

University of the Western Cape



People's Understanding of TB in a setting of high HIV/TB prevalence: Case Studies in Gugulethu Township, Western Cape Province

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ABSTRACT

Tuberculosis (TB) infection is present in many people but it is sometimes latent until one's immune system is compromised. As such, it increasingly manifests in people, especially those whose immune system has been compromised by e.g. HIV, as an opportunistic disease. TB is thus closely interlinked with HIV and efforts to eradicate TB have been integrated with the fight against HIV in South Africa. The study revealed that factors such as poverty and stigma - be it enacted or perceived - has an impact on how people with TB deal with the burden of having the disease. Using qualitative research as the choice of methodology and collecting data using observations, in-depth interviews and structured interviews among 18 participants the study focused on the ways in which people understand TB in an area that is known to have high HIV prevalence. The researcher explored people's experiences with TB and investigated their understanding of the disease as well as explored how people on Directly Observed Treatment Strategy (DOTS) make sense of and interact with this programme in Gugulethu Township. During the study it emerged that people have significant understanding of TB and its symptoms but their initial reaction to those symptoms is self-medication and this results in delayed treatment seeking. TB is stigmatised in Gugulethu despite some people acknowledging that the environment itself is partly to blame for the rapid spread of the disease. The study revealed that there is good healthcare provision in Gugulethu and it is accessible but the burden of suffering from TB is a difficult one that requires family support, financial support and good relations with clinic and hospital staff in order for one to adhere to treatment and recover from TB.

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I am sincerely grateful to God Almighty, without whom none of this would have been possible.

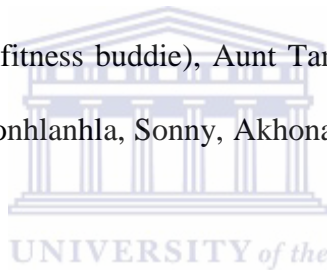
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DEDICATION

I dedicate this thesis to my parents Victor and Sikhathele Ncube whose ceaseless prayers and support encouraged me to complete my studies. You are a wonderful blessing. I would also like to dedicate this thesis to my late Grandmother Bakaka Nkala who, would have been so proud of me if she was here .



DECLARATION

I, the undersigned, hereby declare that this mini-thesis is my own work and that I have not previously submitted it to any other university for a degree. All the sources that I have quoted have been indicated and acknowledged by means of references.

Signature _____ Date _____



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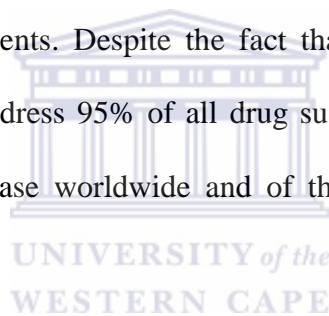
LIST OF ABBREVIATIONS/ACRONYMS

AIDS	- Acquired Immune Deficiency Syndrome
ART	- Anti Retroviral Treatment
BCG	- Bacille Calmette Guerin
DNA	- Deoxyribo Nucleic Acid
DOT	- Directly Observed Treatment
DOTS	- Directly Observed Treatment Strategy
GACVS	- Global Advisory Group of Experts
HIV	- Human Immunodeficiency Virus
MDGs	- Millennium Development Goals
MDR-TB	- Multi-Drug Resistant Tuberculosis
Mtb	- Mycobacterium Tuberculosis
NIAID	- National Institute of Allergy and Infectious Diseases
NSP	- National Strategic Plan
SADoH	- South African Department of Health
SAGE	- Strategic Advisory Group of Experts
SANAC	- South African National AIDS Council
TB	- Tuberculosis
WHO	- World Health Organisation

CHAPTER 1

1.1 Introduction

It is well established that tuberculosis (TB) is a common public health problem faced by many countries. The burden of TB is highest in Asian and African countries, but worldwide TB mortality rates have dropped since the 19th century in Europe and North America, partly owing to shifts in civil arrangements: better nutrition, housing, sanitary arrangements and ventilation. Africa accounts for 25% of the TB cases globally (World Health Organization, 2012) hence the focused efforts to combat it. Weis *et al.* (1994) highlight that there is a 95% treatment success rate among patients with drug-susceptible mycobacterium provided they comply with treatment requirements. Despite the fact that first- line TB treatment shows positive results and is able to address 95% of all drug susceptible TB, in 2008 almost two million people died of this disease worldwide and of these, 500 000 were HIV positive (Wingfield 2010).



The World Health Organization (WHO 2013) states that in 2012 an estimated 8.6 million people developed TB and 1.3 million people died from the disease - including 320 000 deaths among HIV positive patients. Considering that TB is preventable, this is a significantly large part of the population and it therefore constitutes a major public health concern. The WHO (2013) reports that although there have been a few successes in the fight against TB in terms of the Millennium Development Goals (MDG) global target of reducing HIV/AIDS, malaria and other diseases, including TB, have not been reached. Many of the strategies are unlikely to be achieved by 2015. This is owing to factors such as resource constraints, conflict and societal instability, as well as the HIV epidemic in Africa. Mortality also remains high owing to poor diagnosis and treatment of Multi- Drug Resistant TB (MDR-TB). Less than 25% of the people estimated to have MDR-TB were detected in 2012 (WHO 2013).

The study focuses on how people in an area where there is high sero-prevalence of the Human Immunodeficiency Virus (HIV) understand tuberculosis (TB). While the general assumption is that there is a link between HIV and TB, this study seeks to understand the ways in which people affected by TB give meaning to their illness in an HIV-prevalent environment. Kleinman (2006) argue that there is a distinction between a disease and illness, the former being the malfunction of biological and psycho-physiological processes and the latter being the personal, interpersonal and cultural reactions to disease. Illness may occur in the absence of disease and this explains why 50% of the visits to the doctor are complaints that have no evident biological basis (Kleinman 2006). One of the issues that may affect treatment choices and actions is the fear of stigmatization – especially in an environment where TB is increasingly understood as being contingent to HIV infection. Thus the research seeks to explore the ways in which people seek treatment and the meanings they give to TB, as well as their lived experiences with this disease.

This research aimed to find out how people who live in an area that has high HIV prevalence understand TB, bearing in mind the relationship between the two diseases and the high rate of opportunistic co-infection. The study also seeks to explore the lives of those who have or are TB survivors in an effort to comprehend what having TB means to them and how they deal with directly observed treatment (DOT). Understanding the meaning that people give to TB might enable policy makers to improve TB treatment and make it more focused on the patient, e.g., by shaping interventions to their experiences with the disease.

1.2 Background to concepts

Tuberculosis, is a communicable disease caused by Mycobacterium Tuberculosis (Mtb). It is transmitted through inhaling air that contains tubercle bacilli (Shrestha-Kuwahara *et al.* 2004). The National Institute of Allergy and Infectious Diseases (NIAID 2012) states that

Mtb is an aerobic bacterium which needs oxygen to survive and for that reason, during active TB disease, nodules are found in the upper air sacs of the lungs. The tuberculosis bacillus gradually hollows out the lung. When a person breathes air that is contaminated with Mtb they may develop a TB infection but this does not necessarily develop into TB disease (NIAID 2012). This (dormant) infection is known as latent TB, which is not infectious. However persons who have latent TB may develop active TB if the disease is triggered, because the immune system has failed to stop the TB bacteria from growing and spreading (*ibid*). TB is an opportunistic disease condition that often manifests in people who have been infected with the Human Immunodeficiency Virus (HIV), or who have Acquired Immune Deficiency Syndrome (AIDS) and whose immune systems are compromised (WHO 2013).

Co-infection means infection with more than one disease at the same time. HIV infection is the strongest of all known risk factors for the development of TB (Sharma *et al.* 2005). HIV increases the risk of the progression of latent TB to active TB by suppressing the immune system responsible for protecting the body. TB/HIV co-infection results in a double burden of disease which means treatment has to focus on managing both diseases at the same time and this creates complications. Because especially HIV/AIDS is often stigmatised, and many people who have tuberculosis also have HIV, TB has become more stigmatised. Such stigma within wider society can be understood as a form of structural violence. This means that social structures can cause harm by e.g. not enabling or even preventing people from meeting their basic needs (Christodoulou 2011). People who are stigmatised because they suffer from a certain disease, are often assumed to have “brought it upon themselves” (e.g. in the case of HIV infection) and this becomes a reason for justifying rejection of those who are stigmatised (Christodoulou 2011). Stigma is therefore a socially constructed phenomenon. Yang *et al.* (2010) explore various definitions of stigma and propose that it encompasses internal psychological processes, interpersonal social processes between individuals and groups, and

large scale processes at cultural or political level. They define stigma as a relationship between an attribute and a stereotype. It could be a physical blemish, a functional impairment or a disturbing psychological trait that taints a person (Yang *et al.* 2010).

In this regard it is of importance to understand that most people tend to prefer to identify with TB rather than with HIV because TB is thought to be transmitted 'naturally' but HIV is associated with sexual behaviour and thus the individual is subjected to judgment (Wood *et al.* 2011). Nevertheless many sufferers do not want to be associated with TB either -because people may conclude that they are HIV positive. In Khayelitsha, for instance, Wood *et al.* (*ibid*) found that people disclose their TB status rather than HIV infection because in the area it is more acceptable to have TB. Those who are co-infected with both are faced with a dilemma of disclosing that they have TB and arousing suspicion of their HIV status and this affects the outcome of health interventions.

There is concern over the association that TB has with HIV; not only in terms of co-infection but also in terms of how people understand the relationship between HIV and TB. It is assumed that the boundary is blurred and this has led to many myths attached to TB. Wood *et al.* (2011) assert that in 2007, South Africa was the region with 25% of all global HIV-related TB infections.

Abney (2011) argues that in Khayelitsha many TB patients do not disclose of their own accord that they have TB because of the associated risk, fear and anxiety associated with disclosure to family and friends. Even though TB can be treated, such complexity reinforces the need to make TB interventions not only biomedical but socio-economic as well, in order to achieve better results. Stigma is worsened when one who is suffering from TB is associated with conditions that are already stigmatised, such as poverty, drug use, poor living conditions and other aspects that lead to marginalization. Policy efforts to integrate TB and

HIV treatment may have unintended consequences, which will result in even further stigmatization of patients (Pebody 2012).

Discrimination is closely related to stigma, e.g. when a person is treated less favourably because (s)he suffers from a particular disease (Baral *et al.* 2007). It may also take the form of self-discrimination, when an individual feels unworthy or guilty, and this results in isolation and depression. Stigma results in discrimination and singling out of persons based on a disease that is socially regarded as undesirable due, e.g. to its perceived contagiousness or linkage to 'immorality' (*ibid*).

Illness experience is defined as the socially constructed meaning that people give to disease and how they manage it in the social and cultural context of the patient (Conrad and Barker 2010). Illness experience explores how individuals make sense of their illness and how they cope with physical and social restrictions. Ellis *et al.* (1997) explores dimensions of viewing diseases, namely the biomedical and the socio-medical. The former deals with the diagnosis and treatment of a disease whereas the latter focuses on the experience of patients and their understanding of a disease. The sick individual's behaviour can be altered by a disease label (e.g. AIDS, leprosy, schizophrenia) as they identify and live with their disease (Conrad and Barker 2010). Illness experience also encompasses the embodied sense of feeling unwell such as tiredness, discomfort and general depression.

1.3 Tuberculosis Globally

Nearly 20 years after the WHO declaration of TB as a global emergency, the fight for its eradication still requires a great deal of research to devise new and more effective ways of combating it. Baltussen (2005) refers to TB as reaching epidemic proportions due to its co-infection with HIV/AIDS as well as the rise in drug resistant strains of TB. If it is left

untreated, it causes the patient to lose weight, become weak and eventually waste away and ultimately die (Ryan 1993). This research seeks to contribute to knowledge on TB, focusing on an area that has a high TB prevalence namely Gugulethu (Lawn *et al.* 2010). While there are global and national policies that guide the fight against TB, it is necessary to consider that in different settings disease may be understood and responded to by the sick in a variety of ways. In the case of Gugulethu, the healthcare facilities are good and accessible without discrimination.

Cases of failure in treatment are usually the result of non-adherence, drug resistance, relapse or non-completion of a therapy regimen (Weis *et al.* 1994). Weis *et al.* (1994) argue that demographic factors such as age, sex, racial classification, marital status, education level and socio-economic status are not related in any way to the degree to which patients adhere to treatment. Research concludes that by the time non-adherence to medication is detected, drug resistance or the further spread of infection may have occurred and this contributes to the challenges faced in efforts to eradicate TB. There is also a need to recognise behavioural change as a key element in the fight against TB. Not only is integrating treatment for TB with treatment for HIV paramount, it is necessary to employ measures that prevent new infections through practising a lifestyle that minimizes the risk of infection. In an ideal setting, effective treatment combined with a reduced number of new infections will result in a lower mortality rate. In reality however, creating an environment where TB can be contained is not as easy as it may seem. Places such as townships are already affected by underlying socio-economic factors that can affect TB, but which cannot be easily changed. This research seeks to identify those factors and by so doing, highlights the social structures that policy makers can be aware of and incorporate in their efforts to fight TB.

