convenient sampling techniques are used to fill the necessary number for the study. Patients will be selected on their availability for the study, and based on inclusion and exclusion criteria which will be elaborated on in more detail under the inclusion and exclusion criteria section. The other section of the study will be gathered from the five identified South African TB policies.

Based on the Yamane Formula, the sample size was determined as follows:

Brooklyn Chest hospital is a 320-bed hospital.

However of the 320 patients at the time of data collection, 20 beds were vacant which saw the total patient population being 300.

When adding the exclusion criteria:

- 60 patients were under the age of 18 due to there being two paediatric wards.

- Another exclusion criteria were patients with a Glasgow Coma Scale score of less than 15/15 which excluded a further 70 patients.

Taking the exclusion criteria results into consideration the total patient population at the time of data collection was 170 patients.

Therefore the Yamane Formula:

$$n = N / (1 + N(e)^2)$$

$$n = 170 / (1 + 170(0.05)^2)$$

$$n = 119$$

The sample size is 119 participants.

Therefore based on the above formula at the time of data collection the number of participants needed for the sample size to adequately represent the population was 119 participants. The participants were randomly selected based on the willingness to partake in the study and convenient selection was used. The study population was confined to one area being Brooklyn Chest Hospital however the admission pool for the hospital is not specified to Substructures of the province and admits patients from all over the Western Cape Province. This provides participants from a wide variety of locations and geographical areas in the province.

3.5 Inclusion Criteria

- All participants must be over the age of 18.
- All participants must be cognitively sound

- iii. All participants must possess a GCS of 15/15
- iv. All participants must have the diagnosis of TB and be admitted at BCH

3.6 Exclusion Criteria

- i. All people under the age of 18
- ii. Patients who are cognitively impaired.
- iii. Patients who score less than 15/15 on the GCS
- iv. Patients without a TB diagnosis

3.7 Data Collection and Instrumentation

The data collection will be guided initially by a data gathering instrument which is in the form of a questionnaire which will be strictly followed in the structured interviews of the participants.

The use of a questionnaire is seen as an important tool for the extraction of information, to scientifically gather data to answer a question. The questionnaire this study will incorporate is based on patient-specific components of TB policies in South Africa. The question will follow a structured nature where all participants will be required to answer a standard set of questions designed by the researcher. Kazi and Khalid (2012), find that structured questionnaires are best when looking for epidemiological information to ensure data are analysed based on the uniformity of the questions, which allows for accurate measure. (Kazi and Khalid, 2012). This approach is followed in the questionnaire process of this study.

The questionnaire will be administered in person by an interview of participants following the strict adherence to the designed questionnaire. Kazi and Khalid find that positives to this method include one on one interaction with all participants allowing for better buy-in from

candidates. It allows an introduction to the study which improves the likelihood of participants agreeing to participate. Another major benefit is that the method of interviewing allows for less misunderstanding and allows a trained individual to be present to answer all questions participants might have ensuring the superior quality of the data. Negatives are also found, such as this process is time-consuming to the people administering the questionnaire and it could also be more costly than for example self-administered questionnaires. With this in mind, this research will overcome these barriers as the population used for the study is situated in a singular location making access to the population achievable and I will be performing the interviews to avoid any cost. (Kazi and Khalid, 2012).

When considering the design of the questionnaire a deductive scale development approach was used. Hinkin et al. (1997) describes deductive scale development as the use of existing theories for the design of the construct which the researcher uses to develop items on the questionnaire. In the case of this questionnaire used in this research, the theory or theoretical framework is based on the patient-specific areas of the TB policies in South Africa, which were identified to be used in this research paper. The questionnaire was then designed based on four aspects of the TB policy. The four areas identified were:

1. TB specific areas
2. Treatment-specific areas
3. Adherence specific areas
4. Education and information specific areas

These four areas form the theoretical constructs and items were developed around these constructs. Each patient specific area was further divided to ensure all patient-specific information was identified for the questionnaire.

Table 3.1: Patient Specific Themes

1. TB specific areas	2.Treatment specific areas	3.Adherence Specific areas	4.Education/ Information Specific Areas
1.1 Diagnosis of TB	2.1 Length of treatment	3.1 Reasons for non-adherence	4.1 Access to information
1.2 TB contacts	2.2 Types of treatment		
1.3 knowledge of signs and symptoms of TB	2.3 Monitoring of TB		

(Author's construct, 2018)

Once this information was gathered from the policy analysis, the questionnaire was designed. The questionnaire consisted of three sections. Section A: identified demographic information e.g. age, gender, race etc. section B: identified medical information e.g. Diagnosis episodes of TB and TB contacts etc. section C: identified social history e.g. Number of children, living conditions and employment status and lastly section D: measure patient knowledge based on TB policy. The questionnaire has a combination of open and closed-ended questions. The participants were interviewed by the research based on the strict following of the

questionnaire however predetermined scoring was not used. Patients were encouraged to answer all questions based on their perceptions and knowledge and upon completion, all information was analysed. The information was analysed and read through many times to provide clarity. This will allow me to develop themes which will be analysed.

Upon completion of the first draft of the questionnaire, a pilot study was done at DP Marias Hospital in Tokai which is a specialist TB hospital. The Hospital is amalgamated with Brooklyn Chest Hospital to form Metro TB Hospital Complex however the premises are separate, as Brooklyn Chest Hospital is situated in the Brooklyn Milnerton area and DP Marias Hospital is situated in the Tokai area. Kazi and Khalid (2012) highlight the importance of a pilot study for the design of a new questionnaire.

This is used to identify if the tool is measuring what it is intended to measure and if it is doing so reliably. Five patients were used for the pilot study to identify if the questionnaire was easy to understand and were done in a manner in which all participants could understand the content. The process was also used to identify any questions which gathered answers that did not measure the objectives of the study and provided clarity on any items which produce the same answers and were found to be redundant. Boynton (2004) also identifies the importance of piloting a questionnaire and makes specific reference to the quality of questions; the time period needed to complete the questionnaire as if it is too long participants will not provide the best quality data due to fatigue. The article also shows the importance of documenting questions to see if any explanation is required around the same questions showing possible confusion or vagueness in the question being asked. (Boynton, 2004)

Based on the pilot study of the questionnaire, two questions were found to provide the same themes of answers from all participants of the pilot study which led to confusion. These questions were:

Question number 6: what is the reason for you being admitted to BCH?

Question number 7: Do you understand why you are at BCH, please explain?

These two questions generated similar answers and caused confusion among participants which led to question number 7 (Do you understand why you are at BCH, please explain?) being excluded from the list of items on the questionnaire. When analysing the data from the pilot study it was found that information regarding marital status found in section C of the questionnaire which looks for information on social history had no impact on achieving the objectives of the study, and this information was also excluded from the data gathering instrument.

When considering the validity of the data gathering instrument, Worthington & Whittaker (2006) points out that a vital step in this process is to have the instrument reviewed by experts in the field. This assists in the assessment of the quality of the instrument and the items of the instrument. Experts should be able to assist in identifying if the tool measures the objectives of the study and the experts should comment on the length of the questionnaire etc.

(Worthington & Whittaker, 2006). For the design of the data gathering instrument in this study, the questionnaire developed was reviewed by two experts in the field of TB at Brooklyn Chest Hospital. The first person is the Chief Physiotherapist and physiotherapy HOD at Brooklyn Chest hospital and DP Marias Hospital with 16 years of experience in this TB setting, and the second is the clinical psychologist and Allied Health Supervisor at

Brooklyn Chest Hospital and DP Marias Hospital and also a Ph.D. candidate in the field of TB and non-adherence. Small changes were made with regards to the structure of the questions to make it more reader-friendly and the sequence of questions to ensure a logical flow of questions. These changes were made and the data gathering was conducted.

The data capturing instrument was designed to extract information which I will use to answer the research question. The instrument is divided into four sections. Section A seeks to gather demographic information, namely: age, gender, race, and area of residence. This information will be used for statistical purposes only. This will provide an average age of the sample group which will provide an idea of the mean age of the high-risk group suffering from TB. Lastly, the area of residence will provide a small indication of areas in the province which show the largest amount of TB cases presenting at BCH.

Section B aims to extractor general medical information, namely: diagnosis, number of times the patient has presented with TB, TB contacts, the current length of treatment and substance and alcohol abuse history. The diagnosis aims to identify the type of TB, people suffer from and to identify any other co-morbidity, which could influence the immunity of these patients and have increased their risk of acquiring active TB disease. Next the number of episodes of TB, patients has presented with, will give me an indication of the reason for admission at BCH and also provide evidence of the likelihood of re-occurrence of TB; also this will speak to the rate of non-adherence and default for current patients at BCH. Information of TB contacts meaning people who most likely spread the active TB disease will give us an indication of how many people know where primary infection occurred. I will be looking at the length of current treatment, which will provide an indication of how far the patients are

currently in the program. Lastly, I will identify links between TB disease and alcohol and drug abuse history.

Section C will provide social information, namely: the number of children living with the patients, living conditions and employment status prior to admission. Children living within the household may indicate at-risk populations; living conditions play a part as TB may be predisposed to people living in overcrowded households. I will also analyse employment prior to admission as jobs like mining etc. are linked to TB infection. Section C also broadly will determine which parts of society are most affected by TB in the Western Cape Province.

Section A, B, and C will be gathered from patient records, as this information is routinely documented in the clinical notes of the institution and any irregularities or omissions will be filled by the patients.

Section D of the data gathering tool will require input from the patients at Brooklyn Chest Hospital. This section is an open-ended questionnaire, with questions designed to extract information based on the South African Government policies and guidelines for the treatment of TB in the country. The themes used to design the question is based on areas of the policies that have a direct link to the patient population of TB, and areas focused to medical experts or lab technicians will not be used. Although the TB policies identified will be used as a theoretical framework, the participants will not be bound by pre-conceived sets of criteria, and instead will be encouraged to express their knowledge. The perceptions of patients will be carefully read for clarity and the re-occurring themes will be developed. Based on the themes the data will be analysed using the Statistical Package of Social Sciences (SPSS) version 23, where descriptive statistics will be used to analyse the data and the results will be compared to the information presented in the policies. This will allow the researcher to

understand the perceptions of patients at BCH and measure if knowledge of patients is in line with patient-specific aspects of TB policies. For the complete version of the questionnaire please see Annexure I.

3.7.1 Treatment Outcomes

The last section looks at treatment outcomes of the participants who took part in the study. Due to the participants being discharged into the communities from which they came, measuring treatment outcomes based on follow-ups with the patients was not possible due to time constraints and geographical distances of the participants. Therefore the outcome of treatment was based on the National Health Laboratory Services (NHLS) computer program called TrackCare.

The program provides results on all laboratory studied tests for all patients in the government service and it is the system which is used for TB testing. Using this system, I was able to analyse the results of sputum microscopy and therefore deduce the treatment outcome of all participants. The outcome was based on the results provided by the program and the knowledge of treatment times for each category of TB. Based on these two criteria the researcher was able to monitor treatment completion or cure, treatment default, treatment failure, and death.

Next, this section aims to identify the significance of the length of stay in hospital on the TB outcome and to identify if there is any statistical significance between these two variables. To ascertain the length of admission at Brooklyn Chest Hospital, the computer program Clinicom was used. This program is used by the Department of Health and all public hospitals in the country, with the purpose of bookings, admissions and diagnosis monitoring

of all participants. Using this program the researcher was able to identify the length of stay for all participants at Brooklyn Chest Hospital.

In order to identify if any statistical significance exists between the length of stay and the treatment outcome, the researcher choose to use the chi-squared method. However for chi-squared to be used adequately both variables must be categorical. With the variable of treatment outcome already being categorized as treatment cure, treatment default, treatment failure, and death, the researcher chose to allocate categories to the length of stay variable. To achieve this, these categories were designed based on average length of stay at Brooklyn Chest Hospital over the period of 2015-2016. Therefore the categories were defined as:

- 0-80 days (Below average length of stay)
- 80-160 days (Within the average length of stay)
- 160+ days. (Above average length of stay)

With the chi-squared test, the significance will be based on a p-value of 0.05 and the Null hypothesis will be that there is no statistical significance between the variable of the length of admission and treatment outcomes. Therefore the variables are independent of each other and no relationship exists.

3.8 Ethical Considerations

Research is people driven and information gained is personal and specific to an individual. It is important for the researcher to anticipate ethical issues and find solutions to overcome in all aspects of the research process. The information gained is needed from participants and therefore researchers should aim to protect the participants and hold up the ethics of research. All misconduct should be avoided and integrity is mandatory in this process. (Creswell,

2014). Based on this it is vital to maintaining high standards of ethical integrity when dealing with participants which will aid in building good relationships with research participants.

Ethical clearance has been approved by the University of the Western Cape's Higher Degrees senate (see Appendix V). Approval was also provided by the CEO of Brooklyn Chest Hospital for the cross-sectional portion of the study. Informed consent (see Appendix II) has been gained from all participants. This has been accompanied by an information sheet related to the study and all participants have the right to end their participation in the study at any time (see Appendix III). All details and views will be handled with confidentiality and all information is read and stored by the research. To ensure anonymity, all participants will be identified by numbers only and no names will be used. All the participants will be informed of the purpose of the study and the relevance of the study before informed consent is obtained. The participants will be educated on being allowed to exit the study at any time, and if participants chose not to partake in the study no differential treatment will be given to them. All results will be made available to Brooklyn Chest Hospital if they so desire.

Due to the nature of the conditions which the participants will be questioned, the interviews will take place in a private setting at BCH hospital to ensure confidentiality. Information will not be shared with any person unless serious medical risk is found at the time of data collection. The study posed minimal risk, however, if any participant should become affected by the interview the participant will be referred to the counsellor or psychology services available at BCH.