As mentioned, TB is both a socio-cultural disease and a biomedical one. There is a possibility that caregivers may focus on the biomedical dimension, i.e. the disease (and excluding the

illness, or personal experience of the sickness condition) of the treatment while patients may be more concerned with the socio-cultural aspect of it and how they understand and experience the illness (Ellis *et al.* 1997). It is important for patients and caregivers to have an understanding of both dimensions because a lack of knowledge of either decreases the chances of intervention strategies being successful. By paying attention to people's understanding of TB, the research takes into account the role of human agency in the outcomes of disease control interventions. Knowledge on what people understand about TB and their experiences with the disease gives insight into the burden of the disease from the patients' standpoint.

Disease causation, treatment and non-adherence can be understood in the context of the social environment of the patients, which entails beliefs, living conditions, political and economic conditions as well as the nature of the community health service in place (Ellis *et al.* 1997). Social scientists state that it is imperative to link TB to its social context. For this reason they argue that combating TB requires social reform. Improved nutrition, better sanitation and better housing are measures that can be taken in order to reduce the disease (Feldberg, 1995). In addition to that, patients could play their part and take medication consistently and correctly. In essence, this means that biomedical responses will be met with socio-medical factors that cannot be ignored when dealing with disease treatment because these determine how well the intervention programmes are received and used. The argument that underpins this study is that TB interventions could potentially be improved by understanding its impact on the lives of sufferers.

1.4 Contextualising the study

Historically TB was known as a disease ‘independent’ of any other diseases. Initially named consumption it was the iconic disease of the 19th century, displaying a high correlation with poverty and poor living conditions. It is estimated that 75% of TB infections affect people during their most productive time between the ages 15 and 54 years (Global Alliance for TB Drug Development 2013). In addition to the physical impact, TB has economic and social consequences (Brncik 2010). In the past individuals who had been diagnosed with active TB were sometimes quarantined to prevent the disease from spreading. This also affected their work as they could not be productive during this period (Brncik 2010).

In most instances, TB is an opportunistic disease and in cases where one’s immune system has been weakened, the disease is often fatal (Brncik 2010). There has been an emergence of TB which is associated with HIV and this relation between HIV/AIDS and TB has led to difficulty in viewing the epidemiological profiles of the two diseases as distinct (Draper *et al.* 2007, Cramm and Nieboer 2011). Currently the stigma associated with TB is reinforced by its relation to HIV/AIDS, which research has shown can be highly stigmatizing; a lack of knowledge and perceived contagiousness also contribute to the stigmatization of TB patients (Courtwright and Turner 2010, Cramm and Nieboer 2011, Abney 2011).

Draper *et al.* (2007) identify Gugulethu as one of the TB ‘hot spots’ in the Western Cape Province. Other high prevalence areas are Nyanga, Delft and Mfuleni. Research done in an Anti-Retroviral therapy (ART) clinic in Gugulethu showed that more than half of the patients had had one or more cases of TB before seeking treatment and two thirds had TB before or during the time of the research (Churchyard and Eldred 2009). This in itself raises questions as to why people delay to seek treatment when there are available healthcare facilities in the area. In the township, the TB incidence among people who are taking Anti-Retroviral drugs

(ARVs) had decreased by 80% but it remained stable among those who are HIV negative and those who are HIV positive but not on ARVs (Wingfield 2010). This shows that ARVs for people infected with HIV can have an impact on the reduction of TB incidence. For this reason, among others, the fight against TB and HIV has been integrated. In this research the relationship between HIV and TB from the point of view of the people of Gugulethu, was explored as their understanding of this link had an impact on their experience with TB illness.

The National Strategic Plan to combat HIV, Sexually Transmitted Infections (STIs) and TB 2012-2016 (published in 2011) outlines four main objectives that guide the fight against HIV and TB. The focus is on preventing new HIV, STI and TB infections, sustaining health and wellness, increasing protection of human rights and increasing access to justice while also addressing social and structural barriers to HIV, STI and TB prevention, care and impact. The NSP guides programmes and strategies such as Directly Observed Treatment Strategy (DOTS) which incorporates the above-mentioned aspects in its implementation plan.

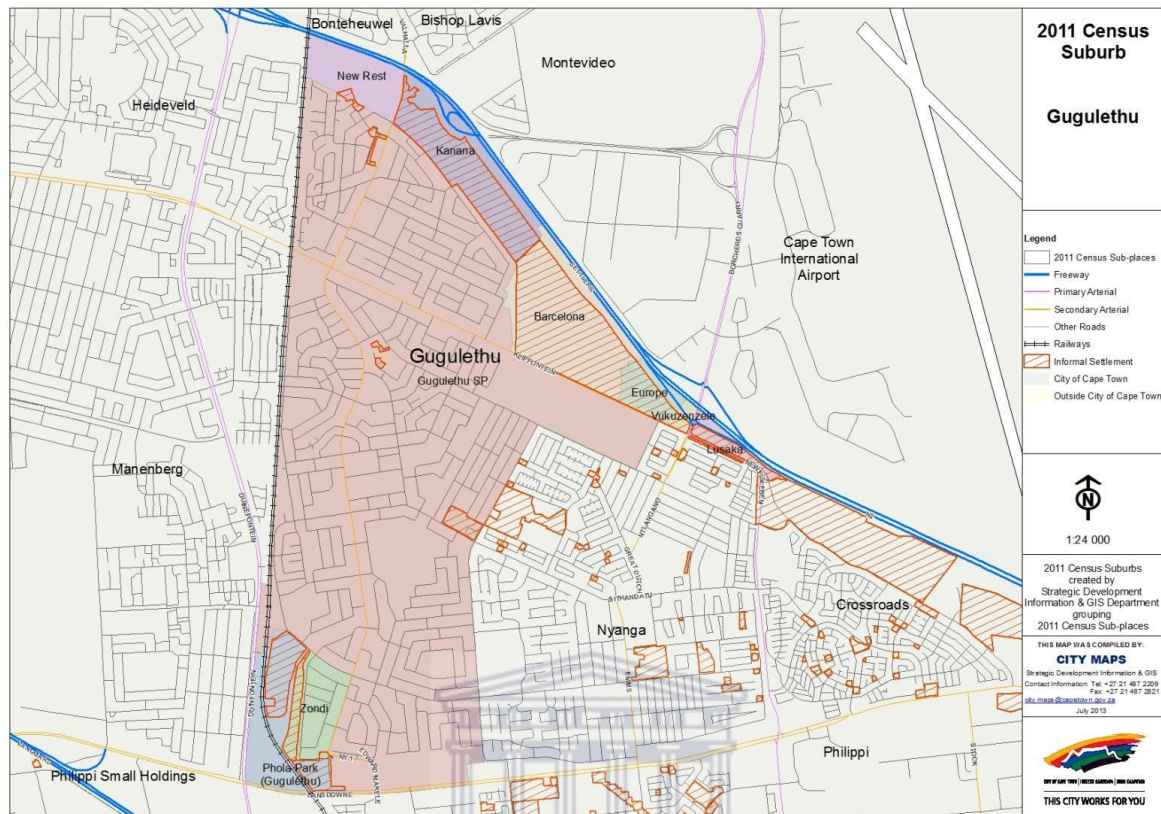
The World Health Organization (2009) showed that an increasing number of TB infected people have access to high quality anti-TB treatment and related interventions such as Anti-Retroviral Therapy (ART); however, up to 96% incident cases of Multi-Drug Resistant Tuberculosis (MDR-TB) are not diagnosed and treated according to international standards. One gap pointed out by WHO (2009) was that the majority of HIV-positive TB patients did not know their HIV status and the majority of HIV-positive TB patients who know their HIV status, did not have access to ARV drugs. As a result, it became apparent that it was essential to fight TB and HIV simultaneously. Even though studies such as these are important in coming up with trends of diseases, they lack detail in explaining factors that influence the spread of HIV/TB which are specific to each demographic location in order to implement TB control mechanisms designed specifically to address the concerns of each area.

The Western Cape Government (2014) states that the Western Cape still has one of the highest burdens of TB in the country. Although the province also has the highest TB cure rate in South Africa, the high risk of new infections still poses a serious challenge. The Western Cape Minister of Health has expressed concern about the confined environments and poorly ventilated dwellings which increase the risk of contracting TB in townships in particular. Gugulethu is no exception in this regard, and will be discussed next.

1.5 Profile of Gugulethu

The research was set in a township which is defined by Statistics South Africa (SSA 2004) as an urban residential area which was originally created for black migrant labourers to live outside the city (Draper *et al.* 2007). It was conducted in the areas known as Gugulethu Seven, Langelihle, Kanana, Barcelona, Gugulethu SP and New Rest. Entry into Gugulethu was gained through a community member called Mzi who showed me around and who was my research assistant throughout my fieldwork. Mzi introduced me to a few participants with whom I was able to interact prior to conducting my in-depth interviews. They in turn referred me to others suffering from or who had suffered from TB. I thus used a snowball sample method to find research participants.

Figure 1: Location of Gugulethu Township



Source: City of Cape Town, 2013



Gugulethu is located 18km south-east of Cape Town (Figure 1) in the Western Cape Province (South African History Online, SOHO). Results from the 2011 census show that Gugulethu has a population of 98 468 (City of Cape Town, 2013) and 99% of the population is African. The township has a hospital and a clinic called Vuyani, which serves as a treatment centre for TB patients and there is also a private surgery that belongs to a medical doctor who resides in the area.

The name Gugulethu is of Xhosa origin. When translated into English it means ‘our pride’. The township is a remnant of the apartheid era and the infrastructure is typical of what is termed the Cape Flats townships. There are narrow roads that are tarred but they are damaged and deteriorated and have many potholes. The township has some dilapidated buildings made

of bricks, plus some flats that were being renovated during our research, while inhabitants had been relocated to another informal section of the township where the shacks were made of corrugated iron sheets as shown in Figure 2 and 3.

Figure 2: Gugulethu housing



Source: Washburn, 2011

Figure 3: Overcrowding and poor living conditions



Source: Pettersson, 2010

Figure 4: Poor sanitation and waste disposal



Source: Bearak, 2010

There are many informal dwellings and small ('spaza') tuck shops in most corners of the township. In the informal settlements in particular, sewage runoff has created streams that run parallel to some of the roads (Figure 3). Where there are small clearings these serve as places for garbage disposal, which has accumulated over a period of time. At frequent intervals between the houses there are alcohol outlets also known as shebeens where people meet to socialize and have drinks.

The setting was ideal for this research as it is one of the oldest townships of the Western Cape; hence it illuminates the lived experiences of having TB in South Africa. Like many other townships in the country, Gugulethu is faced with social problems that include poverty, unemployment, poor housing and poor sanitation. According to Statistics South Africa (2013) the census conducted in 2011 revealed that 60% of the people ages between 15 and 49 are employed, 58% of households have access to piped water in their yard and 52% of households live in formal dwellings. The living conditions and economic situation reinforce health concerns, with TB and HIV causing the most concern.

1.6 Methodology

According to Babbie and Mouton (1998) qualitative research designs should give evidence of engagement with the participants. The design should show a selected representative population to be studied with evidence of a number of data sources. Qualitative approaches were used combining secondary and primary data collection techniques. Secondary data was collected through the review of literature on TB. Primary data was obtained from the participants selected for the study. Participants were obtained using snowball sampling (Maree 2007) where the researcher uses the relations that have been established (in this case in Gugulethu) to engage other participants who contribute to the study.


The research made use of in-depth interviews, narratives and structured interviews, which allowed for probing to elicit further responses to the questions. The researcher also had the opportunity to observe some of the participants and understand the typical day of the TB patient. A total of 18 participants were used for the research, a number determined by available time and resources. Interviews were transcribed and combined with field-notes. Then a content analysis was done through coding data developing analytical themes and a wider framework for further analysis.

My proficiency in isiXhosa made interviews easier to conduct. Most of the study participants were in their mid to late 30s and in their 40s. As a result the illness experiences of young people with TB were not documented. Nevertheless, the data collected was sufficient to provide insight into how people in Gugulethu deal with the burden of TB.

1.7 Justification

This study seeks to contribute to existing knowledge on TB and people's own understanding and experience of living with it for the duration of their treatment. Whilst there have been many studies on TB in South Africa, the current literature is mainly based on awareness raising and biomedical intervention, with less focus on personal understanding of TB. People's own experiences in relation to TB underpin the motivation for this study in Gugulethu township (Draper *et al.* 2007). The study aims to find the meanings people attach to TB, to what extent the disease is stigmatised and where this is the case, how this determines the responses of the sick to intervention strategies.

1.8 Problem Statement



Thanks to health promotion education there has been an increase in TB awareness measures but it is still a matter of concern in South Africa that TB persists at high levels despite the availability of effective control measures. In 2011 there was an estimated 1.1 million HIV positive new TB cases globally and around 79% of these were diagnosed in sub-Saharan Africa (WHO 2013). Research shows that TB is more serious than other opportunistic diseases for people with HIV since it (TB) occurs at all levels of Cluster Difference 4 (CD4) count (Badri *et al.* 2002). CD4 cells are part of the body's infection fighting system. Without strict adherence to treatment, TB is fatal in such cases. This research is important because it explores dimensions outside the biomedical sphere in an effort to understand how people interact with TB in order to contribute to knowledge that can be used to improve adherence to treatment.

Despite intensive research into the pathology and epidemiology of TB in at-risk populations, less has been done to explore the social drivers of TB transmission and acquisition, in

particular among South Africa's TB-endemic populations. Areas with high HIV infections invariably have high TB infections, exacerbated in townships by poor housing, overcrowding and poor ventilation, compromised food security, low incomes and practices such as communal beer sharing/drinking. The research highlights the meanings that people attach to TB. It explores the illness experiences of patients and illuminates how they deal with the burden of the disease in an environment that is TB endemic. Understanding their experiences could assist in identifying the areas that can be addressed in order to reduce the burden of disease on the patients – although many of these do not fall within the ambit of the health care services *per se*.

1.9 Research Objectives

1. To establish the meanings people attach to TB.
2. To explore people's experiences of TB.
3. To investigate treatment-seeking behaviour among TB patients in Gugulethu.

1.10 Research questions

1. How do people understand TB and its etiology in a time of high HIV-prevalence?
2. What meaning do people attach to TB in an area with a high HIV burden?
3. Is TB stigmatised and if so, why and how?
4. How do people make sense of and interact with the strategy of Directly Observed Treatment (DOT)?

1.11 Ethical considerations

This study was conducted after the proposal had been submitted and approved by the Post Graduate Board of Studies and the Senate Higher Degree Committee of the University of the Western Cape (UWC). The researcher upheld all the ethical considerations. Participants were informed about the objectives of the research and given consent forms drafted by the researcher and approved by the supervisor and the Senate Ethics Committee. These were signed by respondents to show that they were aware of what the study was about and as a guarantee of confidentiality between the researcher and the participants.

The researcher used pseudonyms to protect the identity of the participants. The data was safely stored and only the researcher had access to the information. Participation was voluntary and those who felt they could no longer participate were free to withdraw without a penalty, at any stage of the research. Observation entailed spending the day with the participant but they were free to say if they were not comfortable and felt their private space was being invaded, and the researcher did not impose on them. In order to make participants feel more comfortable and eliminate possible power dynamics, the researcher paid frequent visits to the participants and interacted with them. Where it was found that questions rekindled memories and disturbed the participants while they were narrating experiences the researcher did not persist, to avoid harm.

Research participants were assured that the research was purely for academic purposes and if it was published, their anonymity would be protected. No money was used to persuade the participants to be part of the research. Thirteen of the eighteen participants were TB survivors and five were still on TB treatment, and the researcher conducted the interviews during the day to minimize inconvenience.

1.12 Limitations of study

Due to the sensitive nature of the research, participants may not have been entirely open about their experiences and feelings. This small qualitative study cannot be generalised to the wider population, but can give some important insights for future study and consideration.

1.13 Chapter summary

Chapter two focuses on the review of literature on related research done in other communities. The literature is related to TB and how some societies give meaning to the disease. It also incorporates different factors that hinder the success of TB treatment. This chapter includes issues that deal with the relationship between HIV and TB and how people make sense of the two diseases, and discusses the relevant theoretical framework used to explain the importance of studying TB in a social context apart from the biomedical views.

Chapter three presents the relevant research methodology that was used in this study. This chapter outlines the method of data collection and collation, with an explanation of how the data was analysed.

Chapter four presents and discusses the themes that emerged from the data that was collected and analysed. It relates the findings to research in other communities that are relevant to the study.

Chapter five draws conclusions on the research and questions whether the objectives of the research were achieved. It also provides recommendations based on perceived gaps that were identified during this research.

Chapter 2: Literature review

2.1 Introduction

This chapter outlines the history of tuberculosis in public health literature and show why it has become a major concern especially in South Africa, and more specifically, in Gugulethu Township. It explores the complexities that HIV adds to TB management and how the understanding of this TB/HIV relationship of the sick and the healthcare providers is shaped by social and cultural factors. It is paramount for those who are infected with TB to have a full understanding of TB as a disease: this knowledge determines the extent to which they conform to the requirements of treatment. This chapter looks at some factors that make TB difficult to manage despite the availability of medication and the Directly Observed Treatment (DOT) strategy under the Stop TB partnership programme. The purpose of this chapter is to show that TB management is more than just the availability of adequate treatment. An insight into the lives of TB patients could be helpful in comprehending the burden of TB on them and hopefully encourage advocacy for equal attention of a social approach in disease control and management

2.2 Old disease, new trends

Daniel (2006) traces the origins of TB to some 15 000-20 000 years ago in East Africa. According to the author (2006), there is not much written historical evidence of the disease but traces of TB strains can be found in skeletal remains and mummies in Egypt, which provide more solid evidence of deformities that resulted from TB infection. Historical evidence of TB exists in other parts of the world as well, such as Greece, America and Europe (Daniel 2006). In Europe and North America TB was associated with the poor conditions that existed during the industrial revolution (Murray 2004). There was

overcrowding, poor nutrition, lack of hygiene and poor sanitation. Murray (2004) proposes that at the end of the eighteenth century in England, one of every four deaths recorded was the result of tuberculosis.

In current literature, it is recognised that social and economic inequality also contributes to TB prevalence (Farmer 1997). This determines not only the distribution of infectious diseases but also the health outcomes of the afflicted (Farmer 1997). Analysing South Africa from this point of view may explain why TB is highly prevalent in townships where poverty and HIV prevail. The decline in TB in Cape Town in general was probably related to improved living conditions (Murray 2004) but this is not the case in Gugulethu. Murray (*ibid*) argues that the fight against TB not only entails dealing with medical aspects but also tackling the underlying conditions that lead to an increase in TB.

In South Africa the rise in TB infection can be traced back to the colonial era when missionaries, settlers and colonialists arrived in the country already infected by the epidemic that had swept through Europe and North America (Edginton 2000). Industrialisation and urban growth encouraged the spread of TB (Packard 1989) especially among black Africans due to their lack of previous exposure to the disease which made them more susceptible to it. As far back as the Anglo Boer war and the creation of Union in 1910, poor living conditions, as people crowded into the newly created locations, became 'breeding spaces' for TB. Water and sanitation were compromised by the rapid growth of urban areas following the 1960s and these conditions combined to fuel the spread of TB.

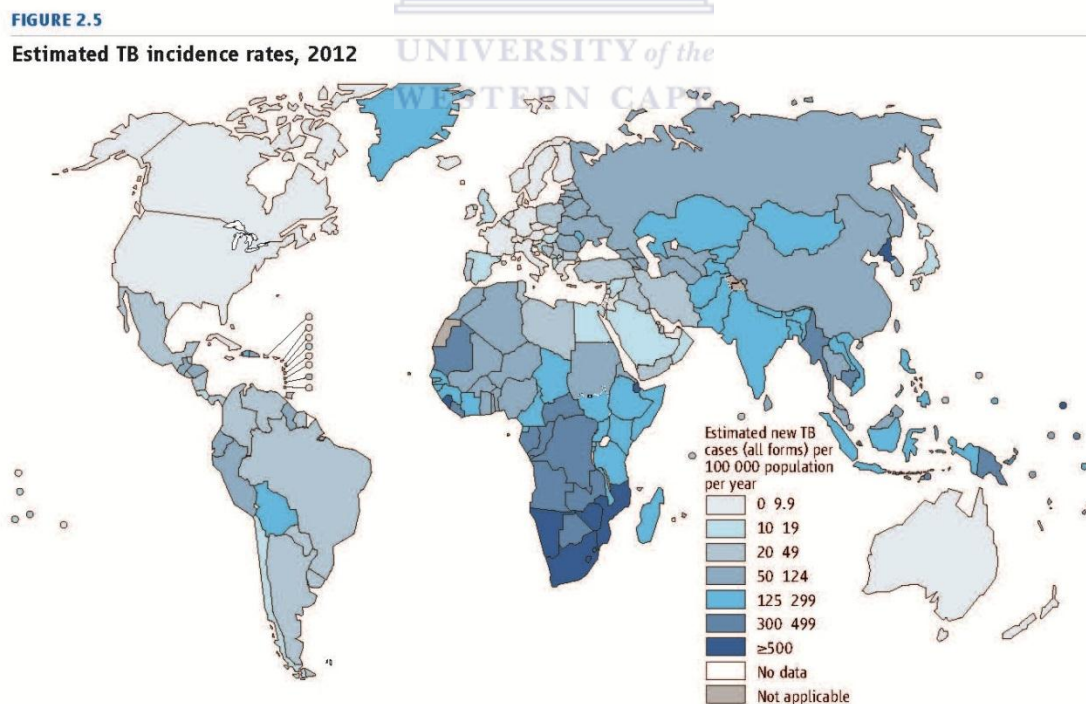
The mining community has long been associated with various lung diseases, among them TB (AIDS and Rights Alliance for South Africa 2008). The mining industry in South Africa accelerated the spread of TB due to the working conditions such as poorly ventilated work and living areas, high population density in living quarters and more recently, high rates of

HIV. In the past prolonged exposure to silica dust resulted in high prevalence of silicosis, especially in gold mines, and this became another major factor that contributed to the increase in TB disease (Edginton 2000). When miners became sick, they returned to their homes and interacted with their families and community members thus spreading TB. Not only did this lead to increased TB prevalence in South Africa but it spread to other countries such as Lesotho as a result of migrant labour (AIDS and Rights Alliance for South Africa 2008). TB triggered by silicosis is still prevalent in the mining sector (Roberts 2013).

2.3 Tuberculosis in South Africa

There is evident success in TB treatment in the South Africa; however, the rate of transmission remains very high.

Figure 5: Estimated global TB incidence rates, 2012



Source: World Health Organisation, 2011

Figure 5 shows that in 2012, South Africa had among the highest estimated TB incidence rates on a global scale, with an estimated 500 or more new TB cases of all forms per 100 000 population per year. Countries such as Zimbabwe, Mozambique and Namibia were estimated to have similar TB incidence in 2012. In South Africa TB is more prevalent in townships compared to other parts of the country (Wood *et al.* 2011). This is because of high population densities, poor living conditions and high HIV prevalence. High sero-prevalent pockets in the Western Cape region have a high rate of HIV-positive individuals among whom there is a high probability of TB occurrence (Draper *et al.* 2007). The province also has a vulnerable population of HIV-negative people who live in disease-burdened and socio-economically deprived conditions and Gugulethu is no exception (*ibid*).

The South African National AIDS Council (SANAC) identified certain key at risk TB populations in South Africa (SANAC 2013). These populations include health care workers, miners, prisoners and prison officers. There are also some groups who are more likely to develop TB disease from latent TB and among these there are children, people with HIV, smokers, substance abusers, migrants from South Africa's rural areas and people who suffer from malnutrition (SANAC 2013). Smoking is more common among men as well as women in the Western Cape than any other area of the country. This too results in increased vulnerability to TB in the province (*ibid*).

There are social and economic factors that determine the well-being of individuals. In this regard Bekker and Wood (2010) stress that urban growth has led to population growth in townships, with the majority of the people being of low income status. They estimate that 61% of South Africans are urbanized and 57% of these persons live in slum conditions where the HIV and TB burden is greatest. The general assumption is that people who live in poverty have a higher burden of disease than those who do not and for this reason, the WHO (2005) proposes the need to fight this disease through promoting equity, in addition to various other

strategies that may be implemented. This approach cements the idea that the fight against TB is more than just a biomedical one. The idea behind promoting equity therefore is to implement a strategy that is more pro-prevention rather than depending on treatment. Poverty if not addressed, becomes a barrier to TB control and prevention therefore it is important to explore its role in fuelling TB.

2.4 Tuberculosis (TB): A disease of poverty

There exists a symbiotic relationship between poverty and TB. Not only does poverty lead to an increase in TB infection, TB also reinforces poverty (Grange and Zumla 1999). One of the consequences of poverty is poor health – which in turn affects unemployment. Grange and Zumla (1999) argue that poor people not only suffer financially but also from human resource poverty. They are deprived of education and resources that would enable them to gain adequate health and well-being. TB control requires financial and material resources. Besides the political will to enforce socio-economic policies, the government needs to find ways to ensure access to good nutrition – especially for those who are diagnosed with, e.g. TB. The Directly Observed Treatment (DOT) programme requires patients to visit the clinic and take medication under observation. They thus also have to be able to get to the clinic or hospital for the duration of their treatment and this may require money for fares.

Farmer (2001:199) gives a comprehensive account illustrating the impact that poverty has on tuberculosis treatment in a research done in Haiti. The author argues that in TB treatment, the agency of patients is exaggerated. Farmer (2001) gives an example of a patient who upon being diagnosed with TB, is instructed by a doctor to drink clean water, eat well and to sleep in an open room away from others in order to facilitate his recovery and to avoid spreading the disease. The patient was unable to ‘comply’ with the doctor’s instructions because he lacked the means to improve his diet, to find an alternative source of clean water or build an

extension to his house, away from others and with better ventilation. Through this situation, Farmer shows that TB treatment does not illustrate awareness of the effect of social structure on agency; it ignores the question of the patient being able control his environment. Where poverty and deprivation exists, these dynamics may hinder the implementation of the DOT programme and thus makes TB control more difficult.