Chapter Four

Results: The Influence of Health Information on the Perceptions of TB Patients at Brooklyn Chest Hospital.

4.1 Introduction

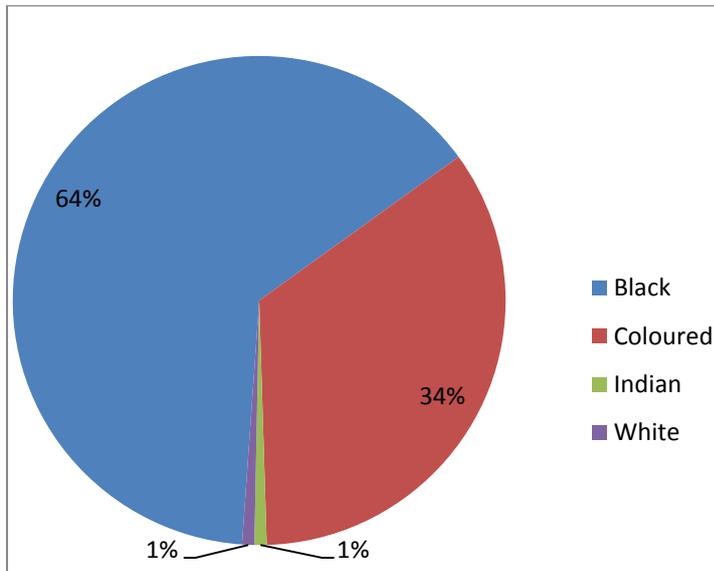
The results section will represent the data gathered from the structured interviews. The information will be presented as it was structured in the questionnaire used for the structured interview. Section A will look at demographic information, section B will focus on the medical information, section C will identify social information and section D will measure the participant's knowledge on the patient specific areas of the TB policies. The final section will measure the treatment outcomes and participant length of stay and statistical significance will be measured using the chi-squared method for the variables.

4.2 Section A: Demographic Information

The age of the population covered a wide spectrum of age groups. The mean age of the population being studied was 33.7 while the median and mode was 32. The youngest participant in study was 18 years old while the oldest participant was 75 years old.

The population of this study consisted of a male population of 37.8% (45) and a female population of 62.2% (74). The population of the races varied according to figure 4.1.

Figure 4.1: Profile of Study Participants



(Author's fieldwork, 2018)

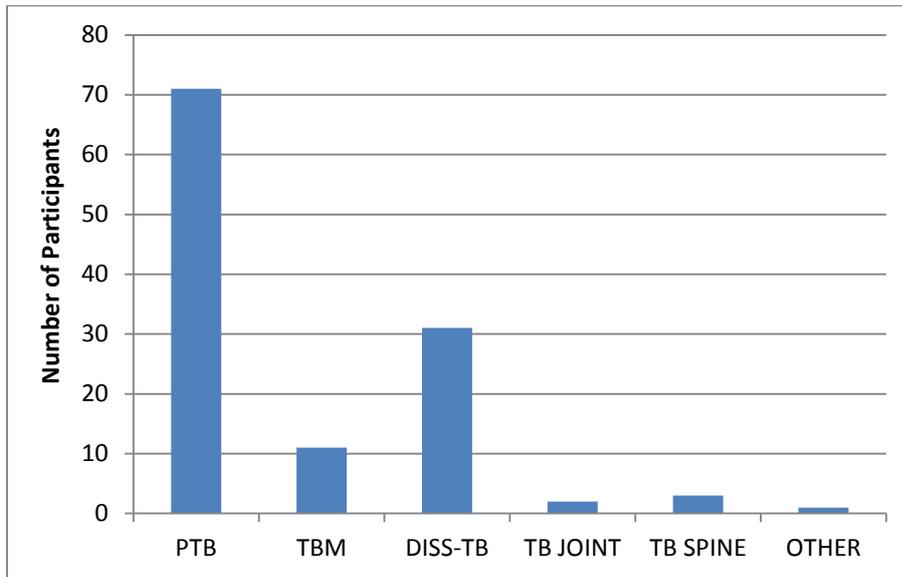
Figure 4.1 shows that of the participants included in the study, 63.9% (76) were Black, 34.5% (41) were Coloured, 0.8% (1) were Indian and 0.8% (1) were White.

The last demographic information was the location of the patients. The participants had come from all across the Western Cape Province however the areas which saw the most participants live in was firstly Khayelitsha which saw 10 participants, second was Phillipi, which had 8 participants and Langa, Mitchells Plain and Nyanga had five participants each who lived in these areas.

4.3 Section B: Medical Information

The first section identified the diagnosis of the participants of the study and they had presented with various types of *Tuberculosis* as shown in Figure 4.2 below.

Figure 4.2: TB Diagnosis of Participants

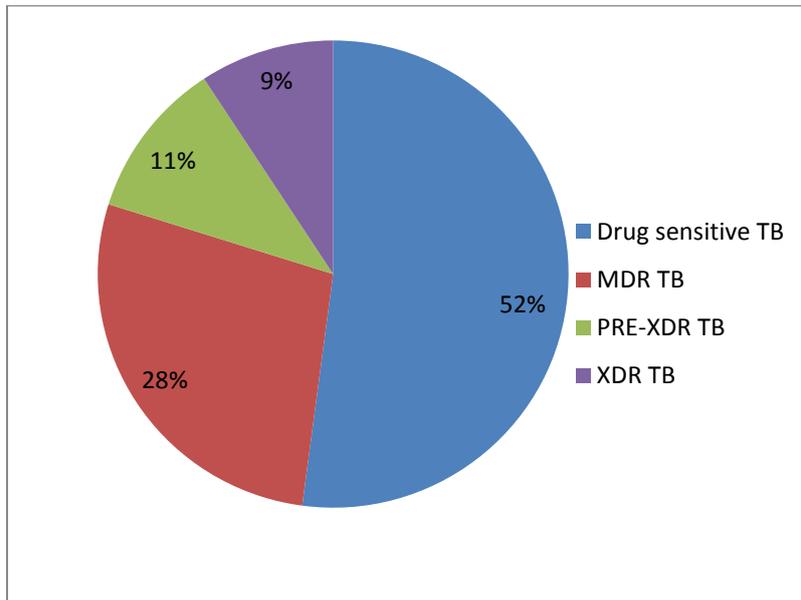


(Author's fieldwork, 2018)

Figure 4.2 shows the various TB diagnoses among the study population. Based on the graph, 59.7% (71) of participants were diagnosed with pulmonary TB (PTB), 9.2% (11) is diagnosed with TB of the meninges (TBM), 26.1% (31) were diagnosed with disseminated TB (DISS TB), 1.7% (2) was diagnosed of TB of the joint, 2.5% (3) were diagnosed with TB of the spine and 0.8% (1) of the study population was diagnosed with another form of TB.

Also looked at under the diagnosis, was the strain of TB each participant was diagnosed with, and this is illustrated in Figure 4.3 below.

Figure 4.3: Drug susceptibility of TB of participants



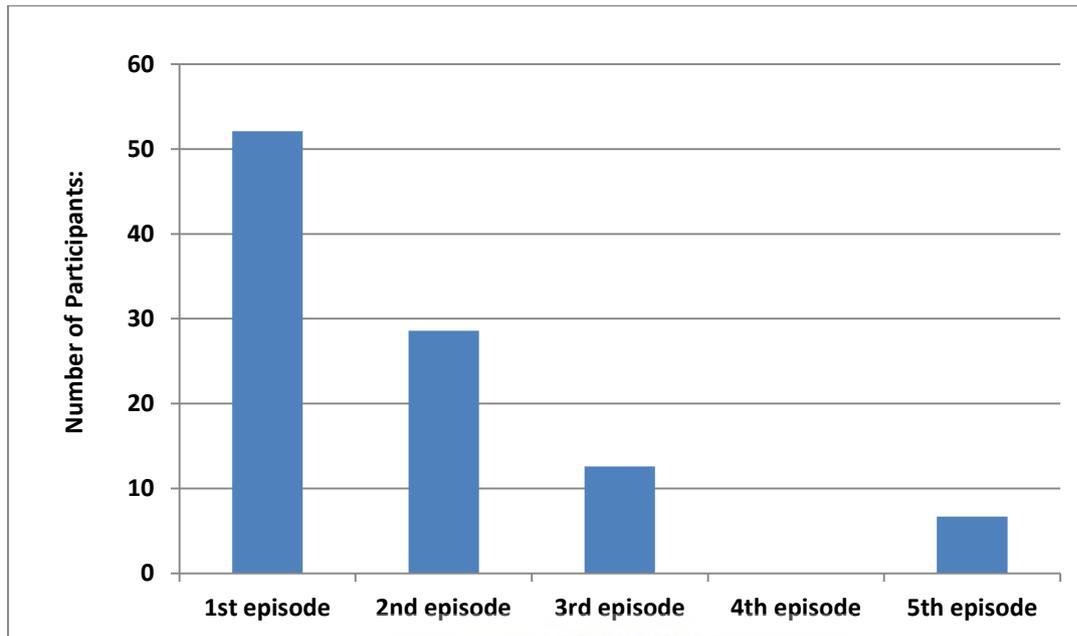
(Author's fieldwork, 2018)

Figure 4.3 identifies the strain of TB found in the study population. 52.1% (62) of the study population was found to have drug sensitive TB, 27.7% (33) had Multi-Drug resistant TB (MDR TB), 10.9% (13) were Pre-Extensively Drug resistant (Pre-XDR TB) and 9.2% (11) of the population studied were Extensively Drug resistant (XDR TB).

The results of the study also show that 57.1 % of the study population is diagnosis as HIV+, while 42.9% of the population was HIV-

The next question looks at episodes of TB, Figure 4.4 shows the results below:

Figure 4.4: Episodes of TB of Participants

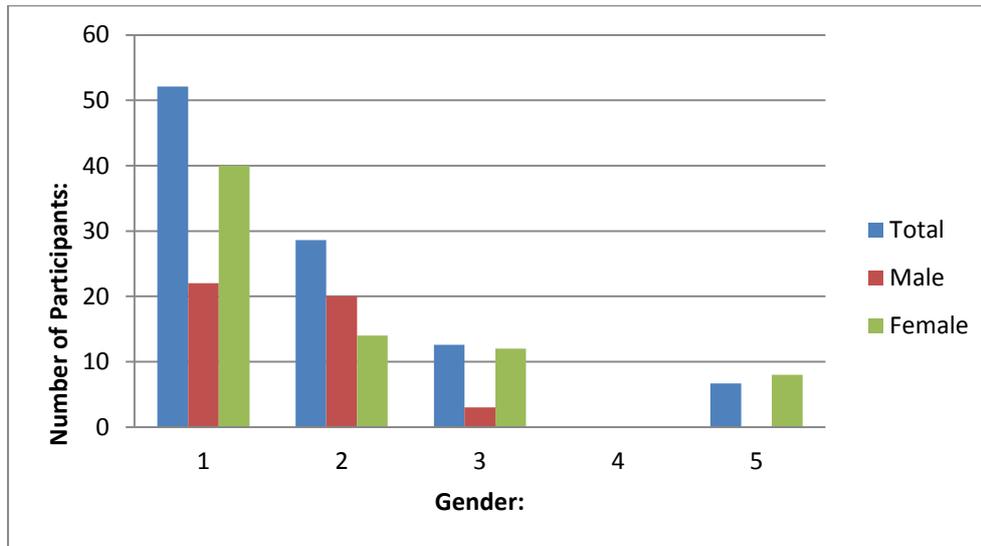


(Author's fieldwork, 2018)

Figure 4.4 above shows the amount of episodes of TB each participant had. The results show that 52.1% (62) of the participants were on their first episode of TB, while 47.9% (57) of participants had experienced TB before the current episode of TB. Of this 47.9% (57) who have had TB before, 28.6% (34) of these individuals had TB two times, 12.6% (15) of the participants had experienced three episodes of TB and 6.7% (8) of the individuals had been diagnosed with TB five times.

When looking at information regarding episode of TB and specifically the differences found between males and females regarding the episodes of TB. This can be seen in Figure 4.5 below.

Figure 4.5: Episodes of TB among Males and Females



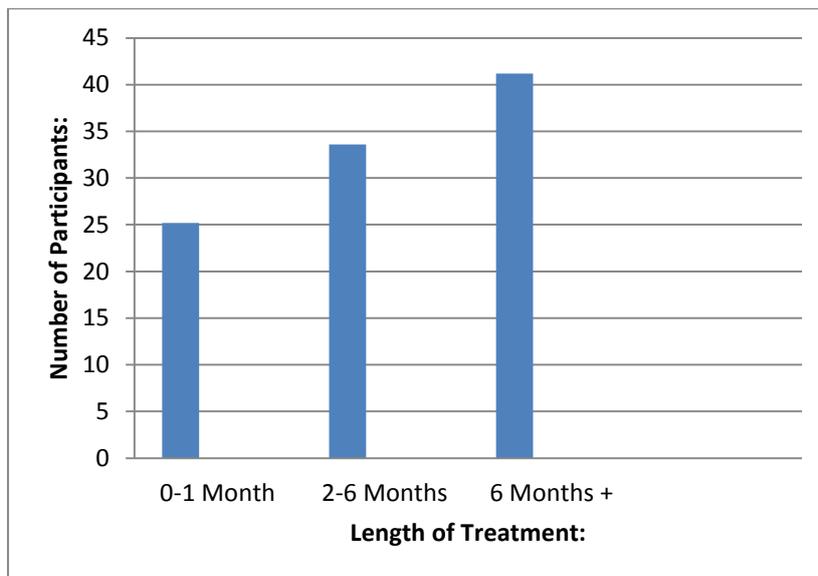
(Author's fieldwork, 2018)

Figure 4.5 indicates the number of episodes of *Tuberculosis* among the male and female participants. With the first episode of TB the female's participants were higher than the male participants. For the second episode of TB the male participants were higher than the female participants. The female participant's third TB episode was higher than the males. The fifth episode of TB was only among the female participants.