May (2010) explores the dynamics of poverty in South Africa and argues that there is no simple solution to its eradication. There are, however, strategies that can be put in place to reduce poverty. Economic growth has thus far failed to translate into what can benefit those who need it most. Suggested solutions to poverty include improved service delivery and infrastructure development through decentralised local governance, the provision of social grants, redistribution of assets such as land and investment in education (*ibid*). Some of these solutions would only have short-term effects but others strategies such as education are long term. May (2010) mentions HIV as a constraint to achieving poverty reduction because research has shown that the effects of HIV-related illness and death of income earners include a decrease in household income and consequently a reduction in people's ability to deal with illness. As such, TB is an opportunistic HIV-related disease that has a similar impact on poverty. There is increased expenditure on health, money which would have otherwise been used on other household necessities.

The WHO (2013) estimates that on a global scale lower middle income countries account for more than 90% of TB cases and deaths, and 76% of the world's population lives in these countries. Low income countries with 42% of the world's population account for 65% of TB cases and 71% of deaths from the disease (WHO 2013). These statistics underline the relationship between poverty and the burden of TB. Spence *et al.* (1993) state that even historically, TB has been associated with high levels of poverty. They propose that poverty results in poor nutrition and a compromised immune system, which makes one vulnerable to

disease-causing organisms, such as mycobacterium tuberculosis. Overcrowding is one of the characteristics of poverty mentioned by Spence *et al.* (1993) which results in living conditions that increase the risk of transmission. Poverty also exposes people to other risk factors including pollution, risk behaviour, HIV, lower levels of awareness, lack of basic health services, poor water and sanitation; all of which contribute to the spread of TB and add to the difficulty of controlling it.

Not only does poverty influence TB, the disease results in increased levels of poverty. It leads to poor health, which in turn aggravates poverty and reduces human productivity (Murray 2010). The WHO (2013) states that the burden of TB takes up US\$12billion from the incomes of the world's poorest communities every year and this causes a massive strain on national budgets and patterns of expenditure. High TB incidence means an unhealthy labour force, a strain on limited health services and shackled economic growth (WHO 2013). Murray (2010) says that in poor countries, 17% of those who die of TB belong to the economically productive age group of 15-49 years. He states that the main reason for death among this age group is poor adherence to treatment due to competing priorities such as the need to earn a living and substance abuse as a coping mechanism. Studies also show that the average TB patient loses three to four months of work time per year and earnings drop by up to 30% of annual household income (WHO 2013). Not only does this affect the patient, it can also affect the person's dependents and have an impact on the work output of the patient as an employee.

As part of TB alleviation intervention, scholars advocate poverty reduction as a strategy (Murray 2010). The WHO (2013) proposes that countries focus on poverty alleviation and channelling the flow of resources from high income to low income countries, thereby ensuring the dual fight against poverty and TB. Murray (2013) however states that according to the WHO, poverty is viewed as a barrier to successful implementation of TB programmes

and not necessarily a direct cause of TB. The author argues that such vague conclusions affect the way TB strategies are designed because policies connecting poverty and TB remain unclear. As a result interventions continue to concentrate more on service delivery than poverty alleviation as a TB control strategy. Sometimes, however, there is need for immediate relief and intervention which may not be very sustainable and one such example is that of economic support.

2.5 Economic support as a solution: Case study of South Africa

Russel (2004) proposed that ill-health contributes to impoverishment. Household assets become depleted; income and assets are lost, resulting in a decrease in consumption to levels that are below minimum needs. Russel (2004) argues that the costs that people incur due to illness are central to healthcare interventions. Even if health services are free, indirect costs are incurred and households have to come up with means of dealing with the shock of this vulnerability. Often, assets are sold and resources are borrowed from friends, relatives and money lenders and this increases household poverty and vulnerability.

Russel (2004) similarly calls for health policies that can protect households from all illness costs. He proposes that focusing on disease prevention is paramount to disease control but policy makers should recognise the impact of household poverty on disease control and devise measures to protect households from sinking further into poverty due to illness.

There is a general consensus that poverty undermines the health outcome of patients who are on treatment for TB. Poverty also potentially imposes barriers on access to treatment. In South Africa, according to Lutge *et al.* (2014), deprivation is an important determinant of the use of primary healthcare services where TB care is delivered. Research shows that financial constraints are a major obstacle to the completion of TB treatment among patients in South

Africa (Lutge *et al.* 2014). Economic interventions may be one strategy that can be used to address this issue; therefore Lutge *et al.* (2014) conducted a study to investigate the impact of economic intervention on the outcome of TB treatment.

The research was conducted in KwaZulu Natal province in South Africa in a randomized controlled trial on the extent to which economic support - in the form of a voucher - would improve TB treatment adherence (Lutge *et al.* 2014). KwaZulu Natal is one of the poorest provinces in South Africa and it has the highest joint TB and HIV burden in the country (*ibid*). In this research, the trial was conducted in two districts of KwaZulu Natal, namely Uthungulu (a rural district) and eThekweni (an urban district encompassing Durban). The two districts have the 5th and 6th highest incidence of TB in the country respectively, out of a total of 52 districts.

In South Africa, there is an ongoing debate about the provision of social welfare and the provision of economic support to people with specific ailments. There are concerns that if people are provided with such assistance they will behave in ways that ensure that they continue to benefit from the grant. In the case of TB, there is a fear that patients may not take their medication in order to remain ill and continue to receive financial support. Conducting this research was aimed at investigating these issues and concerns (Lutge *et al.* 2014).

Although the results showed that patients who received vouchers had a higher treatment success rate than those who were in control clinics, these results were not statistically significant (*ibid*). This was because of two major reasons: the perception of the nurses that there was inequity in the criteria used to determine the eligibility of patients to receive vouchers and logistical issues to do with voucher administration: which together meant that the results were not accurate. Despite these limitations, the research brought insight into the

provision of financial support as a method of addressing diseases that are of public health concern: in this case, TB.

The above study showed that vouchers were used to benefit not only the patients, because most patients shared them with their families. Lutge and others (2014) state that research findings on conditional cash transfers to patients in Mexico produced similar results, consistent with the social values of the patients. The scholars argue that this sharing of vouchers is also evident in other social grants in South Africa and policy makers should be aware that the material benefits of grants or cash transfers are distributed throughout the household. It would be unimaginable for the beneficiary to keep the benefit to themselves. Lutge *et al.* (*ibid*) suggest that if the value of these financial assistance programmes were larger there would be a chance of them actually improving the nutritional status of other household members but since they are relatively small, sharing them may mean that neither the patient nor their household benefit significantly from the vouchers.

Finally, the authors (*ibid*) argue that public service workers who deliver government services are not passive mediums through which policy or interventions pass from the designer to the recipient. Public service workers constantly interact with community members and sometimes use their own discretion while carrying out their activities. This means that interventions have to take into consideration inconsistencies that may arise as a result of power dynamics. By extension, implementers should actually be considered and involved in the formulation of interventions in order to maximise their fidelity.

Although nurses and TB managers who were interviewed in the study above agreed that financial assistance was needed for successful TB eradication strategies, the managers raised the concern of the money being used for other dependents and the possibility of grants creating on-going dependency (Lutge *et al.* 2014). The researchers raised the issue of the

‘deserving poor’ a term referring to those who are poor and deserve social assistance from the state. These include the very young, the elderly and the disabled. The term suggests that there are some who may be poor but not poor enough to warrant assistance from the government. This becomes a concern in South Africa where current opportunities for formal employment are decreasing and people are unable to work and provide for their needs (*ibid*). Social grants become a crucial means of survival for many and yet they may not be accessible to all, save those who have been classified as ‘deserving’ cases.

The complex interrelatedness of poverty and TB is further exacerbated by the high prevalence of HIV. According to Daftary and Padayatchi (2012) “the burden of accessing dual treatment due to indirect medical costs and job loss, and having to juggle social responsibilities” results in the patients experiencing additional stress and frustration because of their limited access to social assistance. In South Africa, people living with HIV have access to social assistance if their CD4 count is below 350 cell/mm³. Daftary and Padayatchi (2012) note that such policies neglect the financial burden of TB/HIV co-infection and the responsibilities that infected patients are unable to escape from. Despite the availability of health services in South Africa, TB diagnosis is not a very simple exercise and its complexities contribute to the high rate of TB disease.

2.6 Tuberculosis Diagnosis

South Africa declared the need to fight TB by improving aspects of TB screening, prevention, access to diagnosis and treatment of drug susceptible and drug resistant TB in the extensive National Strategic Plan of South Africa (SANAC 2011). This is also being done through integrating TB and HIV services, in line with the global plan to curb TB. Effective drugs for TB have been available since the 1940s but an estimated two million people die of TB each year, with the highest number of deaths in low income countries (Volmink and Garner 2009).

Treatment takes six to eight months and this is one of the reasons why people fail to adhere to it. Failure to adhere to treatment results in a relapse of TB, drug resistance, prolonged infection and death (Volmink and Garner 2009).

TB diagnosis is expensive and for this reason, one has to undergo screening by answering questions that may indicate whether the individual possibly has TB (Bonet 2005). There is a chance that these questions may eliminate an individual who in fact needs to undergo testing. It is difficult to diagnose TB in children because often they are unable to cough out the sputum needed for the tests (Bonet 2005). The sputum test is designed to detect signs of TB in the sputum but frequently, especially in HIV positive TB suspects, patients would have developed some types of TB that are difficult to detect using this method (Bonet 2005). Diagnosis may require even more expensive testing methods such as the use of x-rays. Sputum negative results may cause delay in treatment until the patient is tested and diagnosed using other methods.

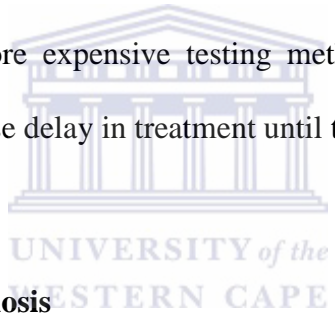
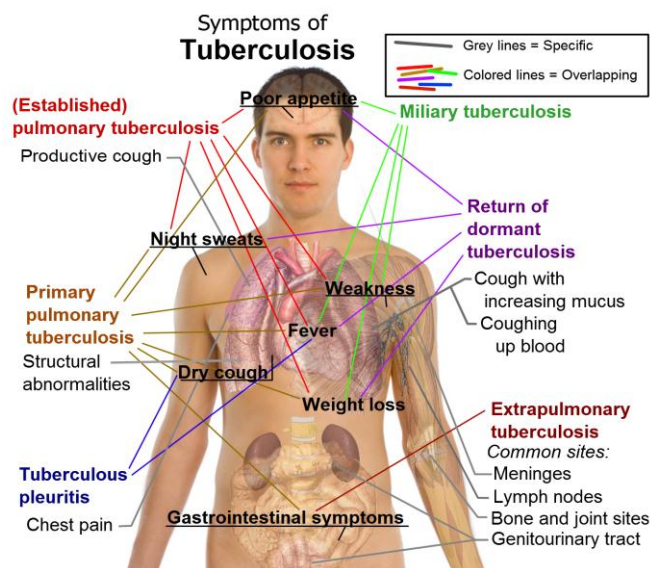


Figure 6: Symptoms of tuberculosis



Source: Vella, 2014

There is constant need for improved ways of diagnosing and treating TB that are more effective than those that are already available. Figure 6 shows TB symptoms and the areas of the body where they may be experienced. Not all symptoms are specific to certain types of TB but some such as coughing, lymph nodes and chest pains may overlap and appear in more than one type of TB. There are various tests that can be done to diagnose persons suspected of having TB and these include skin tests, chest x-rays and sputum tests (Evans 2011). These tests are usually done in conjunction with each other because one test may not necessarily reveal a person's TB status. In this regard Evans (2011) gives an example of the weakness of a sputum test, which may necessitate other methods of diagnosis. A sputum sample when examined under a microscope may not indicate the presence of TB bacteria but other symptoms may arouse suspicion that there is TB. In such cases, based on the person's history and exposure to TB, doctors may decide to conduct x-ray examinations. Evans (2011) argues that there is improved technology in TB testing which involves the use of Deoxyribo Nucleic Acid (DNA) but these are very expensive at present and using them in high-incidence populations such as South Africa would not be practical.

Studies show that most people are aware of TB and its symptoms but rarely take the initiative to seek a medical opinion when these signs are noticed (Liefoghe *et al.* 1997; Ngamvithayapong, *et al.* 2000). In countries such as Botswana and in Kenya, for instance, research showed that people understand the symptoms of TB but often do not deal with these in time, or seek medical help at all. As a result treatment becomes complicated because it is affected by the social matrix and other factors that may not be understood universally but make sense in the context of the respective local socio-cultural settings. As a measure to reduce morbidity and mortality, the WHO has recommended a standardised strategy as a TB control intervention in order to eradicate the disease on a global scale (Stephens 2011). This strategy is known as Directly Observed Treatment Strategy (DOTS).

2.7 Directly Observed Treatment Strategy

The WHO (2005) identifies Directly Observed Treatment Strategy (DOTS) as an effective way of treating TB. It entails political commitment to make available resources, access to sputum tests for TB suspects, standardized treatment under direct observation, and a free supply of drugs for all TB patients, as well as an effective monitoring and evaluation system. Bacille Calmette Guerin (BCG) is a vaccine given to children in order to boost their immunity to TB and this is a preventative measure to reduce TB infection. Donegan (2000) notes that BCG protection against TB varies from 0% to 78% effective. Research shows more success in the developed world than in developing countries leading to the conclusion that the vaccine does not work well where it is needed most, hence the need to combine proactive efforts with strong reactive ones.

In South Africa, research shows that the BCG vaccine- when given to HIV-infected infants at birth - may have some adverse effects (Hesseling *et al.* 2009). The Western Cape recorded 6% of children enrolled in a public access HIV-treatment programme as having experienced adverse effects from BCG. For that reason the Global Advisory Committee on Vaccine Safety (GACVS) and the Strategic Advisory Group of Experts (SAGE) recommended that BCG should not be given to HIV-infected infants even in areas of high TB prevalence (*ibid*). This revised policy presented complications in the fight against TB because in South Africa, HIV-exposed infants have a high risk of exposure to TB in their early lives (Hesseling *et al.* 2009).

A study conducted by Balasubramanian *et al.* (2000) in India on whether direct observation does indeed take place as required by the policies embodied in the DOTS programme, showed that although India does apply the DOTS programme as a strategy for TB eradication, more than a quarter of the patients in the programme did not receive treatment

under observation. Instead, they were given a supply for self-administration and instructions on how to take the medication. Health workers admitted to recording that the treatment was taken under observation even when it was not, most commonly for fear of stigma. Patients perceived a lack of confidentiality in the programme and feared that they would be stigmatised by community members. This fear came up more frequently among women than men. Patients who were not being directly observed had a higher chance of defaulting on treatment than those who were being observed. DOTS has been proved as an effective programme for TB management but there are many dynamics at play that may result in loopholes in its implementation, and thus it may not be as effective as expected.

2.8 Adherence to treatment

Adherence is a key factor that determines the success of treatment. According to the South African National Department of Health (2008) promoting good adherence is more effective than spending time and resources on dealing with defaulters. In order to support adherence, the Department of Health suggests that it is vital to ensure access to treatment, simplify treatment and ensure that services are convenient and client-centred. It is necessary to see to it that clients understand the treatment process so that they are motivated to comply with it. TB treatment often means taking medication for a long period of time and this can lead to fatigue and nausea. Some clients experience unpleasant side effects and decide to default. It is imperative not to place responsibility for a client's recovery fully on the shoulders of healthcare personnel, but rather to develop a treatment partnership between the healthcare provider and the patient in order to share responsibility and possibly obtain better outcomes.

Failure to adhere to TB treatment frequently results in the emergence of Multi-Drug Resistant TB (MDR TB), leading to further complications in TB control and efforts to eradicate the disease (Fourie 1999). It is more expensive to treat patients who have MDR compared to

those who have ordinary TB because MDR requires prolonged and expensive treatment - which is nonetheless not always efficacious (Fourie 1999). Patient non-adherence is therefore not only costly but also harmful to health. The reasons for poor adherence are multifaceted and complex. Away from the scrutiny of the provider, patients decide independently whether or not they are going to take medication, and this requires self-management. Other forces that can disrupt the treatment process range from socio-economic factors to personal traits.

2.9 Factors affecting adherence to TB treatment

2.9.1 Socio-economic factors

As mentioned, social and economic factors such as poverty may pose a challenge to treatment adherence. Money to pay for medication could be directed to other needs (Kagee 2005). There are expenses that come with access to treatment, including the cost of transport and child-care when patients have to visit the doctor, and poor nutrition as a consequence of poverty also affects one's ability to adhere to treatment. Kagee (2005) argues that the competing demands of responsibilities such as work, family life and the stress that is associated with poverty and difficult circumstances are likely to result in defaulting. In short, facing the daily frustrations that come with poverty detracts from treatment adherence and cause people to default.

In a study done by Harling *et al.* (2008) in South Africa on the social epidemiology of tuberculosis, the results showed that TB is associated with low levels of household, individual and community socio-economic status. Individuals who lived in areas where there were high levels of inequality showed a higher prevalence of TB disease regardless of their individual household-level risk factors. In addition to socio-economic factors, the study found that smoking and alcohol abuse were among the main drivers of TB in South Africa.

According to Harling and others (2008), the risk of contracting TB was increased when people frequented locations where they smoked and used alcohol as an important part of their social lives. The research points out that there is a correlation between poverty and engaging in these activities but this relationship has not yet been thoroughly researched. The study therefore concludes that socio-economic status has an impact on health outcomes and TB in particular.

2.9.2 Psychological factors

Social support and encouragement from family and friends have been mentioned as major contributing factors to adherence to treatment (Kagee 2005). Kagee (2005) argues that high levels of adherence are also associated with high levels of education, higher perceived self-efficacy and better knowledge of treatment and the consequences of poor adherence. Research shows that the relationship between the health care provider and the patient also matters because the former are often viewed as people of authority. In this regard studies show that patients trust doctors and are more likely to adhere if the guidelines on treatment are given by a medical doctor rather than a nurse (Kagee 2005).

Research done in the Eastern Cape suggests that the belief that one has been cured of TB leads to a tendency to default on treatment (Cramm *et al.* 2010). When symptoms disappear, patients discontinue treatment especially because of the fatigue associated with prolonged treatment (*ibid*).

2.10 Stigma and Discrimination

Moller and Erstad (2006) view TB as more than just a medical condition. They propose that there are various social dynamics at play that determine the success or failure of proposed

interventions. Stigma, discrimination and cultural beliefs are social aspects that deter people from seeking TB treatment and thus contribute to the evident failure of intervention strategies in South Africa. It has been determined that stigma related to TB has a negative impact on TB treatment and adherence. It also leads to a situation where people who possibly have TB, delay seeking diagnosis and treatment. In this regard the fear of stigmatisation can be seen as a social determinant of health in South Africa (*ibid*).

Stigma can be classified into three types: anticipated stigma, lived experience of stigma and self-imposed stigma (Deacon *et al.* 2009). From their understanding of their society and its views on the disease, TB clients sometimes assume or foresee the likelihood that they will be stigmatised. In some instances this stigma stems from the actions of others and often patients become withdrawn because of a feeling of unworthiness, as a result of their illness. Abney (2011) argues that stigma is a form of violence that affects the individual and their social networks by targeting that individual and setting them apart from others. Stigma in any form has an impact on patients and how they experience and deal with the disease. If not understood and dealt with, its adverse effects impact on TB control strategies.

Courtwright and Turner (2010) explore the issue of stigma more deeply. They argue that when the particular trait of an individual is singled out by others as undesirable the individual internalises this and adopts an attitude of shame, disgust and guilt. The individual then alters behaviour to conceal what they deem to be undesirable, and this can ultimately lead to non-adherence to treatment or a delay in seeking TB treatment. All these factors affect the outcome of TB interventions and for this reason, studying stigma is paramount; implementing ways of reducing it may result in improved healthcare-seeking behaviour. Pebody (2012) suggests that those who have both HIV and TB tend to lean more towards that which they feel is associated with less stigmatization and as a result they downplay the other ailment, ultimately affecting their uptake into and adherence to treatment. Patients are faced with a

dilemma and may not disclose that they have both TB and HIV; instead they may disclose the disease that they feel is less likely to be stigmatised.

Abney (2011) argues that visible signifiers of illness promote stigma. The researcher states that symptoms such as weight loss, discoloration of one's skin, weakness and a gaunt face are associated with both TB and HIV. These visible symptoms become an apparent sign of the absence of health and the presence of illness. Abney (*ibid*) proposes that individuals deal with this by moving to a private space or home of a family member, as people begin to gossip about these visible symptoms, thus affecting the social relations of the TB sufferer.

Most authors identify perceived contagiousness as the main cause of stigma although they admit that there are geographic and cultural variations in the patterns of stigma against TB (Courtwright and Turner 2010). Lack of knowledge about or understanding of TB transmission may contribute to stigma. Among individuals who have a good knowledge of TB transmission, stigma may be caused by a perceived risk of transmission. Courtwright and Turner (2010) mention that there are communities that believe TB is a punishment from a divine power as a result of wrong-doing on the patient's part. This may result in stigma because people may not want to associate with somebody who has failed personally spiritually, and in the process has "attracted punishment" in the form of a disease.

2.11 Tuberculosis and gender differentials

Epidemiological evidence shows that in low income and middle income countries, TB prevalence is higher among men than women (Jimenez-Corona *et al.* 2006). Gender disparities determine the social context of exposure as well as vulnerability to infection. This could be due to gender differences in social interactions which show that men socialise more outside their homes, often with people who are likely to have TB, whereas women are more

likely to spend time in home areas (Atre *et al.* 2004). It is important to understand the role of gender in TB so as to know how social meanings influence social responses (Atre *et al.* 2004, Vlassoff and Moreno 2002). These social responses determine the accessibility and utilization of healthcare resources. In this study, the experiences of men and women will be investigated to determine the social dynamics of gender in the experience of suffering from TB.

Gender has an influence on health seeking behaviour (Atre *et al.* 2004). Women in India, for example, are more likely to delay seeking treatment than men and research shows that they face more barriers in TB control and adherence. Jimenez-Corona *et al.* (2006) contradicted this idea with his research in southern Mexico which showed that men were more likely than women to be non-adherent and that men disproportionately contributed to the increase in the number of MDR TB patients. According to Atre *et al.* (2004), cultural ideas about the role of women in the home and community make it difficult for them to seek help outside, resulting in delayed diagnosis of TB. The authors argue that women are more susceptible to the impact of stigma because of their social vulnerability and as a result they may default, or only seek treatment when the illness is at an advanced stage. Jimenez-Corona *et al.* (2006) propose that unemployment, fewer years of formal education and lower literacy levels may also contribute to the factors leading women to put off seeking treatment. Research shows that in South Africa both males and females have equal access to health care services, but gender determines the way they utilize it. Gender also affects how they cope with the disease (South African Department of Health 2007).

2.12 Factors affecting health-seeking behaviour

Research surveys on TB prevalence in resource-poor countries show a high burden of infectious TB patients who remain undiagnosed and are thus at risk of infecting others (Mavhu *et al.* 2010). Even though the Western Cape is a province with relatively well

functioning health care services and an emphasis on TB treatment, the prevalence of TB is still very high (Western Cape Government 2014). Diagnosis of TB often relies on individuals self-reporting to a health facility and presenting their symptoms for screening. This means those individuals' perceptions of, and behaviour with regards to, TB symptoms are imperative elements of TB control.

Mavhu *et al.* (2010) furthermore propose that TB/HIV related stigma may be a factor preventing formal care-seeking for coughs suspected to be TB related. They argue that other factors such as cost, family priorities, a perception of health facilities and severity of the illness may also inhibit care-seeking. They add that people use multiple service providers as they attempt to find a cure and this further delays treatment seeking (Edginton *et al.* 2002).

A study conducted (Mavhu *et al.* 2010) in Harare, Zimbabwe sought to investigate the reasons why some people who had been identified as having chronic cough during a population based TB prevalence survey had neither reported the symptoms they experienced to a community team offering TB diagnosis, nor sought TB treatment elsewhere. The participants, aged 18-60 years, were asked about TB symptoms and had culture taken for TB testing whether or not TB symptoms were reported. Those who had reported chronic coughing for two weeks or more were asked about their previous health seeking behaviour. The criteria for selecting participants included having a chronic cough, not having reported their symptoms to the community-based study team in the preceding fortnight and not having sought healthcare elsewhere (*ibid*).

As discussed above the issue of possible stigmatisation arose. According to Mavhu *et al.* (2010) people with chronic coughs decided to delay seeking treatment from formal health-care facilities because of the perceived association between TB and HIV/AIDS. Participants did not wish to know whether they had TB or not: because to them it is linked to HIV/AIDS.

People often side-line TB as the reason for their chronic cough and instead suggested that the cough is caused by a common cold (Mavhu *et al.* 2010). Most participants ascribed their illness to occupational exposures, whether they worked at home or in the industrial sector.