The next question was regarding TB contacts to find out if the participants knew who their TB contacts were. The results show that 31.1% (38) of participants knew who their TB contacts were whilst 68.9% (81) of participants did not know who their TB contacts were.

The next question focused on the current length that each participant had been on treatment for and Figure 4.6 shows:

Figure 4.6: Current Length of Treatment of the Participants

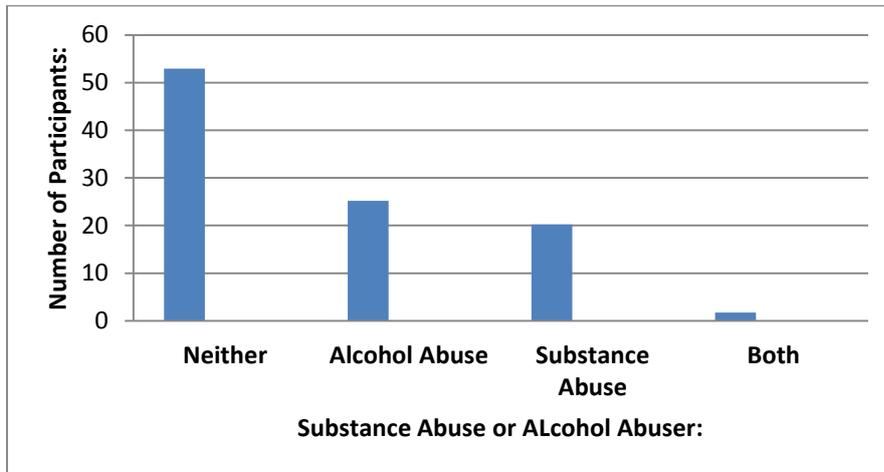


(Author's fieldwork, 2018)

Figure 4.6 shows the current length of treatment of the participants in the study. The results show that 25.2% (30) of participants have been treated for 0-1 months, 33.6% (40) have been treated for between 2-6 months and 41.2% (49) have been treated for more than 6 months.

The last question in section B sort information regarding alcohol and substance abuse history and figure 4.7 reveals:

Figure 4.7: Number of Participants Using Alcohol, Substances, Both or None



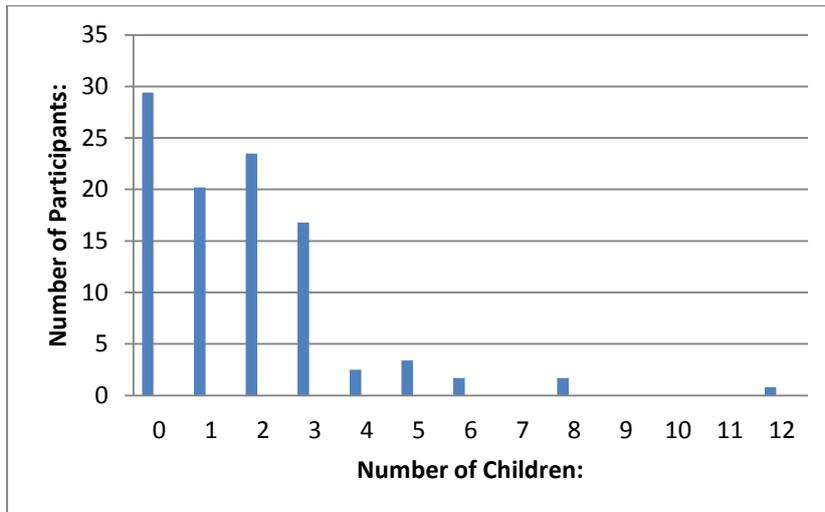
(Author's fieldwork, 2018)

Figure 4.7 measures the number of participants who use alcohol, substances, both alcohol and substances or neither alcohol nor substances. The result show that 52.9% (63) do not use alcohol or substances, 25.2% (30) admit to alcohol usage, 20.2% (24) admit to substances usage and 1.7% (2) admit to both substance and alcohol usage.

4.4 Section C: Social History

The first question asked identified the number of children each participant in the study had who stayed with them. This can be seen in Figure 4.8

Figure 4.8: Number of Children of Participants



(Author's fieldwork, 2018)

Figure 4.8 represents the number of children the participants have in their households. Of the participants 29.4% (35) had no children, 20.2% (24) had one child, 23.5% (28) had two children, 16.8% (20) had three children, 2.5% (3) had four children, 3.4% (4) had five children, 1.7% (2) had six children, 1.7% (2) had eight children and one participant had 12 children.

The next question looked at the living environment, more specifically identifying the type of living structure each participant has. The results regarding the Living structure shows that 48.7% (58) of participants lived in houses while 51.3% (61) did not live in houses. Of the 51.3% (61) who did not live in houses, 42.0% (50) lived in shacks, 2.5% (3) were homeless, 5.9% (7) lived in flats, and 0.8% (1 participant) lived under a bridge.

The final question of section C highlights the employment status of the participants. Prior to admission 27.7% (33) of the participants were employed and 72.3% (86) of the participants were unemployed.

4.5 Section D: Participant's Knowledge on TB Policies

When participants were asked if they were aware of what treatment they were expected to take and are currently taking, the results showed that 22.7% (27) of participants knew what TB treatment they were currently on, while 77.3% (92) of participants did not know what their TB treatment regime entailed.

When asked if the participants knew the length they were expected to remain on treatment, 70.6% (84) of participants are aware of the length of treatment they are expected to adhere to, whereas 29.4% (35) of participants were unaware of the length of treatment expected.

Next the participants were asked if they are aware of the manner in which they contracted TB, they answered as follows:

Figure 4.9: How TB was Contracted by Participants



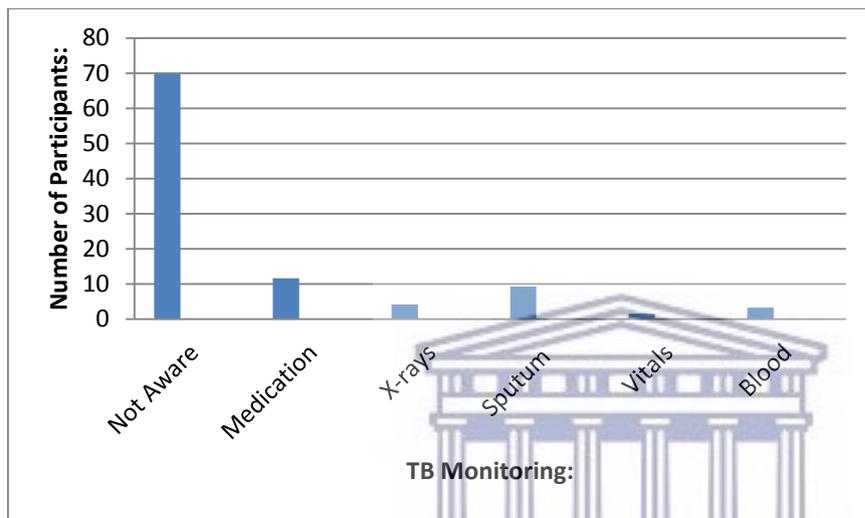
(Author's fieldwork, 2018)

Figure 4.9 shows: When asked how did the participants contract TB, 18.5% (22) said from friends and family, 70.6% (84) were not aware, one person said because the person was surrounded by people who spits a lot, one person said due to drug abuse, 2.5% (3) said they

contracted TB at work, 1.7% (2) said they contracted TB because of alcohol abuse and 5% (6) said they contracted TB in public transport.

The next question asked sort information regarding awareness of how participants TB were being monitored. The results are shown in Figure 4.10 below

Figure 4.10: Participants Perception of Monitoring TB

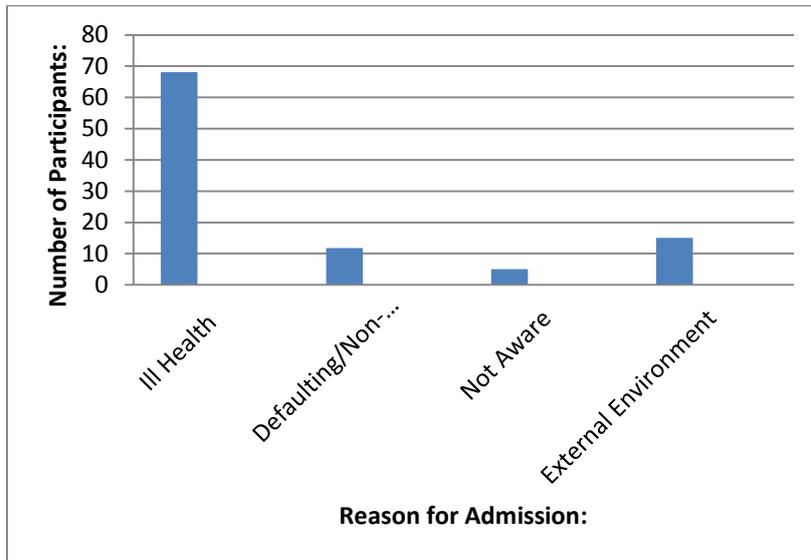


(Author's fieldwork, 2018)

Figure 4.10 shows participant perceptions of how TB disease is monitored. Of the participant population, 69.7% (83) was not aware of how TB is monitored, 11.9% (14) said through medication, 3.4% (4) said with x-rays, 9.7% (10) found their TB to be monitored by sputum sampling, 1.8% (2) said by the recording of their vitals and 3.5% (4) said through blood work-ups.

The next question asked was, if participants could identify the reasons for being admitted to Brooklyn Chest Hospital, which is illustrated in Figure 4.11 below:

Figure 4.11: Reasons for Admission to BCH of Participants



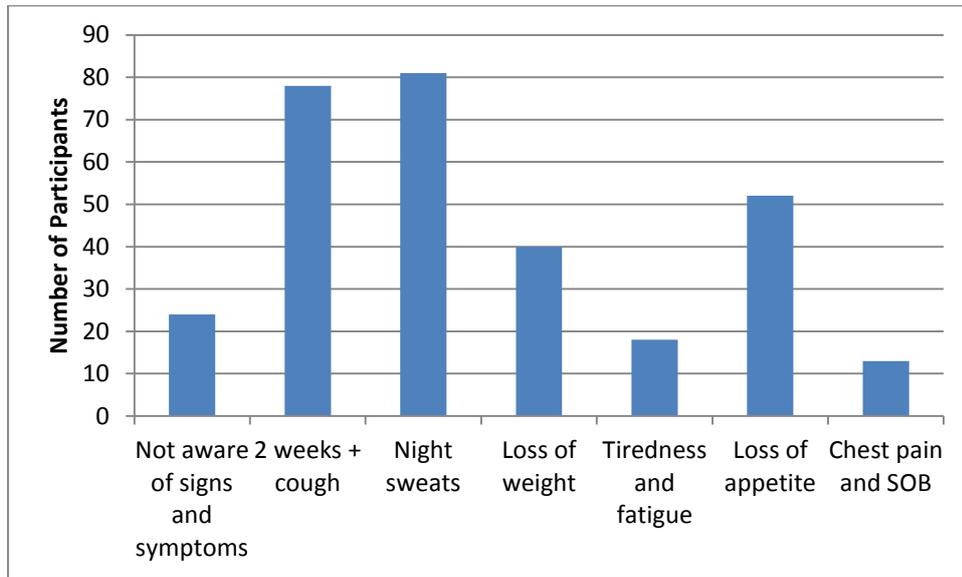
(Author's fieldwork, 2018)

Figure 4.11 shows the reasons for admission at Brooklyn Chest Hospital, which saw 68.1% (81) of participants being admitted due to ill health, 11.8% (14) was admitted due to non-adherence to medication in the community, 5% (6) were not aware of why they were admitted and 15.1% (18) was admitted due to external environmental issues like lack of permanent fixed abode, excessive substance abuse, distance of clinics and work commitments etc.

When asked about knowledge of the DOTS program 98.3% (117) had never heard of the strategy, one person had hear about it but could not explain while one person had insight into the direct observation aspect of the DOTS strategy.

The next question asked, was to identify knowledge of Signs and Symptoms of TB among the participants and Figure 4.12 below shows:

Figure 4.12: Knowledge of Signs and Symptoms

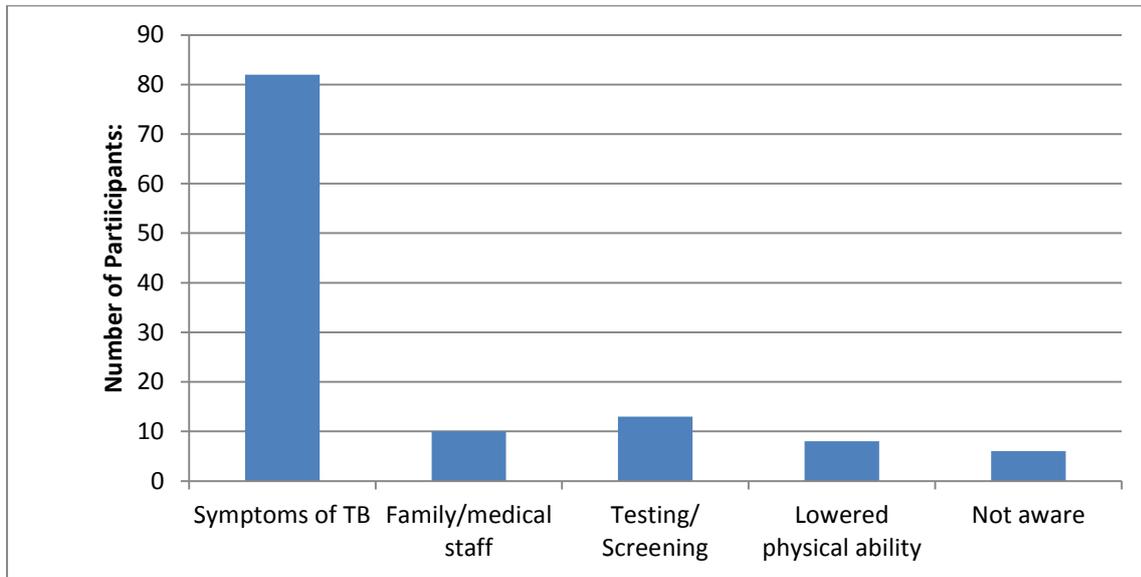


(Author's fieldwork, 2018)

Figure 4.12 above shows that 20.2% (24) of participants was not aware of any signs and symptoms of TB. Of those who had known signs and symptoms of TB, 65.5% (78) of the participants were able to identify coughing for more than 2 weeks as a sign and symptom, 68.1 % (81) identified night sweats, loss of weight was identified as a symptom of TB by 33.6% (40) of participants. Tiredness and fatigue was identified by 15.1% (18) of the study participants, loss of appetite was chosen by 43.7% (52) and 10.9% (13) had seen chest pain and shortness of breath as a sign or symptom of TB.

The bar graph below shows the results for patients who were asked what their reasons were for getting tested for TB, the results shows:

Figure 4.13: Reasons for TB Testing of Participants



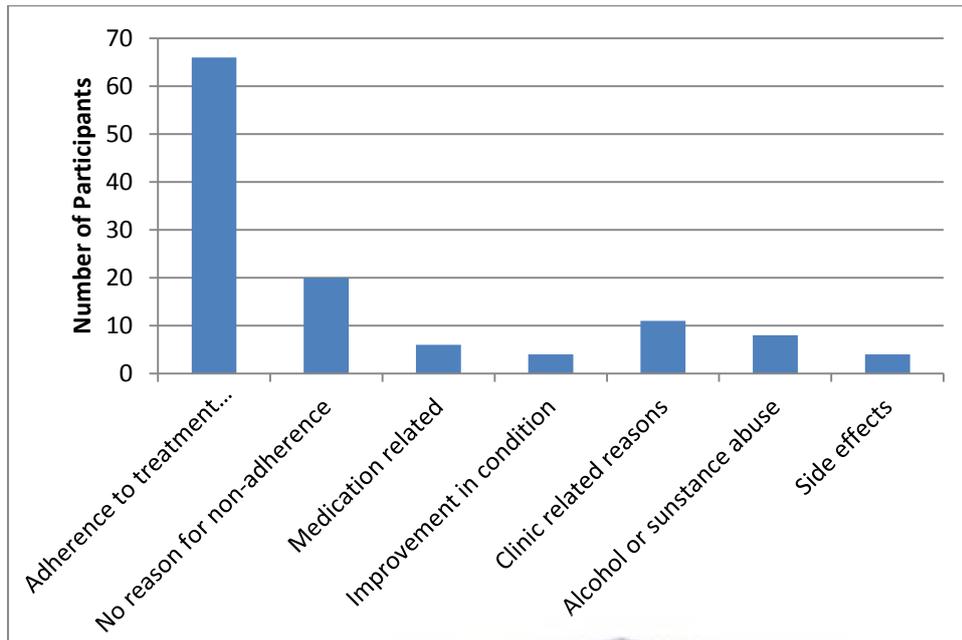
(Author's fieldwork, 2018)

Figure 4.13 is a bar graph representing the reasons for getting tested for TB amongst the participants. The leading reason for participants getting tested was because 68.9% (82) had presented with symptoms of TB, 8.4% (10) of the participants were forced by family or medical staff, 10.9% (13) was diagnosed because of general testing and screening, 6.7% (8) was due to deterioration in physical ability and 5% (6) were not aware of why they were tested.

Participants were asked if they have ever not adhered to medication and the results show that 44.5% (53) have had episodes of non-adherence while 55.5% (66) of the participants have adhered to medication regimens.

The next question focuses on the reasons for non-adherence of the participants and Figure 4.14 shows:

Figure 4.14: Reasons for Non-Adherence to TB Treatment of Participants



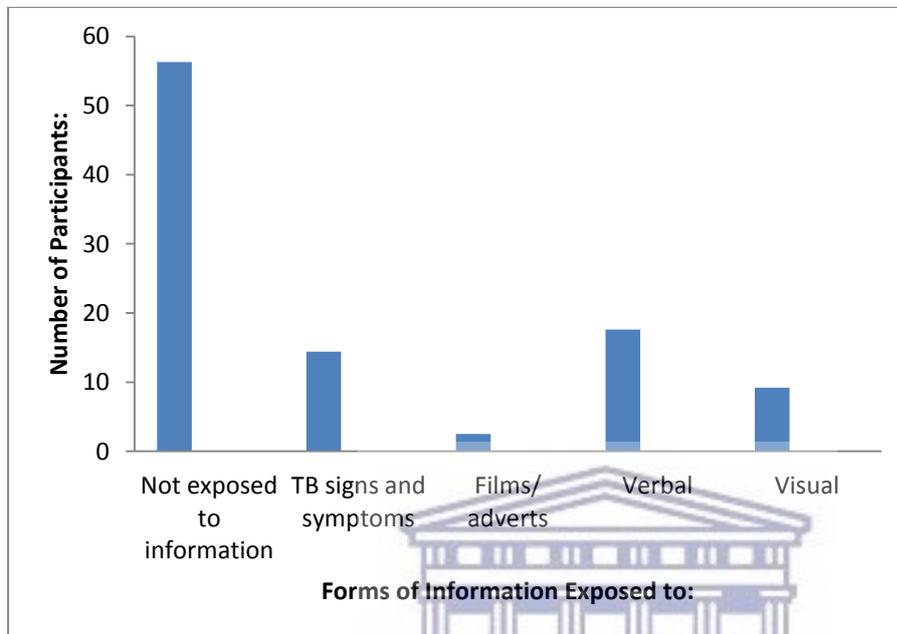
(Author's fieldwork, 2018)

Figure 4.14 represents the reasons for participants not adhering to TB treatment. Of the participants in the study, 55.5% (66) have adhered to TB treatment regimens, and of the 44.5% (53) that have not adhered to TB treatment, 16.8% (20) cannot explain the reasons for non-adherence, 5% (6) said it was due to medication related issues like high pill burden, 3.4% (4) had stopped treatment because they had clinically improved in condition, 9.2% (11) had not adhered due to clinic related issues like the distance to clinic or patients too lazy to go to the clinic, 6.7% (8) had not adhered to treatment because of alcohol and substance abuse issues and 3.4% (4) had not adhered due to bad side-effects of treatment.

The research participants were asked if they had received TB related information prior to their TB diagnosis. 52.1% (62) had experienced some sort of information regarding TB prior to the diagnosis of TB while 47.9% (57) of the participants had received no information regarding TB.

The study participants were then asked what type of TB related information they were exposed to and the answers are presented in Figure 4.15 below:

Figure 4.15: Exposure to TB Related Information Prior to Diagnosis



(Author's fieldwork, 2018)

Figure 4.15 represents exposure to TB related information prior to the diagnosis of TB in the study participants. This shows that 47.9% (57) was not exposed to any information regarding TB prior to diagnosis, of the 52.1% (62) that had been exposed to information about TB prior to diagnosis, 22.7% (27) were exposed to informal information specifically around the signs and symptoms of TB within the community and family structures. Furthermore 2.5% (3) were exposed to information through the mediums of films and adverts, 17.6% (21) were exposed to formal verbal information like outreach programs or discussions with healthcare staff and 9.2% (11) were exposed to information in the form of formal visual information like posters at healthcare facilities.

The next question looked at family understanding of the TB diagnosis. Of the participants, 83.2 % (99) had family who understood their diagnosis while 16.8% (20) of participants had family who did not understand their TB diagnosis. The questions were then more specific to Brooklyn Chest Hospital, and participants were asked if they seek advice from medical staff at BCH, which saw 47.1% (56) of participants do seek advice from medical staff at BCH while 52.9% (63) of participants did not seek advice from medical staff. From this more than 40% (48) of the participants were not happy with the answered they got. They found that even though they had received answers from staff it was not easily understandable or not answered correctly.

Participants were asked if they feel that enough is being done for them with regards to TB, and it was found that 84.0% (100) of the participants agreed while 16.0% (19) felt that there was not enough done for them.

The last question asked for any other comments participants would like to add. Many of the participants said no they have no comments. Of the participants that had answered, some of them used the opportunity to find out more about aspects of their condition while the researcher was there. Some of the comments or questions that had been said or asked were:

- *How long does it take for the wound from a chest drain to heal?*
- *Four of the participants were upset at the length of stay that was required of them, and said they miss their families or were worried about their families.*
- *One participant who had loss his ability to walk due to the side-effects of his medication, enquired about the likely hood of him returning to 100% function.*
- *There were a few patients who complained about the staff at the institution.*
- *Some of the participants expressed desires to go back home.*

- *One participant indicated how dangerous TB is and he would encourage everybody to look after themselves and protect themselves from TB.*

4.6 Cross Tabulations

Table 4.1 shows a cross tabulation analysing the relationship between substance and alcohol use vs the strain of TB. The significance threshold was set at .05.

Table 4.1: Substance and Alcohol Use vs Strain of TB

Strain of TB	No Substance of Alcohol Abuse	Alcohol Abuse	Substance Abuse
Drug Sensitive	32	18	12
MDR TB	25	4	4
PRE-XDR TB	2	7	4
XDR TB	4	2	5

(Author's fieldwork, 2018)

The results show that the majority of drug sensitive patients 26.89% (32) do not have a history of alcohol and substance abuse, while Multidrug resistant participants are equally prone to alcohol abuse and substance abuse 3.36% (4). Of the Pre-XDR participants the majority of the group used alcohol 5.88% (7) and in the participants diagnosed with XDR-TB 4.2% (5) had used drugs. Chi-square test, 6 df, $P=.004$ -value of 0.004

Table 4.2 explores the relationship between the living conditions of participants versus their drug and alcohol history.

Table 4.2: Living Conditions vs Drug and Alcohol Use

	No Substance of Alcohol Abuse	Alcohol Abuse	Substance Abuse
House	27	15	16
Shack	28	14	8
Homeless	1	1	1
Flat/apartment	7	0	0
Other	0	1	0

(Author's fieldwork, 2018)

The results show that the majority of people in the study who do abuse alcohol and or drugs are found to be living in houses, while people who live in shacks also show a high a level of alcohol abuse. Fisher's exact test, $P = .96$

Table 4.3 shows the correlation between employment status prior to admission to BCH and alcohol and substance abuse.

Table 4.3: Employment Status versus Alcohol and Substance Abuse

	No Substance of Alcohol Abuse	Alcohol Abuse	Substance Abuse
Employed	10	14	9
Unemployed	54	17	15

(Author's fieldwork, 2018)

The results show that majority of the participants were unemployed and unemployed participants in the study had admitted to the usage of drugs and alcohol. Chi-square, 2 df, $P=.001$

Table 4.4 shows the relationship between adherence and employment status.

Table 4.4: The Relationship between Adherence and Employment Status

	Default or non-adherence to TB treatment YES:	Default or non-adherence to TB treatment NO:
Employed	18	15
Unemployed	35	51

(Author's fieldwork, 2018)

The results show that the majority of participants that had not adhered to treatment are unemployed in the study population. However of the participants that had adhered to treatment the majority of this group was also unemployed. Chi-square, 1 df, $P= .174$

Table 4.5 measures the relationship between living conditions and exposure to information.