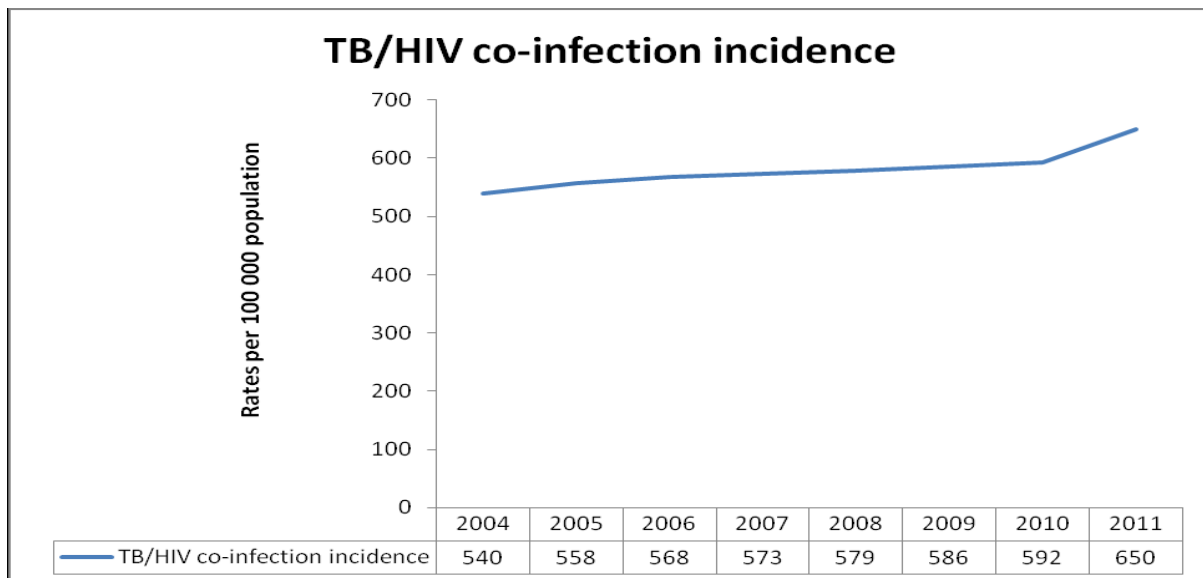
The above results were similar to a study done in the Limpopo Province of South Africa. In this province 30% of the study participants attributed TB to exposure to dust, dirty air and chemicals (Promtussananon and Peltzer 2005). Eating dirty food, using dirty dishes, drinking unclean water, drinking alcohol and smoking were some of the TB causes that were mentioned as well.

Participants furthermore raised the issue of maltreatment and stigmatisation by nurses as a deterrent to seeking TB treatment. The way in which patients are treated at clinics discourages them from making frequent visits and this leads to them defaulting. There are clear benefits of integrating TB treatment with that of HIV but there is an evident need to conduct more research on the TB/HIV stigma and how it affects people's decisions to seek treatment (*ibid*).

2.13 TB/HIV co-infection

The stigmatisation of TB, as seen above, has a great deal to do with its increased association with HIV and AIDS. HIV infection is the most powerful risk factor for Mycobacterium Tuberculosis infection and progression to TB disease (Pawlowski *et al.* 2012). TB is the most common cause of deaths related to AIDS. TB and HIV combined lead to the deterioration of one's immune system functions and if either or both diseases are left untreated, it eventually leads to death. Together, TB and HIV are the main burden of infectious diseases in countries where resources are limited. Pawlowski *et al.* (2012) reported that an estimated 14 million individuals are dually infected with TB and HIV annually on a global scale.

Table 1: TB/HIV co-infection per 100 000 population



Source: TB Electronic Register, Department of Health, 2011

Table 1 shows the gradual increase in TB/HIV co-infection rates in South Africa between 2004 and 2011. In 2004 TB/HIV co-infection incidence was estimated at 540 per 100 000 of the population. This number increased to 650 per 100 000 of the population in 2011. According to the Department of Health (2011) efforts to detect and cure TB have improved since 2004 but the number of TB patients still remains high and this is partly due to the increase in the number of patients with MDR-TB. In the Western Cape TB incidence rates have been showing a downward trend since 2008; however the rate is far short of the goals outlined in the MDGs (City of Cape Town 2014)

One of the major challenges in dealing with TB/HIV co-infection is that diagnosis of active TB disease in people who are infected with HIV is difficult (Getahun *et al.* 2010). This is because patients who have HIV-associated TB have fewer bacilli in their sputum compared to those who are HIV negative, but have pulmonary TB. The observation that coughing for more than three weeks is not enough to be viewed as a valid symptom of TB among HIV infected persons makes it even more difficult to screen them for TB (Getahun *et al.* 2010).

According to Getahun *et al.* (2010), TB diagnosis in most regions depends on examining sputum smears, but since bacilli is low in HIV infected people this method of testing overlooks a number of co-infected people. HIV infection also compromises the validity of chest radiography in the diagnosis of pulmonary TB and for this reason, researchers call for the use of advanced and innovative technology such as digital imaging in order to improve diagnosis.

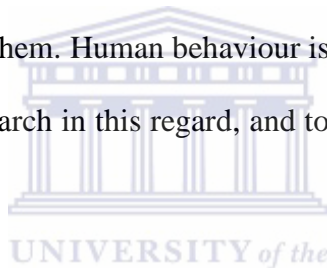
In a research done by Corbett *et al.* (2003) findings show that not only does TB/HIV co-infection result in increased mortality among those infected but at local level it also threatens the health of those who have neither disease. The researchers argue that an increase in the number of TB/HIV patients holds a potential increased risk of disease contraction among healthy populations. Corbett *et al.* (2003) argue that the burden of TB/HIV co-infection increases as HIV spreads and co-infection prevalence has reached startling proportions in countries such as Botswana, Zimbabwe and South Africa. They postulate that even in countries that have low TB incidence such as the United States of America (USA), HIV prevalence rates in persons with TB was high and 26% of TB cases were attributed to HIV.

Woods (2011) state that the transmission rates reported for South Africa among children and adolescents are the same as those recorded in Europe before there was treatment for the disease. Hansel (2004) conducted a study in Thailand of high AIDS awareness and its effect on treatment seeking behaviour in a high HIV sero-prevalent area. Findings show that when people have high awareness of HIV and inadequate knowledge of TB the result can be delays in treatment seeking and non-adherence to treatment. The argument is that HIV and TB symptoms are similar (weight loss, fever, chronic cough) and the two diseases are related. Therefore when one perceives TB symptoms to be those of HIV there is reluctance to seek diagnosis and treatment is exacerbated by the possible reality of having HIV and the stigma associated with it. As a result people do not seek treatment until symptoms persist or the

illness cannot be contained. This makes TB control more difficult because delay makes the disease load more advanced and difficult to treat (*ibid*). This could be a possible explanation to the slow progress in TB eradication in Gugulethu, a township that bears the harsh realities of the dual burden of TB and HIV.

2.14 Meanings and perceptions attached to TB

It is vital to study the meanings people attach to TB as well as their perceptions of the disease because these have an impact on the way people respond and their course of action upon diagnosis. Understanding these meanings also sheds light on the illness experiences of people with TB and how intervention strategies may be designed in a way that reduces the burden of TB on patients and those around them. Human behaviour is a critical element in TB treatment and there is need to continue research in this regard, and to understand diseases from a social perspective.



Steen and Mazonde (1999) explored the meanings that people attach to TB in Botswana, a country that has a high HIV/TB co-incidence but which, unlike most African countries, experiences considerable economic growth. Research revealed that in Botswana people may seek medical assistance for TB symptoms but they also combine these with consulting traditional healers in an effort to find out why they became afflicted with TB (Steen and Mazonde 1999). A traditional healer may then state the “real” cause of the disease as bewitchment, thus giving meaning of the disease to the patient. This diagnosis is done through the ‘throwing of bones’ (Steen and Mazonde 1999). People view modern medicine as a ‘quick fix’ and a way of relieving the symptoms of TB, whereas traditional medicine is seen as a way of addressing the root cause of the disease. Divine intervention is also sought through spiritual healers and ‘prophets’ who are affiliated with religion. They may offer prayers or use holy water to eliminate the root cause of TB. The study in Gugulethu explores

the ways in which people in that area treat TB symptoms and what implications having TB has on their lives.

According to Steen and Mazonde (1999) the use of traditional healers and prophets serves as a means to bridge the gap between western medicine and indigenous cultural practices and the extent to which these methods are used by a society is influenced by their understanding of the disease. TB patients seek answers to questions that modern medicine does not address. Studies show that few understand TB from a biomedical point of view. They may agree that TB is caused by 'germs' (i.e. mycobacteria) but as far as their illness is concerned, there is assumed to be a deeper cause that modern medicine does not explain. Of the 212 participants in the study in Botswana, 15% perceived TB as caused by engaging in heavy work; 5% said it resulted from poisoning and witchcraft and 6% stated that TB was caused by smoking. 8% of the participants said that TB was a result of infection from another individual who also had TB and only 19% gave medical reasons for their illness (Steen and Mazonde 1999). Thirty-one percent of the patients used home remedies, 26% visited a traditional healer and 13% visited a faith healer. This study revealed how people's perceptions of TB have an impact on the course of action they choose to take. The findings in Botswana show a dual utilisation of the modern and traditional health sectors in TB treatment.

A similar study conducted in Kenya reveals that some communities generally accept TB is diagnosed and treated using allopathic medicine but they view treatment itself as prolonged and agonizing (Liefoghe *et al.* 1997). In Kenya, traditional healing is viewed as a valid alternative to 'modern' medicine and it is believed to be effective and of much shorter duration.

In a study done by Promtussananon and Peltzer (2005) in Limpopo province some participants believed TB is hereditary whereas others said that it was caused by smoking,

alcohol, hard work and prolonged exposure to cold conditions. These perceptions led people to treat symptoms in line with what they understand the causes to be. Similarly, in Namibia people who suspected that they had TB but who, because of a range of structural issues, had not yet been diagnosed, used medicinal plants and even healing ceremonies to treat the symptoms (Gibson 2010). Sometimes delay in treatment resulted from prolonged self-treatment, consultation with the traditional health sector as well as the social stigma attached to the disease (Liefoghe *et al.* 1997). It is only after symptoms have persisted for some time that bio-medical based health services were consulted.

A study conducted by Abney (2011) in Khayelitsha explores the stigma that is experienced by TB patients. In the study, the researcher for instance explores the meaning attached to wearing a mask in Khayelitsha and how people react to those who wear one. The mask used by TB patients is called the N95 and it is bigger than a regular mask and covers most of the wearer's face. Abney (2011) argues that wearing a mask is a signal that changes the identity of the wearer. In the South African context a mask has a different meaning when it is worn outside the medical setting (*ibid*). According to Abney (2011) the N95 mask heightens the visibility of the wearer thus prompting stigmatization. In Khayelitsha the N95 mask was associated with what the researcher termed 'a big disease', and wearing the mask became an indicator of illness. It was a signal that whoever is wearing it is suffering from a 'big disease'. TB is therefore viewed as a big disease from which people run especially when associating with a patient who is wearing a mask for preventative measures. All these none-biological aspects of disease and illness can be explained using the Explanatory Framework and narratives of illness which will be discussed further.

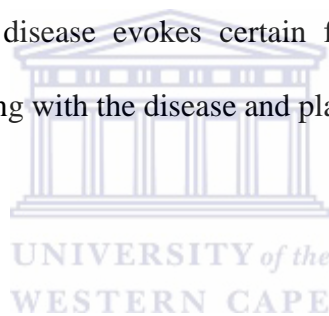
2.15 Conceptual framework: illness aetiology and narratives of illness

Arthur Kleinman (1988) proposed illness narratives as a conceptual framework in a bid to understand disease, illness and sickness as more than just biological phenomena. Illness is defined as how a sick person, family or society perceives, lives with and responds to symptoms and disability (Kleinman 1988). It is different from disease which is based on how health practitioners label symptoms based on their training, in their particular practice. Kleinman (1988) goes on to define sickness as the understanding of a disorder across a population and in relation to macro-social forces. Sickness can be analysed as a reflection of political oppression, economic deprivation and other social forces which can be deemed related to a particular disorder. The illness narrative conceptual framework accords value to understanding the experiences of patients in relation to disease. Their judgement on how to deal with distress, determines the course of action they take as a response to the physical symptoms. Kleinman (1988) uses the term *illness behaviour*, stating that this behaviour consists of initiating treatment and deciding when and where to seek it. In this context, TB is more than just an infection or disease. Its consequence not only affects the individual's well-being but can be translated to their work and ultimately become a social problem. Scheper-Hughes (1990) argued that the explanatory framework, especially as used in cultural epidemiology, can be problematic.

Over time, Kleinman (1995) moved away from his original conceptions of the explanatory model framework and focused more on subjective studies of illness. Kleinman also broadened his approach to include biomedicine within ethno-medical health care systems as a cultural institution within the professional sector. Kleinman and Kleinman (1991) promoted the use of the experiential as it mediates and transforms the relationships between a person

and his/her context, between meaning and psychobiology in illness, and healing. In contrast, biomedical models of disease give supremacy to pathological causes of disease and undermine the patient's understanding and experience of the symptoms, especially where illness may occur in the absence of disease. The assumptions that underpin biomedical models include the notion that disease has a single underlying cause, and elimination of that cause results in good health (Wade and Halligan 2004). These models do not account for the 50% of visits to the doctor which involve complaints that have no evident biological base (Kleinman *et al.* 2006). Society is more complex and dynamic than biomedicine portrays it to be. Explanations for illness are not always attributed to disease and this research focuses on socio-cultural explanations of TB and experiences of illness as a starting point for the study. It acknowledges that having a disease evokes certain feelings and induces behavioural changes that lead to one identifying with the disease and playing the role of one who is ill.

2.16 Conclusion



The above section has looked at the origins of TB and justified why it is at present a public health concern globally and in South Africa. In this chapter, issues such as stigma and discrimination, poverty and gender have been examined for how they affect TB interventions. The chapter has discussed DOT as well as factors that affect adherence to treatment. It has also discussed meanings and perceptions attached to TB, linked to Kleinman's explanatory framework. In short, the chapter has focused on socio-medical factors surrounding TB in a bid to illustrate that TB is not only a biomedical disease that requires biomedical treatment. There is a need to understand the social dynamics surrounding the disease and the experiences of people who suffer from TB in order to improve interventions to mitigate the disease.