Table 4.5: Relationship between Type of Living Structures and Exposure to Information

	exposure to TB related information prior to TB diagnosis Yes	exposure to TB related information prior to TB diagnosis No
House	29	29
Shack	15	35
Homeless	1	2
Flat/apartment	6	1
Other	1	0

(Author's fieldwork, 2018)

The results show that people who live in houses were split down the middle with 24.37% (29) receiving information regarding TB and 24.37% (29) of participants not receiving any information regarding TB prior to diagnosis. However there is a substantial difference in the participants who live in shacks, with 29.41% (35) of participants in shacks not having received and information regarding TB compared to 12.61% (15) of participants who had received information about TB before they were diagnosed. Chi-square, 4 df, $P = .012$

Table 4.6: HIV Dispersion among Racial Groups in the Study

TABLE 4.6	HIV Positive	HIV Negative
Black	50	26
Coloured	17	24
Indian	0	1
White	1	0

(Author's fieldwork, 2018)

Table 4.6 shows that the black population were the highest group of HIV + participants with the coloured participants presenting 14.29% (17) of HIV + participants. The black population accounted for 42.02% (50) of the HIV + population in the study. Chi-square, 3 df, $P = .36$

Table 4.7: Relationship between the HIV Statuses of the Participants Versus the Non-Adherence History

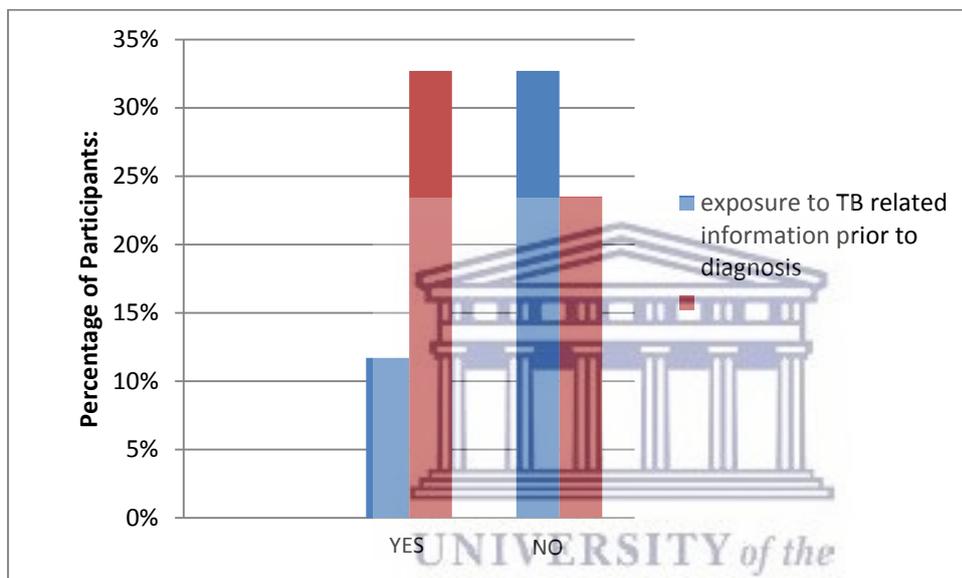
	HIV Positive	HIV Negative
Default or non-adherence to TB treatment YES:	26	27
Default or non-adherence to TB treatment NO:	42	24

(Author's fieldwork, 2018)

The results show that people who are HIV+ are more likely to adhere to TB treatment regimens as opposed to those who are HIV - in the study population at Brooklyn Chest Hospital. Chi-square, 1 df, $P = .110$

Figure 4.16 shows the results of the relationship between the study participants exposure to information related to TB and the non-adherence rate to TB treatment

Figure 4.16: Exposure to TB Related Information versus Non-Adherence



(Author's fieldwork, 2018)

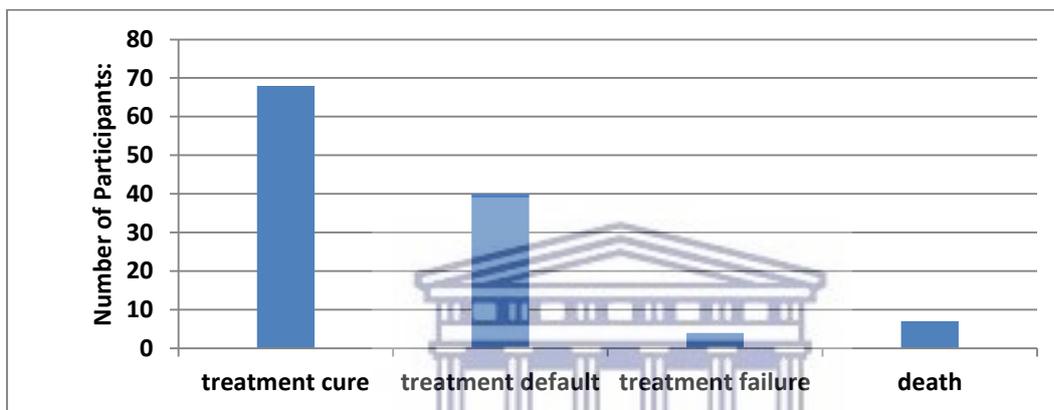
Figure 4.16 shows that of the participants that were interviewed, 32.7% (39) had not adhered to TB treatment and had not been exposed to any TB related information prior to the diagnosis of TB. The participants who had never defaulted treatment showed that 31.9% (38) of the interviewed participants had been exposed to TB related information prior to admission while 23.5% (28) had not been exposed to information.

4.7 Patient Outcomes

This section looks at the results of the treatment outcomes of the participants of the study. It also identifies links between admission length at Brooklyn Chest Hospital and treatment outcomes.

The graph below shows the results for the outcome of TB treatment of the study participants.

Figure 4.17 Treatment Outcomes of Participants



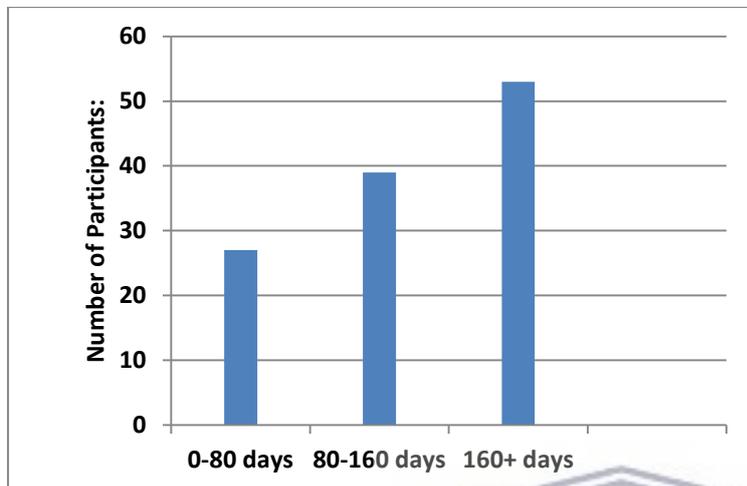
(Author's fieldwork, 2018)

Figure 4.17 shows that of the participants included in the study 57.1% (68) were cured of this episode of TB, 33.6% (40) of the participants were found to have defaulted there TB treatment, 4 (3.4%) of participants had failed their treatment regimen and 5.9% (7) had passed away while being treated for TB.

Based on the average length of stay at Brooklyn Chest Hospital in the period 2015 and 2016 the average length of stay was found to be between 80-160 days. The length of stay or admission period was divided into three categories. Which were those who were admitted for a period less than the average length of stay (0-80 days), second was those admitted for the average length of stay (80-160 days) and those who were admitted for longer than the

average length of stay (160+ days). The figure below shows the number of participants admitted in each category mentioned above.

Figure 4.18: Length of Admission at BCH



(Author's fieldwork, 2018)

Figure 4.18 above shows the number of participants in each category of admission length. Of the participants that were admitted, 22.7% (27) were admitted for 0-80 days, 32.8% (39) were admitted for 80-160 days and 44.5% (53) were admitted for more than 160 days.

To identify the relationship between the length of admission and the treatment outcome, and to identify if there is any statistical significance chi squared was chosen to analyse the data.

Table 4.9 below shows the results of a cross tabulation, measuring treatment outcomes versus the length of admission to Brooklyn Chest Hospital

Table 4.9: Treatment Outcome and Length of Admission Cross tabulation

Count		Length of Admission			Total
		0-80 days	80-160 days	160+ days	
Treatment Outcome	treatment cure	12	30	26	68
	treatment default	12	8	20	40
	treatment failure	1	0	3	4
	death	2	1	4	7
Total		27	39	53	119

(Author's fieldwork, 2018)

Table 4.9 above shows that the majority of participants who were cured of the current episode of TB were admitted between 80-160 days, and the highest rate of default from treatment was found in the category of participants who were admitted to Brooklyn Chest Hospital for more than 160 days. Also the majority of participants who have failed treatment or have died whilst being treated had been admitted for more than 160 days.

Table 4.10 below shows the statistical significance test results, using the chi-square test to measure the significance of the relationship between treatment outcomes and length of admission to Brooklyn Chest Hospital.

Table 4.10 Results of Chi-Square Test

Chi-Square Tests			
	Value	df	Asymptotic Significance (2-sided)
Pearson Chi-Square	10.480 ^a	6	.106
Likelihood Ratio	11.874	6	.065
Linear-by-Linear Association	.172	1	.678
N of Valid Cases	119		

a. 6 cells (50.0%) have expected count less than 5. The minimum expected count is .91.

(Author's fieldwork, 2018)

Based on the chi-square test shown above in table 4.10, due to the expected count being 6 cells (50%) which is greater than 5, this violates the assumption and therefore the likelihood ratio is used, $P = .065$ which is greater than 0.05, which means there is no statistical significance between the chosen variables, which is length of admission versus treatment outcomes. Therefore the length of admission does not impact on the outcome of TB treatment.

Table 4.11 below shows the relationship between treatment outcomes and HIV status.

Table 4.11: Treatment Outcome versus HIV Status

Treatment outcome and HIV status		
Treatment outcome	HIV +	HIV -
Treatment cure	44 (36.9%)	24 (20.2%)
Treatment default	19 (15.9%)	21 (17.6%)
Treatment failure	3 (2.5%)	1 (0.8%)
Death	2 (1.7%)	5 (4.2%)

(Author's fieldwork, 2018)

Table 4.11 shows the relationship between HIV status and treatment outcomes. The results show that 36.9% (44) of the participants who were cured were HIV + compared to 20.2% (24) of the participants who were cured which was HIV -. The results also show that the largest percentage of participants who had defaulted from treatment was HIV - and the participants who had passed away were mostly HIV -.

Chapter Five

Discussion: Understanding the Impact of Health Information on the Perception of TB Patients: Current Policies and Practices at BCH

5.1 Introduction

This chapter focuses on the analysis of the above-mentioned results with explanations of these statistics. The information found will be compared to current literature to identify trends similar to literature on the subject. All deviations and interesting observations will be explored. The discussion will be divided into five themes namely: TB specific areas, treatment specific areas, adherence specific areas, education/information Specific Areas and length of stay in hospital versus treatment outcome. All the areas identified will be matched to what is expected based on TB policies used in the study and furthermore the literature on the subject. Based on the information found I will look to answer the research hypothesis which is:

The study hypothesizes that TB is on the rise and patient-specific policy implementation around education could impact the TB burden. I hypothesize that the knowledge of patient-specific aspects of TB policy in South Africa lacks adequate dissemination which therefore leads to the inadequate implementation of patient-specific areas of these policies and may have an impact on treatment outcomes.

5.2 Demographic Information

When looking at the demographic information of the study participants, it is important to note that the mean age found was 33.7 years of age. This shows that the majority of people who

suffer from TB in this study population are young and in their prime productive years. This corresponds with research in an article where Karim et al. (2009) finds that TB most commonly affects the younger generation with females in their twenties and males in their thirties. Also looking at the sex of the participants it is clearly evident to see that the majority of participants were female (62.2%). This is contrary to previous research which states that men are more commonly infected with TB than women which are shown in articles by Karim et al. (2009) and Ali et al. (2003). However, this can be explained due to the study setting, as Brooklyn Chest Hospital houses more female wards than male wards. Due to convenient sampling method, participants were selected based on meeting inclusion criteria and availability and willingness to participate. These factors may have slightly altered the gender distribution of participants.

The racial profile shows that the large majority of the study population were classified as black (63.9%) followed by the coloured race. This is in keeping with the South African scenario which shows the poverty groups in the country are made predominantly of the black race. Due to the low socio-economic circumstances, this group of people is more susceptible to TB. May, (1998) finds that poverty is not only found in one race group and but in all, however, it is mostly concentrated in the black community.

Lastly, the study looked at the geographical areas which the study participants are from and it was found that the largest portion of the participants had come from poverty-stricken areas in the province such as Khayelitsha, Phillipi, Langa, Mitchells Plain, and Nyanga. This further shows the burden of TB disease being most prominently found in disadvantaged areas.

Studies show that contributing factors such as overcrowding, limitations in accesses to health

care and social ills like drug and alcohol abuse are contributing factors to the TB burden and these areas are known for these factors.

Just based on the demographic information gathered in the study, it is easy to identify the most affected people in the community which should present healthcare policymakers with a target population and group to focus policy implementation on.

5.3 TB Specific Areas

This section focuses on the areas of the health policies which directly explores the information of the participants related to the diagnosis and disease process of *Tuberculosis*.

The analysis was further demarcated based on the policy to identify information such as:

- The diagnosis of TB (strain and type of TB)
- TB contacts
- Episodes of TB
- Contraction or source of infection of TB disease
- Knowledge of signs and symptoms of TB
- Reasons for TB testing and
- Reasons for admission to BCH

Based on the results it is evident to see that the majority of patients presented with pulmonary TB (59.7%) followed by disseminated TB (26.1%). The result is in line with the literature as the National Department of Health (2014) shows that this is the normal picture of the TB disease pathway, as TB is contracted by the inhalation of infected droplets of TB bacilli

which makes the initial area of infection the lungs. Interestingly the second highest category of infection was found to be disseminated TB. This can be explained by the National *Tuberculosis Management Guidelines* (2009) which shows that disseminated TB has seen an increase due to the emergence of HIV which predisposes these patients to become infected with the active disease. When infected with HIV the natural immunity of the body is suppressed, which allows for an easier pathway for the TB disease to spread to more areas of the body. The results further emphasize this fact as 57% of the study population has been diagnosed with HIV, which can clearly explain the high percentage of disseminated cases of TB found in the study. A study by Naing et al. (2013) also identifies the link between HIV and extra-pulmonary TB but also indicates that more research must be done to fully understand the pathophysiology of the relationship.

The strain of TB had also been identified showing that more than 50% of the participants had been diagnosed with drug sensitive TB. This is the most common form of TB in the communities however almost 10% of the participants had been diagnosed as extensive drug resistant TB and a further 10.9% had been diagnosed with Pre-Extensive drug resistant TB. This shows that almost 50% of the participants are diagnosed with drug-resistant TB and these participants are not able to be managed in the community. Based on the admission criteria of BCH, the number of Drug-resistant cases clearly indicates high disease severity, which can be attributed to a number of negative factors, such as late presentation to facilities or non-adherence leading to the need for hospitalization etc.

The participants were then questioned on their knowledge of TB contacts. This is the knowledge of the possible person with whom the participant may have come into contact with, which could be the means of contracting TB. Only 31.1% knew whom they could have

contracted their TB disease from. A possible reason limiting knowledge of contact identification could be due to the stigma associated with conditions such as TB and HIV. TB policies identify negative stigma as an area needing emphasis, as this could decrease the notifiable aspect of TB in communities, and lead to late presentation to healthcare facilities. Previous research has found stigma related to HIV and TB in communities especially widespread and difficult to overcome. The main reason for the stigma of HIV and TB is due to fears within the communities of the infectious nature of the conditions. It is also found that the stigma has socio-economic implications most notably for women in society and is a barrier which is commonly overlooked, or not emphasized in the implementation of control strategies. Another interesting aspect is the stigma of healthcare providers who also fear TB and may not be adequately trained or have appropriate protection in the South African health facilities especially in rural areas. (Courtwright, & Turner,2010; Bond & Nyblade, 2006 and Dodor & Neal,2008,). Therefore if stigma is addressed this could lead to better contact identification and earlier diagnosis of accurate strains of TB, and better screening and initiation of prophylactic treatment for high-risk groups.

The information showed that the participants who had knowledge of the possible TB contacts, found that they had come in contact with family and friends whom they had known was infected with TB. This is difficult as due to lack of knowledge on the TB disease, many participants although knowing of the contact did not take appropriate action to prevent the spread of TB.

The results found that with regards to episodes of TB 47.9% of participants had contracted TB on more than one occasion, with 6.7% of the participants who were experiencing their fifth episode of TB. With TB being a curable disease it is alarming to think that almost half

the participants involved in the study had contracted TB before. This indicates the likelihood of an increase in drug-resistant TB cases. Crampen, et al. (2010) finds that one of the reasons for reoccurrence or re-infection of TB is due to high HIV prevalence and is most commonly found in HIV positive people, also women are more prone to multiple episodes of re-occurring TB and lastly that drug resistant strains are more likely to result in re-occurrence of TB. She also finds that re-occurrence was more commonly found within the first 6 months after treatment completion (Crampen et al.2010). In addition to this, the results found that the majority of people who had experienced TB for the first time were females. Males were found to be more likely to experience multiple episodes of TB occurring on multiple occasions. Thorson, (2007) and Hudelson (1996), finds that females are most affected by TB and face slower diagnosis times of around two weeks compared to males (Thorson, 2007 and Hudelson, 1996). However, the results indicate that men are more likely to have had more episodes of TB which is interesting showing that more females are infected with TB but more males are likely to not complete treatment or become re-infected with TB.

When asked about knowledge of signs and symptoms almost 80% of all participants had some knowledge of the signs and symptoms. Interestingly most of the participants were mostly able to identify the signs and symptoms the participant had experienced and 20.2% of the participants had no knowledge of any sign and symptom. This proves difficult as most patients must have experienced some symptom prior to diagnosis. The most common symptoms identified by the participants were night sweats, coughing, and loss of appetite.

When identifying dissemination based on patient perceptions it is clear to see that education regarding signs and symptoms are improved, however, it is difficult to distinguish if this knowledge was gained prior to infection or based on the lived experience of the symptoms.

The research shows that 80% of patients do understand and have knowledge of signs and symptoms which could lead to earlier presentation to facilities leading to better treatment outcomes.

I then looked to understand the reasons for getting tested for TB among the participants. Only 5% of the participants were not aware of the reasons for being tested while 68.9% of participants were tested due to the presentation of symptoms of TB. Participants who were diagnosed due to general screening had amounted to 10% which according to TB policies should be much higher. Based on the National Strategic Plan on HIV, STI's and TB (2012-2016) the aim is to improve opportunities for all South Africans to have the availability of HIV testing and TB screening every year as part of the wellness programme. The participants were also asked to explain the reasons for being admitted to BCH and 68% of participants were admitted due to ill health, which needed management at an institutional level and not community level. Only 11% of participants were specifically admitted for non-adherence, while 15% were admitted due to social and environmental factors. BCH is a specialist level 1 TB institution which admits people with TB, which present with deteriorating health conditions due to TB, admissions due to social and socio-medical reasons which makes community or clinic level care insufficient, which include patients with histories of default and non-adherence from treatment. (MTBHC/20, 2013)

Looking at these results it is clear to see that in areas such as TB diagnosis and clinical signs and symptoms, most of the participants were well educated and informed of their condition. However the results do indicate that for this theme, areas such as reasons for being admitted and reasons for TB testing was mostly due to ill health which can be prevented if diagnosis and treatment are made early, and if patients present to clinics early for screening. The

screening of patients only accounted for a small portion of the participants which shows more must be done to target high-risk groups for screening, as this is seen as an important tool for the early detection of TB cases. The episodes of TB are alarming as almost half of the population studied has had more than one episode of TB. With TB being a curable disease, education must be constantly provided

5.4 Treatment Specific Areas

This section focuses on the areas identified in the selected policies which explore knowledge related to the treatment of TB, and the insight of participants related to the treatment of TB.

The results were analysed based on questions pertaining to:

- The current length of treatment
- Knowledge of treatment regimen
- Length of the course of treatment based on type and strain of TB disease
- Knowledge of the method of monitoring treatment and
- Knowledge of DOTS program

When identifying knowledge based on treatment specific areas, the results had shown that 41.2% of participants had been treated for more than 6 months for TB. This indicates that the majority of participants had been receiving treatment which means they have had access to education regarding TB disease and treatment. However, when participants were asked if they are aware of the treatment they are currently taking only 22.7% of the participants could identify the treatment they were expected to take. This indicates a lack of education specific to TB treatment which is an integral part of ensuring adherence of treatment to cure people

with TB. This is consistent with the National *Tuberculosis* Management guidelines (2014), which states that a more comprehensive method must be used to address all issues relating to incomplete treatment, which includes information on treatment compliance, the drug therapy being used and the possible side-effects that may occur. In contrast to this, 77.3% of participants are aware of how long the regimen requires the participants to remain on treatment. By understanding this data it is evident to see that more education is directed to the length of treatment and not to the actual treatment which must be consumed.

The participants were then asked if they could identify means in which the treatment success is measured monthly. The department of health indicates that disease monitoring for TB must be identified monthly through bacteriological monitoring, clinical monitoring example weight gain, radiological monitoring using X-rays and other laboratory tests like urine tests or blood tests. (National Department of health, 2011 and National Department of Health, 2014). The results show that 69.7% were not aware of how treatment success was monitored while only 3.4% identified X-Rays and 9.4% correctly identified sputum microscopy as a means of monitoring treatment success. The results show that a significant shortfall exists in the knowledge of participants on how TB treatment is monitored. This creates an equation where people do not entirely understand the processes expected of them to follow which could lead to late presentation for testing at the community level and therefore non adherence.

The DOTS strategy to control TB was the next question asked. For the sake of understanding knowledge and perceptions of the participants, the only information sought was that of directly observed treatment. The other aspects of the strategy are implemented at a level above the patient and are therefore not a patient-specific aspect and not considered in the questions asked. The participants had no knowledge of the program and had not heard of it

before. Of the study population, 98.3% of the participants had not heard the term DOTS before and could not explain what this meant for them. However, all the participants were admitted to BCH at the time of data collection and had all therefore been subjected to directly observed treatment by staff at the hospital. Therefore information regarding the way treatment must be taken may not be appropriately explained and may lead to patients not understanding the reasons for the daily presentation to health care facilities, which may lead to non-adherence. Most other chronic conditions like hypertension or diabetes which require long-term treatment are not as closely monitored as TB. This is because TB must be reported upon and treatment compliance must be ensured, as our health system follows the DOTS protocol. Without education explaining DOTS and the reason for directly observed treatment, people might find a commute to the clinic every day not conducive to their lifestyle and this could further lead to non-adherence to treatment.

5.5 Adherence Specific Areas

The next section explores the areas based on TB policies specific to areas relating to adherence. Themes identified to understand this section were:

- Number of episodes of TB
- Default or Non-Adherence to medication
- Reasons for non-adherence or default

This theme looks at all adherence-related factors which were found based on the perceptions of the study participants and the policies which form the framework for the fight against TB. The first clear indication of adherence is to identify the number of episodes of TB found in the study population. The number of episodes of TB could indicate non-adherence but also

this could indicate high-risk groups who may have completed treatment and become re-infecting on different occasions. However, due to the research setting being BCH, one of the criteria, as mentioned earlier for admission, are social or socio-medical barriers which impact care at the primary level, which require admission to hospital. This includes people with a history of non-adherence. Therefore, the number of people who have had TB more than once (47.9%) in the study indicates a high rate of non-adherence. Furthermore, 6.7% of participants had experienced five episodes of TB which is significantly high.

Adherence to medication is a constant discussion when considering strategies to combat TB and many other conditions which require medium to long-term treatment regimens. With regards to the study population, 44.5% of participants had indicated that they have defaulted or not adhered to treatment protocols. This is an alarming number as non-adherence has been found in the literature to be the leading cause of the increase in drug-resistant cases of TB. Although considering earlier results it can be seen most of the participants identified the reason for being admitted to BCH was due to ill health, this could also be attributed to non-adherence. The National Department of health finds that people who default from treatment are more likely to experience advanced disease which leads to deterioration in general health and also leads to late presentation to healthcare facilities (National Department of Health, 2014). Therefore non-adherence is a predisposing factor to ill health and can explain the rise of people being admitted to BCH due to deterioration in general health. Ill health creates a barrier to access to health services for daily treatment, which leads to hospitalization of people with TB.

When considering reasons for default 16.8% had no explanation for not adhering to treatment regimens. The remaining participants identified reasons such as high pill burden, clinical

improvement, clinic related issues like distances to clinics or unwillingness to go to clinics due to work and financial or family responsibilities. A further 6.7% had not adhered to treatment due to drugs or alcohol abuse and the last reason found for non-adherence were the experience of bad side-effects due to TB treatment. The above-mentioned barriers to treatment have been widely emphasized in studies by Sing et al.(2007), Coetzee et al.(2004), and Pronk, (2001). Interpreting this, it is evident to see that many socio-economic factors exist which complicates the fight against TB. These reasons are common in low socio-economic communities and the same can be found of the participants in this study. However barriers such as high pill burdens, non-adherence due to improvement in clinical condition and side effects, this may be prevented with adequate education around these barriers to ensure all new TB cases are aware that these are common barriers. If knowledge is improved, this could deter default of medication or decrease deterioration in clinical conditions leading to hospitalization.

5.6 Education/Information Specific Areas

This section identifies the exposure of participants to information and education with regards to TB prior to the diagnosis of TB. This was explored by gathering information such as:

- Knowledge of exposure to any information regarding TB
- The type or form of information which the participant was exposed to
- Understanding of diagnosis by family
- Seeking of medical advice from staff at BCH
- Do the participants feel enough is being done about TB

Based on the patient-centred care approach adopted by the National Department of health in TB policies, a strong focus is placed on education and the dissemination of information. The education component is seen as pivotal to achieving far-reaching access to knowledge which will aid in the early presentation of people to health care facilities leading to early detection and initiation of treatment and improving treatment outcomes. (National Department of Health; 2014 and Luxford et al.; 2010)

The results show that when knowledge of exposure to TB related information prior to diagnosis of TB was tested, 52.1% of participants had indicated that they have been exposed to some information regarding TB however 47.9% of all participants had received no information regarding TB. When interpreting this result it is clear to see that almost half of the study population was not able to be reached by sources of education. If the education of people is paramount to the success of the TB control strategies the statistics show that this goal is not being achieved.

Many reasons could be found for the above-mentioned result, like not reaching the appropriate target audience or inadequate mediums of education. However, it is clear to see that efforts to educate the South African public on TB is not far-reaching and may add to the difficulty in the treatment success of TB. This can also be found in the results which shows that of the participants in the study, 32.7 % of people who admitted to non-adherence had not been exposed to TB related information. Kiwuwa et al. (2005) find that education is an important factor to achieve early presentation to healthcare facilities. One of the reasons found in the above-mentioned study for delayed diagnosis was a lack of education around signs and symptoms especially prolonged coughing which was attributed to smoking. This shows that education is important to ensure early diagnosis and treatment cure. Luepker

(1994) finds that a strong and well-implemented health program has the ability to change behaviour to benefit the patient with good far-reaching education strategies.

Based on the above findings the researcher looked to understand the types of mediums or platforms, that information was most commonly found. The participants were asked if TB specific education was received, also where and how did they receive this information. The results show that of the 52.1% who had been exposed to information about TB prior to diagnosis, 22.7% were exposed to informal information specifically around the signs and symptoms of TB within the community and family structures. Furthermore, 2.5% were exposed to information through the mediums of films and adverts, 17.6% were exposed to formal verbal information like outreach programs or discussions with healthcare staff and 9.2% were exposed to information in the form of formal visual information like posters at healthcare facilities. This shows interesting results as the highest form of information was gathered on an informal platform through conversations with family and friends within the community. The second most prominent source of information was through formal education programmes like staff outreach programmes and general information session run by healthcare providers.

This is a useful insight for health policymakers and people who implement these policies to understand the best ways to achieve information sharing, with the relevant target audience. If informal information session or community-driven session were used, new stakeholders could be identified, like religious leaders or TB programmes could be added to high school curriculum as part of life orientation. A trained health professional could go out into the communities and provide information or TB treatment supporters may be involved on the ground level to disseminate information. Healthcare providers should also use long waiting

times and full waiting areas to provide information to large groups of people, and also providing reading material or visual materials, to people who may, in turn, carry the messages to family and friends ensuring more become aware of the TB disease and its signs and symptoms.