Chapter 3: Research Design and Methodology

3.1 Introduction

This chapter presents the methodology used to find out how people who live in an area of high HIV prevalence understand TB. The chapter provides a description of the study design and the research methodology. It explores the data collection tools used in line with the suitable research method chosen. The chapter also presents how data was analyzed.

3.2 The research design and methodology

De Vaus (2001) defines research design as a logical structure of enquiry used by researchers before embarking on data collection. It is not just a work plan but also serves the function of ensuring that the evidence obtained, enables the researcher to answer the initial questions of the research. The research design also ensures that the researcher obtains the relevant evidence specific to the research questions (De Vaus 2001). It can be viewed as a ‘blueprint’ of the research project that precedes the actual research process (Mouton 1996:107). The research design includes consideration of the selection of participants that would best provide the necessary data as well as the methods used to obtain this data.

An exploratory approach was used in this research. It is flexible and best used in instances where the researcher wants to uncover boundaries of the environment and also learn from the experience of the investigation (Creswell 2013). This approach allows for exploring the illness experiences of people in Gugulethu who have TB. It allows the researcher to have insight into their lives, how they interpret TB symptoms and how they manage the treatment prescribed for them.

3.3 The research methodology

Different research tools were used to obtain the necessary data, including

1. A literature review which involved the use of related secondary data. Gerrard (2013) proposes that a literature review consists of reading, analysing and writing a synthesis of scholarly materials about a specific topic. Literature refers to theoretical and research publications in journals, reference books, text books, government reports, policy statements and other materials about theory, practice as well as the results of scientific research (Gerrard 2013). Bryman (2012) argues that not only does a literature review reveal what is already known in the area of study but it also helps the researcher to develop research questions and identify some possible gaps that may invite investigation.

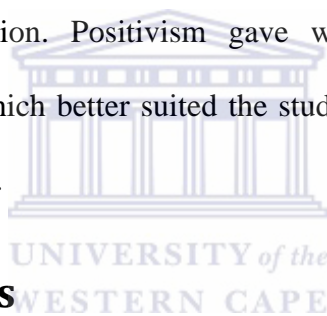
2. Semi- structured interviews and in-depth interviews were used mainly to explore participants' feelings and to plumb their knowledge of TB. These interviews were designed to allow respondents room to express themselves and talk about their experiences with TB disease.

3. Observation was used mainly to describe the environment and to witness the typical day of a TB patient and how they live with the disease. The researcher also observed the participants' body language for cues on their feelings and whether or not they were comfortable with the questions without stating this to the researcher.

3.4 Qualitative research

Babbie and Mouton (1998:278) define qualitative research as the study of human action from the perspective of the social actors. They argue that the method seeks to understand rather

than to simply provide an explanation for human behavior and the approach places value on the insider perspective of society, whose outcome therefore is the behaviour under investigation. Babbie and Mouton (1998) proposes that qualitative research is a broad methodological approach whose focus is on gaining access to subjects, collecting data and analyzing: therefore, it should have evidence of engagement with the participants. It is interested more in narrative rather than numbers (Bryman 2012:380). Qualitative research seeks to explore phenomena and not to simply confirm it. According to Tesch (1990), early research leaned towards positivism as applied in the laws of social science research, where scholars used natural science procedures and experiments to measure social behaviour. This approach was questioned by some scholars who wanted to understand and highlight human feelings, emotions and interaction. Positivism gave way to advocacy for qualitative approaches in social research, which better suited the student who sought to understand the social approach to the TB disease.



3.5 Research Methods

3.5.1 Sampling

Sampling is the process of collecting data for the purpose of generating theory whereby the analyst jointly collects, codes and analyses data and decides what data to collect next and where to find it, in order to develop theory as it emerges (Babbie and Mouton 1998:287). The researcher designates a population of interest and attempts to select a subset of some predetermined size from this population (Bailey 2008:82). The subset should adequately represent the population so that the information gathered from the subset ideally will provide insight into the population under investigation.

In the present study, the researcher used snowball sampling to obtain participants. This sampling technique is also known as chain referral sampling (Bailey 2008:96) because it entails identifying participants using selected characteristics and using those participants to gain access to other participants who also qualify to be part of the sample population. The researcher established contacts in Gugulethu with a community member, referred to as Mzi, who is involved in various community projects. Mzi introduced the researcher to a number of TB patients who in turn identified other participants who were approached and agreed to take part in the research. In all these instances, the researcher introduced herself and explained the purpose of the study prior to interviewing the participants. For some participants who were not free to be interviewed at that moment, alternative arrangements were made and the researcher conducted interviews at more convenient times.

The sample comprised 7 females and eleven males between the ages 31 and 48 years who reside in Gugulethu. Of the eighteen participants, none was formally employed at the time of the interviews. Some survived on piece-work and others were assisted by family and friends. One was on treatment for MDR, eleven were TB survivors and 6 were on treatment for active TB. Data was obtained using various tools.

3.5.2 Data collection tools

Interviews: An interview can be individual in-depth, exploratory, semi-structured or unstructured depending on the most suitable design (Symon and Cassell 2004). The goal of interviewing participants is to see the topic that is being investigated from the perspective of the interviewee and to understand why they view it the way they do. Semi-structured interviews are conversations in which you know what you want to find out (Fylan 2005:65). Because of their flexibility, according to Fylan (2005:66), semi-structured interviews are well suited for finding out ‘why’ rather than ‘how much’ or ‘how many’. Questions were prepared

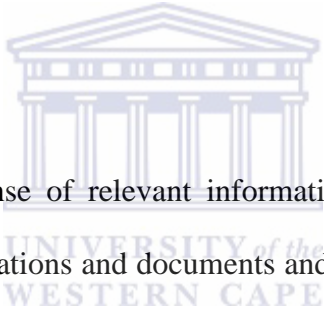
beforehand and these were structured to leave participants with enough room to answer questions and express their views on the subject.

In-depth interviews are purposeful interactions in which an investigator attempts to learn what another person knows about a topic, to discover and record what that person has experienced, what he or she thinks and feels about it and what significance or meaning it might have'-Mears (2012:170). In-depth interviews permit the researcher to cross the boundary and journey into another's perspective about a circumstance or event (Mears 2012:171). In-depth interviews also allow the researcher to understand the experiences of people and what those experiences mean to them. For this researcher the core agenda was to find out how people in Gugulethu interact with TB. Through in-depth interviews, the researcher managed to explore their experiences and unravel what having TB meant to them and how it affected their lives.

Narratives: Illness narratives were used in order to attain data from those who wished to narrate their experiences on the disease as well as the suffering and challenges that they faced. It required the researcher to stimulate the narration by defining the issue and then refraining from any interruption as the participant narrated. Denzin and Lincoln (2011:422) postulate that it is important for the researcher to pay attention to the narrator's linguistic practices such as word choice, repetition, hesitation and laughter. These actions can reveal the participants' feelings and attitude towards that which evokes their emotions. The researcher also probed discussions on the experiences of people with TB and this helped highlight how the community treats people with the disease, whether they are they accepted or stigmatised. TB survivors were more open about providing information about the disease and their experiences than those who were at the time suffering from TB, as this may have been a sensitive time.

Observation: There are two types of observations: simple observation and participant observation (Babbie and Mouton 1998:293). In simple observation, the researcher is outside the field and observes the actors whereas in participant observation the researcher becomes part of the group that he or she is studying. Observation is rarely a stand-alone technique; it usually constitutes the first phase of a research project, and subsequent data collection techniques are dependent on the basic information provided by initial observations (Mears 2012:165). This method was used to collect data that was not verbalized such as the environment, actions, physical characteristics and non-verbal communication. The researcher observed the use of non-verbal communication especially body language as this brought out the participants' feelings and attitudes on the subject matter.

3.5.3 Data Analysis



Data analysis means making sense of relevant information gathered from sources which include interviews, on-site observations and documents and then responsibly presenting what the data reveals (Caudle 2004:417). Data is examined, categorised, tabulated, compared and contrasted and reduced by sifting trivia from that which is significant. Data is summarised, coded and clustered and patterns are identified (Caudle 2004:421). It should be analysed in a systematic and organised manner so that the researcher is able to locate information and trace the provisional results of the analysis back to the context of the data (Fylan 2005:152). In this study, themes were deduced from the qualitative data collected. Auerbach and Silverstein (2003:38) define a theme as an implicit topic that organises a group of repeating ideas.

3.5.3.1 Interpretative theoretical perspective

Interpretivism in general is the idea that when studying humans, the emphasis should be on studying the mind, how humans interpret their surroundings. The aim therefore is to understand and not to explain people. The construction of knowledge not only entails the observation of phenomena but also includes descriptions of people's intentions, beliefs, values and reasons, meaning-making and self-understanding (Henning 2004:20). Interpretive research is therefore a communal process informed by participating practitioners, which is endorsed by others. 'Phenomena and events are understood through mental processes of interpretation which are influenced by and interact with social context' (Henning 2004:20). Discourses become an important factor and the researcher 'analyses texts to look for the way in which people make meaning in their lives, not just that they make meaning, and what meaning they make' (Henning 2004:20). The researcher has to then look for frames that shape the meaning that participants give to phenomena.

Interpretive research encourages the collation of varieties of data and different sources and analysis methods in an effort to achieve validity (Henning 2004:20). Grix (2010) argues that despite the use of scientific methods in research, interpretivism advocates the development of a distinct science bearing in mind that humans cannot be fully studied using the same techniques as those used to study the natural world. In this case, scholars say that one can therefore capture the unique aspects of human behavior. Grix (2010) explores the idea of symbolic interactionism, an argument that humans attach meaning to symbols thereby creating understanding of their actions and interaction. In qualitative research, the researcher aims to understand how participants perceive this meaning of society.

Interpretive research is fundamentally concerned with meaning and it seeks to understand social members' definitions and understanding of situations. The

interpretive paradigm does not concern itself with the search for broadly applicable laws and rules, but rather seeks to produce descriptive analysis that emphasizes deep interpretive understanding of social phenomena. (Henning 2004:21).

What makes interpretivism relevant to this research is that it recognizes that humans are not passive individuals in social, political and historical affairs but have certain capabilities that allow them to judge, perceive and make decisions. The perspective acknowledges that any event or action is explained in terms of multiple interacting factors, events and processes (cause and effects factor). The paradigm also recognizes the difficulty in achieving complete objectivity from individuals who attribute different meanings to different events. Individual cases are recognized rather than universal laws or predictions.

3.6 Criteria for quality of data

When data has been collected it is analysed, presented and published with the idea that the results explain certain social phenomena. If the same research is done on relatively similar people, then the results will be similar and thus it can be considered a valid and credible research exercise. In social research there are some factors that are considered and used as criteria to determine whether the data collected for a particular research is worth using for research analysis purposes. These criteria will be discussed in detail.

Reliability and Validity

Reliability is a matter of whether a particular technique applied repeatedly to the same object would consistently yield similar results each time. It does not ensure accuracy and this inaccuracy is known as bias (Babbie and Mouton 1998:119). Stenbacka (2001) argues that in qualitative research, it is difficult to use reliability to measure the quality of data; it is best used in quantitative data where the structure of data collection is more rigid.

Validity refers to the extent to which an empirical measure adequately reflects the real meaning of the concept under study (Babbie and Mouton 1998:122). In qualitative research, data is valid if the informant is part of the problem area and if he or she is given the opportunity to speak freely according to his or her own knowledge structures (Stenbacka 2001). In this research, all respondents had suffered from TB prior to the research or were still TB patients. Their experiences provided first-hand information on how people in Gugulethu understood TB and dealt with it, since they were in a better position to provide answers to the research questions than people who had never had TB.

Generalising the results

This criterion is used to determine whether resulting conclusions are general for the population and this puts pressure on the sample to be representative of the population being researched (Stenbacka 2001). There has been ongoing debate on whether using a sample taken from qualitative research can give insight into issues that prevail in the general population and Morse (1999) argues that if qualitative research were not generalisable then it would be of little use and insignificant. Morse (1999) proposes that in qualitative research each participant in the relatively small sample has been carefully selected for the contribution that he or she can make towards an emerging theory. The knowledge gained from the research can be applicable beyond this selected group and is considered applicable to all similar situations (Morse 1999).

3.7 Conclusion

In this chapter I have discussed qualitative research as the suitable research methodology for the study. The research tools such as structured interviews, in-depth interviews and observation have been elaborated on, as justification of the need to use qualitative research to

obtain data. The chapter also shows how data was analysed using the interpretive theoretical perspective by grouping common ideas into themes that emerged during data analysis.



Chapter 4: Tuberculosis aetiology in Gugulethu

4.1 Introduction

This chapter presents discussion on the findings of the study. This discussion will be centred on the themes that emerge from the data that was collected. The chapter will discuss the knowledge that people in Gugulethu have of TB, their experiences with the disease as well as their interaction with DOT. The chapter will also highlight previous studies and compare them with the findings of this research.