The next focus area is around family knowledge and the stigma attached to TB. Because TB is still stigmatized, many people in communities are not aware of people who may be neighbours who suffer from TB and may pose a threat to high-risk groups in society. It is therefore also important to have a strong family support structure to ensure assistance is given to those who suffer from TB. The National Department of health in TB policies identify the decrease of stigma as one of the target areas to achieve targets set in TB control. With TB education to families and strong support, stigma can be reduced at least in the household. This will aid in the early presentation for diagnosis and family support during the treatment period and could ensure treatment completion.

With this knowledge the researcher aimed to identify if participants were forthcoming about their condition to family members and if family members had the understanding of the TB disease to provide adequate support while maintaining their own safety. The results show that 83.2% of participant's family members are informed and understand the diagnosis of their family member while 16.8% of participants had families who did not understand their condition or were not informed. The high rate of family support is encouraging as family members can be trained to assist as treatment supporters and ensure that treatment regimens are completed. Even with the high percentage of family support, the participant's non-adherence rate is still close to 50%, which indicates that more education could be done for family, to add an extra re-enforcement element to participants. The adequately trained family

will also be able to provide support and comforting to participants and may be able to identify side-effects and report on them to healthcare providers.

Based on perceptions and experiences of patients at Brooklyn Chest Hospital, health seeking and information seeking behaviour was analysed. The results show that 52.9% of participants do not seek medical advice or information related to their condition, from the staff at BCH.

The participants identified reasons for this being that participants were not happy with the answers they had received, or they had received answers that they had not understood or that questions were answered incorrectly. This is based on the perceptions of the participants.

Based on previous research especially in African countries one of the reasons for not seeking health information from medical staff is due to cultural beliefs. Many people, especially in rural areas, may present to traditional healers for treatment and once this is not effective they may seek western medical assistance (Eastwood, 2004). The National Department of Health (2014) also informs healthcare workers to understand patient beliefs and understand that this could have an effect on treatment compliance. Cultural belief systems and the lack of understanding of the differences by health care providers may also be a reason for not seeking health information.

Considering that TB control strategies are founded on the client-centred approach model and that a large portion of people admitted has defaulted from treatment regimens, it is important to understand that a fundamental role of an institution like BCH, plays is behavioural change. The hospital is equipped with medical, nursing, allied health, and counselling staff who are all trained and equipped to provide knowledge on areas of TB to participants, and yet the results show that more than half of the participants no longer make use of these services to help them understand their condition. Therefore more must be done to gain the trust of the

clients admitted, so that they may feel comfortable enough to engage staff. This education could be the difference between perfect adherence and default. However, when participants were asked if enough is being done for them regarding TB, 84% agreed which shows that they may believe that BCH is providing the best care for them to cure their condition.

5.7 Length of Stay versus Treatment Outcome

Hospitalization is mentioned in the National *Tuberculosis* Management Guidelines (2014), as a means of treating patients who are unable to be treated in the community due to illness or weakness, or for social barriers which render clinics inadequate to ensure positive treatment outcomes. The policy also identifies hospitalization as needed for people who abuse substances, suffer from mental illness and are high risks of non-adherence.

Essentially patients who are hospitalized should be based on the policy, receive an education plan tailored to their TB condition, and counselling aimed at the development of a plan ensuring adherence, equating to completion of treatment regimens. They are also entitled to receive a psycho-social support structure and within the initial two weeks of admission, a discharge plan must be set in place. The plan should involve confirmation of clinics to ensure that treatment plans are met and family education to identify an adequate support structure upon discharge. (National Department of Health, 2014)

The policy also lays out the discharge criterion which shows that all patients admitted to hospital for TB must be discharged when they are stabilized medically as well as the patient must be able to access treatment effectively in the community to complete treatment regimens.

Looking at the policy directives hospitalization is of benefit to patients and is reserved for patients who are ill and have social barriers which could lead to non-adherence. Therefore hospitalization should improve treatment outcomes as education and counselling along with social intervention and treatment planning are pre-requisites of hospital admission. With this in mind, the researcher aimed to understand if a relationship exists between the length of stay at the hospital and a positive treatment outcome. Secondly, the researcher aimed to identify if treatment outcomes were successful in patients who were hospitalized and discharged back into communities to complete treatment.

The last section discussed aims to identify if a statistical significance, based on the chi-square test, exists between the length of stay in hospital and the impact length of stay has on treatment outcomes of participants. Many health policies identified indicate that admission is necessary in cases of extreme social ills, health deterioration and high non-adherence rates of patients. Hospitalization of TB patients is seen as a way to deter behaviour which leads to the emergence of new drug resistant strains of TB. Hospitalization also benefits the more acutely ill patients who could be monitored by staff continuously to overcome the TB disease or side effects associated with TB treatment.

For the purposes of the statistical significance test, length of stay or admission was divided into three categories which are: 0-80 days, 80-160 days and 160+ days. This was based on the average length of stay at Brooklyn Chest Hospital in the period of 2015-2016. The results show that the largest group of people who had been cured were found to be admitted for 80-160 days. The time frame where most non-adherences to treatment, deaths and treatment failure occurred was seen in patients who had been admitted for more than 160 days at Brooklyn Chest Hospital. However, this can be seen due to the fact that the more extensive

the disease process is, the longer the time of admission will be, and also those with adverse socioeconomic circumstances who are considered high risks for non-adherence would have extended admissions. This could explain why the participants who had been admitted for the longest time have the highest percentage of non-adherence.

Based on the chi-square test, it was found that no statistically significant correlation can be found with a P-value of 0.106 which is greater than 0.05. This indicates that there is no significant relationship between the length of admission to hospital and positive treatment outcomes. With this information we can identify that the length of stay is not significant, however, admission regardless of the length may be beneficial.

Interestingly when further examining the results in this section, it can be seen that although participants of the study had been admitted to a healthcare institution, only 68 participants had achieved a successful outcome which constitutes only 57.1%, while a further 33.6% of participants had defaulted from treatment in this episode of TB. The National *Tuberculosis* Management Guidelines (2009) had set targets to be achieved by 2011. These targets are “case detection rates of 70%, cure rates of 85% and Treatment success rate of more than 85%”.(National Department of Health; 2009: 01). Interestingly although hospitalized, treatment outcomes were well below targets set in the policy. There are possible explanations for this.

Due to the nature of patients excepted at Brooklyn Chest Hospital, many of the participants die due to severe disease progression and co-morbidities. Also, people are admitted with poor social circumstances which are generally resolved before discharge by strong social worker department intervention, but many patients despite efforts made to assist them to return to their homes and the social issues. The results also found that 47.1% of the participants,

admitted to the excessive use of alcohol, drugs or both alcohol and drugs. Once patients have been medically stabilized and social circumstances have been adjusted to allow for treatment completion, patients are generally discharged back to the communities for treatment completion at the clinic level. Upon return to the home and community environment behaviour returns to that of which lead to their admission and high default and non-adherence becomes evident. This generally leads to deterioration in the clinical picture and re-admission to BCH.

5.8 Discussion Overview

The aims of the study were to identify if policy information which is patient-specific is being disseminated to patients, to understand if there is a link between information dissemination and non-adherence and to understand the perception of patients with regards to patient-specific areas of policy and its dissemination.

To achieve this, themes were developed to categorize patient-specific information and subthemes were used as indicators for the results in each theme. The overall results are tabulated and show:

Overview of Outcomes Based on Patient Perception

Table 5.1: Outcomes Overview

Themes	Percentage	Outcome
1. Patient specific areas		
1.1 TB Diagnosis (strain and type)		Adequate
1.2 TB contacts	31.1	Poor
1.3 1 st Episodes of TB	52.1%	Poor
1.4 Knowledge of signs and symptoms	79.8	Adequate
2. Treatment specific area		
2.1 Knowledge of Treatment length	70.6%	Adequate
2.2 Knowledge of treatment regimen	22.7%	Poor
2.3 knowledge of monitoring treatment success	30.3%	Poor
2.4 Knowledge of DOTS program	1.7%	Poor
3. Adherence Specific Areas		
3.1 Number of first episode of TB	52.1%	Poor
3.2 Number who have not default or non-adherence to treatment	55.5%	Poor
1.1 participants who defaulted or did not adhere to treatment	44.5%	Fair
4. Education/Information Specific Areas		
4.1 Exposure to TB information or education	52.1%	Fair
4.2 Family understanding of TB	83.2%	Adequate
4.3 Seeking advice from staff at BCH	47.1%	Poor

(Author's construct, 2018)

The purpose of the study was to identify if information is disseminated to patients at Brooklyn Chest Hospital based on their perceptions, and grounded by the patient-centred approach as a framework identified in TB policies in South Africa. The table above shows that in all areas identified only four out of a possible fourteen areas were adequate. This means that patient perceptions showed that majority of the participants had received education in these areas and were able to identify the correct answers. Many other areas have scored extremely low like knowledge of Directly Observed Treatment, treatment participants consume and exposure to information prior to diagnosis of TB. Alarming default rates are high prior to discharge and post-discharge among the participants, and participants show large numbers of previous TB disease history. Lastly, surprisingly the cure rate of participants post discharge from BCH is low.

With this, the hypothesis, which is that the knowledge of patient-specific aspects of TB policies In South Africa lacks adequate dissemination which therefore leads to the inadequate implementation of patient-specific areas of the policies can clearly be answered. The research shows that in most areas identified patients lacked the knowledge expected in the South African TB policies.

Chapter Six

Conclusions: Health Information and the Relation to TB Patient Perceptions at Brooklyn Chest Hospital

6.1 Introduction

In this chapter, the significance and study limitations of the study will be discussed and recommendations for future research and improvements based on the findings of this study will be discussed.

Tuberculosis is a condition that is currently rising in Sub-Saharan African and South Africa is the most affected by TB in Africa. Although much effort through strong policy and standardized treatment based on the World Health Organization's DOTS program, the rate of new infections and non-adherence is still high. This study identified patient-specific policy aspects to understand if dissemination of information was adequate based on the patient-centred approach used by South African TB policy.

The first objective of the study was to measure the implementation of aspects of TB policies in South Africa based on patient perceptions. The information was gathered through structured interviews of participants who are admitted at BCH with TB. The study found that the implementation of a majority of aspects identified in the study is not adequately implemented with regards to education of patients with TB. There is a lack of knowledge found in participants in areas like TB contacts, exposure to health information before they were diagnosed with TB, the medication they are expected to take and why they should be observed taking their medication daily. This proves that some areas of the policies are failing with regards to reaching the target population of patients with TB. The results are alarming

because these participants are admitted to a healthcare institution and receive all the necessary support required, but yet the participants lack the knowledge required, set out in TB policies.

The second objective was identifying which types of information are generally disseminated by healthcare personnel based on patient perceptions. The study shows that there are areas which the participants show great knowledge on. These include areas such as knowledge of TB diagnosis and strain of TB, the signs and symptoms of TB and family education and support for patients with TB.

The next objective identifies if a link existed between a lack of patient-specific information dissemination and treatment non-adherence. The study found that almost half of the study sample had not adhered to treatment prior to admission to the hospital. Also, the high number of episodes which was seen by participants indicates an increased rate of default and non-adherence to treatment. Most importantly, the study found that among the treatment outcomes of the patients post-discharge, a high default rate still exists in the population studied after all in-patient support programs had been made available to each participant. The large number of participants who had not adhered to treatment after discharge from BCH is also discouraging because before discharge all participants should be provided with an extensive discharge plan which included community health facility interaction and planning as per the guidelines provided in South African TB policies.

The final objective of the study was to measure the impact admission to hospital has on treatment outcomes and adherence to TB treatment. This was important because all participants included in the study must have been currently admitted to BCH at the time of data collection. Therefore all participants would have access to appropriate and a constant

supply of treatment, sound medical personnel in all fields and access to education and counselling services before discharge. Upon discharge, all clients would have a treatment plan with follow-ups scheduled and family involvement. However, the results show that the participants are lacking in most areas analysed in terms of education and knowledge on TB, and many have had multiple episodes of non-adherence, with over 30% of participants who have continued to not adhere to treatment upon discharge. If the success rates cannot be achieved in a hospital setting where all services are provided, the community setting will face great difficulty in the case detection, treatment, and cure of TB patients.

A significant finding to note is also the impact HIV still places on the TB burden. The result shows that 57% of the participants were infected with HIV and the number of participants who were diagnosed with disseminated TB further indicates the severity HIV has on the TB population. The demographic and social data still emphasizes that TB is predominantly affecting the poorest and those who live in the worst socio-economic circumstances in South Africa. The vast majority of the population are sorely lacking in education and information which is vital to ensure treatment completion. The study clearly indicates which types of information is mostly disseminated and this leaves room for further education strategies to be implemented. The study proves that more needs to be done by policy makers, health professionals, and other stakeholders to improve the knowledge and education of TB to all patients. This will aid to identify new cases earlier, minimize stigma attached to TB and aid in treatment completion and cure.

The aim of the study was to understand the perceptions of people with TB on areas which TB policies expect the participants to have knowledge off. It was found that although the policy is well structured and all-encompassing, the implementation of the policy, especially at the

level of education of people with TB is inadequate. This is due to the fact that the majority of the participants in the study have scored below standard on areas which are driven by the South African TB policies to be patient specific. Although knowledge and education fall short in most areas studied in this paper, most participants find that the government is doing enough for them with regards to TB. This is surprising as many of the participants had admitted to not being educated appropriately in most areas. The availability of the services and the possibility of cure may be a reason for the belief in the system being adequate.

The study finds that the dissemination of patient-specific information from South African TB policies in most policy areas is not well implemented among the study participants. This has continued to show a high non-adherence rate to treatment of the participants after discharge from hospital.

6.2 Significance of the Study

The study is significant as it covers many areas and may assist many role players. The target group is vast, but two main groups have been identified, which are policymakers and healthcare professionals

Impact for Policy

By using South African TB policies as a theoretical framework for the study, all areas that were found to be inadequate based on patient perceptions are in need of more emphasis with regards to implementation. Policy objectives which are patient specific and require education for behavioural change are identified in this study. The study also found aspects that require more research, which could allow policymakers to understand what patients feel, to aid in the achievement of successful treatment outcomes. Moreover, the study identifies areas were

greater stakeholder collaboration can be beneficial, like implementing treatment supporters for the strengthening of Directly Observed Treatment programmes.

Collaboration with other government institutions can be beneficial. This could include departments such as the department of education, to introduce TB education programmes at the school level to increase awareness of TB. Policy directives in South Africa on TB are well written and cover all areas which ensure standardized treatment, however, implementation is found to be lacking. This study helps to highlight areas where implementation is lacking based on patient perceptions, to direct policymakers to identify solutions.

Impact for Health Care Providers

The second group who could benefit from this study is healthcare professionals who work closely with people diagnosed with TB in the community. The vastly overburdened South African Healthcare system, especially at primary and community level, may result in shortened information sessions due to large patient loads and long waiting times. The study helps to identify areas which are lacking in patient knowledge, which will allow healthcare providers the insight to add this to the education packages given to patients and communities at large. The study will also aid in pointing out which type of educational information is most needed, which could form part of staff run health promotion programmes in clinics. Lastly, the information gathered could help to identify the best mediums for educational programmes to reach the most people possible and avoid using mediums which are not seen to be effective in communities.

6.3 Study Limitations

Some limitations were found in the study which could be improved upon. Firstly when looking at the research setting (BCH), at the time of data collection, it was difficult to find patients willing to participate. In addition, based on the exclusion criteria, many patients were not eligible to part take in the study, mainly due to severe ill health or a decrease GCS score of below 15/15. This led to a small sample size of the participants.

The sample group was 119 participants which made administering structured interviews time consuming for one researcher, which significantly lengthened the time taken to collect all data used for the study. Once the participants had answered the questions, the participants had realised that all knowledge regarding their condition was not adequate. This led to a multitude of questions to aid the participants to understand their condition, which added significantly to the time taken for each interview. All information was based on the participants answering all questions accurately and having a good understanding of the questions asked of the participants. The researcher made sure that questions were phrased in a simple manner with the medical language used every day by all healthcare professional dealing with the patients at the institution. If a patient indicated that they were not sure of the question or did not understand the question, the researcher had explained all questions to a point of understanding.

Another limitation is that the study was conducted at one institution, and results may vary in different hospitals or provinces where services might differ or programmes are run in a different manner. The last limitation found is researcher bias as the researcher is employed at the institution. The researcher also has a personal interest in the topic. To overcome this, a

comprehensively written trail was kept and data were presented as the participant had stated it.

6.4 Recommendations

Based on the findings of this study the following recommendations can be made:

1. The Department of Health should place more emphasis on the education of people and communities to reach more high-risk groups of people who may contract TB. By doing this the stigma attached to TB and fears in the community will decrease which will improve early presentation to healthcare facilities.
2. More training should be given to healthcare professionals on all information which should be provided to patients to achieve treatment success. Also, emphasis should be placed on education over a number of sessions at each visit to ensure patients are constantly reminded, and all information is provided without extending contact times, leading to extended waiting times for other patients.
3. More resources should be provided for programmes such as treatment supporters and family training to ensure treatment completion is achieved. It may be beneficial to use community members and family to ensure the patient is comfortable with the treatment supporter which may lead to superior results.
4. Stronger tracing mechanism must be put in place, as default rates after discharge are high, and having designated treatment supporters who are in daily contact with patients may be a solution.
5. It is recommended that further research should be done on this topic to identify each area individually, to understand why these areas are lacking from a patient

and a healthcare professional's perspective. Also, this case study should be carried out in other hospitals in other provinces to identify if the same trends exist. This would provide stronger proof for new strategies to be put in place to achieve the goal of controlling TB in South Africa.



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APPENDICES

Appendix I: Data Gathering Instrument

Section A (demographic information)			
Age		Gender	Race
Address:			
Section B (Medical Information)			
Diagnosis		Episode of TB	
TB contacts		Current length of treatment	
Substance or alcohol abuse history:			
Section C (social history)			
		Number of children living with you	
Living conditions		Employment status prior to admission	

SECTION D (Patient knowledge on TB protocol)

1. What is your diagnosis?

.....
.....

2. What treatment are you on?

.....
.....

3. How long must you remain on your treatment?

4. Are you aware of how you contracted TB, please explain?

.....
.....

5. Are you aware of how your treatment is monitored each month, please explain?

.....

6. What is the reason for you being admitted to BCH?

.....
.....

7. Have you ever heard of the DOTS program, if so what is it?

.....
.....

8. What are the symptoms of TB?

.....
.....

9. What made you get tested for TB?

.....
.....

10. Have you ever defaulted from your medication?

11. If yes above, what was the reason for defaulting?

.....
.....

12. Have you ever been exposed to any information teaching you about TB before you were diagnosed with TB?

.....
.....

13. If yes what forms of information were you exposed too?

.....
.....

14. Does your family understand your diagnosis, please explain?

.....
.....

15. Do you seek advice from medical staff at BCH about your diagnosis?

.....
.....

16. If yes above, do they answer all questions to the point of you understanding?

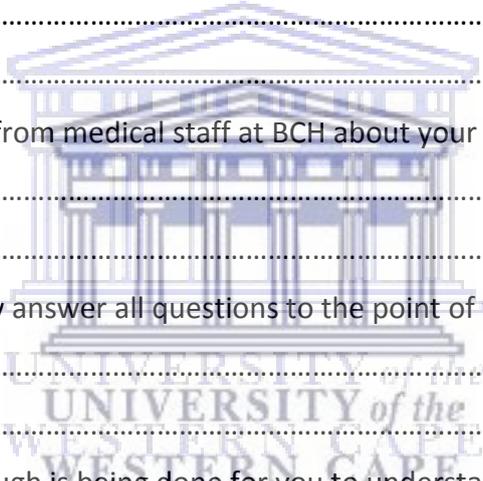
.....
.....

17. Do you feel like enough is being done for you to understand TB?

.....
.....

18. Do you have any other comments?

.....
.....



Appendix II: Consent Form



UNIVERSITY of the
WESTERN CAPE

FACULTY OF ECONOMIC AND MANAGEMENT SCIENCES

SCHOOL OF GOVERNMENT CONSENT FORM

**RESEARCH TITLE: Health information and its influence on the perception of
Tuberculosis (TB) patients: current policies and practices at Brooklyn Chest Hospital.**

I have read the information presented in the information letter about a study being conducted by **Mubashir Goolam Nabie** towards the Masters at the School of Government (SOG) at the University of the Western Cape.

This study has been described to me in a language that I understand and I freely and voluntarily agree to participate. My questions about the study have been answered.

I understand that my identity will not be disclosed and was informed that I may withdraw my consent at any time by advising the student researcher.

With full knowledge of all foregoing, I agree to participate in this study.

Participant Name : _____
Participant Signature : _____
Date : _____
Place : _____

Student Researcher : Mubashir Goolam Nabie
Student Researcher Signature : MGNABIE
Student Number : 2733798
Mobile Number : 0722756076
Email : goolamnabie.mubashir64@gmail.com

I am accountable to my supervisor : professor J.J Williams
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your ability. This will allow me to identify and themes and common areas which could be improved on to help people with TB understand their condition better.

CONFIDENTIALITY

Please be advised that the results of the study will neither divulge the organisation's particulars nor the individual particulars, as to maintain confidentiality at all times. Any information that can connect the responses to an individual or organisation will remain confidential and will be disclosed only with your permission. The researcher shall keep all records and tapes of your participation, including a signed consent form which is required from you should you agree to participate in this research study, and locked away at all times.

VOLUNTARY PARTICIPATION AND WITHDRAWAL

Your participation in this research is entirely voluntary, which means that you are free to decline from participation. It is your decision whether or not to take part. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. If you decide to participate in the study, you are free to withdraw at any time – and without giving a reason. You may also choose not to answer particular questions that are asked in the study. If there is anything that you would prefer not to discuss, please feel free to say so.

PAYMENT FOR PARTICIPATION

There are no costs to the participant for partaking in the study.

INFORMED CONSENT

Your signed consent to participate in this research study is required before I proceed to interview you. I have included the consent form with this information sheet so that you will be able to review the consent form and then decide whether you would like to participate in this study or not.

QUESTIONS

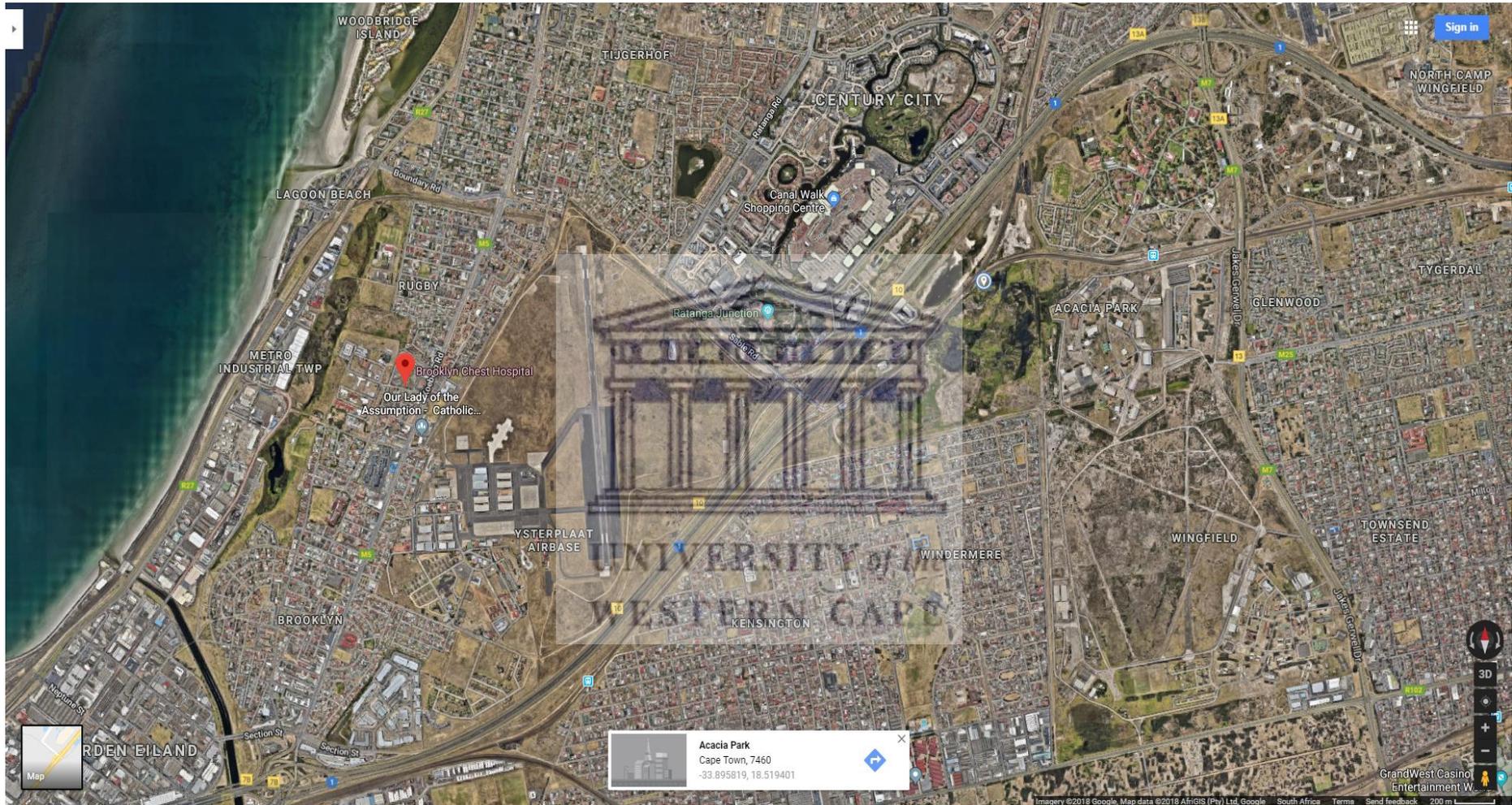
Should you have further questions or wish to know more, I can be contact as follows:

Student Name	: Mubashir Goolam Nabie
Student Number	:2733798
Mobile Number	:0722756076
Work Number	:0215087474
Email	: goolamnabie.mubashir64@gmail.com

I am accountable to my supervisor : Professor J.J Williams
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Appendix IV: Map of Brooklyn Chest Hospital in Cape Town



Appendix V: Ethical Clearance

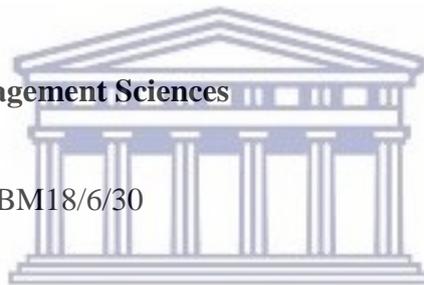


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25 September 2018

Mr M Goolam Nabie
School of Government
Faculty of Economic and Management Sciences



Ethics Reference Number: BM18/6/30

Project Title: Health information and its influence on the perception of *Tuberculosis* (TB) patients: current policies and practices at Brooklyn Chest Hospital.

Approval Period: 19 September 2018 – 19 September 2019

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

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

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

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

A handwritten signature in black ink, appearing to read 'Patricia Josias'.

Ms Patricia Josias
Research Ethics Committee Officer
University of the Western Cape
<http://etd.uwc.ac.za/>