4.2 Knowledge of TB/HIV

TB symptoms and causes

Knowledge of TB was assessed using the definition of the symptoms of TB of the lungs provided by WHO (2013) which are coughing, sometimes with sputum or blood, chest pains, weakness, weight loss, fever and night sweats. The causes, plus important signs and symptoms as well as modes of transmission were the key aspects that respondents were about. These were also used to find out people's understanding of TB.

Seventeen of the participants knew the symptoms of TB and mentioned coughing, fever, sweating at night and loss of appetite among others. What was of concern was that participants were aware of TB but not very knowledgeable about it prior to falling ill with it themselves. The severity of the disease became better understood as a result of their own ailment, whereas prior to that they knew that TB existed but had no comprehensive understanding of the burden of having TB.

In my study participants revealed their knowledge of TB, and mentioned the symptoms of the disease such as coughing for more than two weeks, having night sweats and experiencing loss

of appetite. Most participants initially thought that they had a cold or flu. According to a study participant:

“TB starts like flu. You take Grandpa and Med lemon. When you see that it is not working then you go to the clinic.”(31 year old female)

One respondent had a different idea about TB and did not initially think his symptoms had anything to do with flu and colds:

“I thought I had Congo fever. You get it from interacting with animals and they get it from drinking dirty water.”(34 year old male)

In a study done on TB in Harare, Mavhu *et al.* (2010) found that those who experienced chronic coughing did not consider it as a symptom of TB, despite their knowledge of the disease and chronic coughing as a symptom of possible TB disease (*ibid*). Similar to Harare, in Kenya Liefoghe *et al.* (1997) noted that people failed to distinguish between asthma and TB symptoms. In many cases in Kenya, those experiencing coughing, loss of weight, tiredness, sleeping difficulties, fever and changes of skin complexion - becoming darker - thought it was TB.

In my study participants revealed that they often dealt with symptoms of the disease without knowing what it was unless they were diagnosed. Because they were unwell for some time, they also revealed that they become moody and this impacted on their relationship with others; they always wanted to be alone.

“I felt like I did not want anybody near me and people disliked me because I was always angry.” (48 year old female)

Being “always angry” is presented above as a result of TB. It impacted on how those suffering from TB chose where to go and how to get there, as reflected by one of my participants:

“I was always angry and wanted to be alone because I felt like I did not want to talk to anybody so I wanted to be alone and avoid quarrels” (36 year old male)

The excerpt reveals the different ways in which people with TB adopt particular actions to deal with their conditions. Thus “avoiding quarrels” is a technique for them.

Participants could feel that their bodies were not in their usual state of health but were unable to label this illness:

“At night I would feel hot and I would remove the blankets then I would feel cold again. I knew something was wrong. I was not myself” (44 year old male)

Ideally, this is where biomedicine comes in, defines and interprets symptoms, names the disease and prescribes treatment. Yet the process of diagnosis is not necessarily simple – as described by one participant in Gugulethu:

“I went to the clinic. When I got there they gave me a container and asked that I collect a sample of my sputum first thing in the morning. When I returned to the clinic with the sample they could not detect anything because I had not collected it as instructed. They then took my blood sample and an x-ray of my lungs. The results showed that I had TB”. (42 year old female)

The excerpt above shows that TB diagnosis is not always easy. TB is sometimes difficult to detect using the sputum test and as a result, other means of testing such as skin tests and x-rays are used instead (Bonet 2005, Evans 2011). In some instances more than one test has to be carried out. This is in itself an expensive (*ibid*) endeavour but nonetheless, one which is

accessible to the people of Gugulethu. Early and efficient TB diagnosis is only part of the solution to the fight against the disease. It is paramount for TB treatment to be given just as much consideration.

Kleinman's notion of illness narratives proposes that illness is more than just the presence of disease but also entails how individuals interpret and deal with the symptoms of disease to explain the role of illness experiences in disease control (Kleinman 1988). In Gugulethu, being diagnosed with TB provided relief for some because they could put a name to these symptoms that they were experiencing but did not understand. Yet four of the participants initially (after diagnosis) expressed anxiety and fear because they did not know how having TB would impact on their lives.

Some participants mentioned alcohol intake, smoking, and being exposed to rain, dust and cold weather as causes of TB. Promtussananon and Peltzer (2005) had similar results in their research in Limpopo. These activities such as drinking and smoking are risk factors that may make latent TB become active by compromising one's immune system: participants summed them up as causes of TB. There was a consensus among study participants that TB was spread by coughing with an open mouth.

In Gugulethu, the understanding was that TB is a natural, physiological condition best treated by biomedical intervention:

“If you want to get better you have to listen to what the doctor says and take your tablets the way the doctor tells you to take them. If you do that you can defeat this thing.” (38 year old female)

There was no indication of supernatural beliefs attached to the causes of TB in my research, unlike areas in Botswana where a study showed that few patients believed TB to be a

biological disease (Steen and Mazonde 1999). Even after labelling the symptoms as those of TB, people in Botswana sought the opinions of faith healers and traditional healers for the root causes of TB, because they believed that it was more than just a biomedical disease. There was an understanding that there are social relations that determine whether one gets TB or not. When one does wrong to another, the aggrieved person then ‘sends’ TB as punishment to the patient. When a traditional healer or faith healer provided an answer to the question ‘why?’ the patients became more accepting of their diagnosis and took measures to treat it – this could involve e.g. adhering to treatment and doing the necessary rituals for spiritual cleansing, placating the ancestors and such. The study participants in Gugulethu, unlike Botswana and Namibia where people believed TB was attached to supernatural connotations, understood that to cure TB, they had to take prescribed medication.

‘I went to the doctor and was asked to cough into a cup. The doctor took that sample and after 3 days I went back to the clinic and was told that I have TB. I started taking medication for TB. At first I had to go to the clinic daily to take the medication but now I am given enough medication for a month and when it is finished I go to the clinic for the doctor to check me. I have to take the medication until I finish the course even though I feel strong now.’ (42 year old male)

In Zimbabwe, a study showed that participants were knowledgeable about TB but reluctant to admit to themselves that they might have it and to seek biomedical diagnosis (Mavhu *et al.* 2010). In Gugulethu, on the other hand, 17 participants were aware of the disease but did not perceive themselves as at risk of contracting it.

“I used to see people with TB looking weak so I knew it existed and I knew people died from it but I never thought I could get it. (42 year old female)

The participant illustrates the way in which people view TB as a disease of the ‘other’ – they did not see themselves as susceptible to it. The excerpt above shows that people may also not be aware that they may have latent TB which may not be active as long as their immune system is strong enough not to let the infection progress to become a disease.

As mentioned, one of the symptoms of TB is coughing continuously for more than two weeks. This coughing is usually linked by participants to common colds. As a result they delayed seeking treatment until coughing became severe:

“I was coughing a lot. I thought maybe it was this winter and the flu that many people had. Coughing day and night until I thought it better to see the doctor.” (38 year old male)

From the above it seems that coughing is not only linked to common colds, but that people usually self-treat and use home remedies or over the counter medication to do so. It is only when coughing has progressed and other TB symptoms appear, such as fever, sweating, weight loss etc, that participants sought a medical opinion (Kleinman 1988). The study conducted by Steen and Mazonde (1999) in Botswana also illustrated how people experience symptoms and based on their interpretation of these symptoms, seek suitable treatment.

In the case of Botswana, medical treatment was combined with consulting traditional healers in order to have a holistic diagnosis and explanation for illness. TB symptoms therefore have a different meaning to the people because the disease is understood in a socio-cultural context and its root causes are not interpreted as only natural.

In Gugulethu, when participants realised that their symptoms were severe, their solution was to visit the clinic:

“My family noticed that I was not well. They kept telling me to go to the clinic but I did not go. One day my sister took me to the clinic by force. She said we had to know what the problem was.” (42 year old male)

One of the participants, Thando, knew a great deal about TB her father had died of it. Contrastingly, very few of the study participants had taken note of TB-related prevention information and interventions such as the ‘Stop TB’ signs on display, or the anti-TB campaigns in Gugulethu.

This ‘blindness’ to available information about TB was an aspect that I only became aware of myself over time. For example, when going to do my fieldwork I would take a taxi from the university to Mowbray and disembark at the Gugulethu turnoff where I met Mzi. We would then go to the participants I was due to meet. On numerous occasions I noticed ‘Stop TB’ signs in the taxis but I only began to give attention to these, to actually ‘see’ it, when I learned more about the epidemiology of TB. I often used taxis which had ‘Stop TB’ stickers on the outside and inside, but in the past I had to all intents been ‘blind’ to these. This could be one possible explanation why the study participants all said that they actually came to ‘know’ TB once they were faced with the reality of suffering from it. They also became more aware of anti-TB campaigns, information and such and even sought these out to become more knowledgeable about TB.

Knowledge of TB variations

Most study participants knew that there were various kinds of TB but had difficulty in explaining the variations.

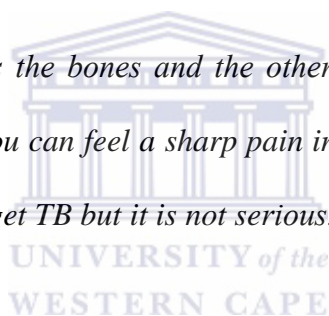
“There is TB of the brain which makes your head swell. You have a headache that lasts for many days then you know it has attacked your brain. People call it meningitis TB. The other TB is for the lungs. This is the type that I had.” (42 year old male)

Some responses also showed that participants had an idea that TB had different strains which varied in intensity, e.g. MDR TB:

“Touch. Touch TB is mild. You feel sick but not very sick. The other type kills you at once. You do not recover from it. I had the touch type. Felt a bit of chest pain and after taking treatment I recovered.”(48 year old male)

Another respondent said about TB:

“There is TB that attacks the bones and the other one kills your muscles and also makes you cough a lot. You can feel a sharp pain in your ribs and you know that it is serious TB. Some people get TB but it is not serious. Others it kills them.”(37 year old female)



The above responses show that patients are aware of the variations in intensity of illness.

Two participants disclosed that they suffered from MDR TB. They said they did not know what it was exactly but assumed that they had developed it because they had not completely healed from TB before and were therefore suffering from it for the second time:

“No I did not finish the medication. I felt better so I thought I was fine but here it is. I have it again. This time I cannot make that mistake because now it has come back stronger.” (42 year old male)

There was consensus among the participants that TB can, if not treated, become serious and deadly. Respondents expressed fear of dying of TB but agreed that it was a disease that could

be treated and emphasized the need to adhere to treatment in order to recover. The two participants with MDR TB stressed the gruelling treatment for it. Their fear of having to undergo even more treatment encouraged them not to default in future. As one participant expressed it:

“There is the pill type which is what I had first and the injection type which is what I have now. The doctor says now he is giving me injections because last time I was not taking my pills correctly so now he is the one who will make sure because I go to the clinic for the injection and this time I take treatment.” (42 year old male)

According to Munro *et al.* (2007) many TB patients adhere to treatment because of fear of it getting worse. This was evident from seven participants in the research. They often gave examples of people they knew who experienced severe TB symptoms, who had become bed ridden and possibly died of the disease. They described the physical appearance of people known to have TB and these included weakness, protruding bones due to weight loss, skin problems, sunken eyes, constantly dry lips and a dark complexion. Abney (2011) argues that these visible signs of illness result in gossip and ultimately result in stigmatization. Seeing people they knew going through such experiences encouraged patients to take the initiative and be responsible for adhering to their treatment.

4.3 TB and HIV

Although all participants made a link between HIV and TB, fourteen of them were somewhat confused about the relationship between the two. These participants understood some connection between TB and HIV but thought that the former somehow transformed into the latter. One participant highlights this notion:

“There is one type that changes. You see TB is one disease but the insect keeps changing and changing that is why it is not easy to cure. If you do not take the right treatment it develops into other diseases like AIDS” (47 year old male)

The description of HIV as TB that has metamorphosed gives one the impression that the belief is that HIV is an advanced stage of TB. There is a relationship between the two diseases, but it is more complicated than that. A minority of the participants understood that— for people with HIV - TB is an opportunistic infection. They knew that many people who have HIV actually die from opportunistic TB.

Research conducted in the Eastern Cape produced similar findings (Cramm *et al.* 2010). Participants considered TB as an African disease and had the misconception that TB patients eventually develop HIV if it is left untreated. In reality people with HIV can easily be co-infected and develop TB compared with who do not have HIV, because HIV compromises the immune system. In the Western Cape most people carry TB bacilli (City of Cape Town 2014). People are exposed to TB infection all the time but do not develop full-blown TB because their immune systems have not been compromised through HIV infection.

The use of kinship metaphors in describing the relationship between HIV and TB gives a picture of how closely linked the people perceive TB and HIV to be. One participant alluded to TB and HIV as cousins:

“TB is a cousin to HIV. They are related.” (32 year old male)

Using the term cousins describes a link between the two diseases as that of close relatives, i.e. they are ‘related’.

“TB causes HIV by killing joints. It kills your joints and muscles and when that happens, some people end up having HIV. They become weak because of the TB and

when that happens, it grows into HIV. Then you know you are finished.”(Bheki 47 year old male, MDR patient)

Ngamvithayapong *et al.* (2000) in their study conclude that in Thailand there is a strong belief that HIV is related to immorality and therefore those with HIV are deserving of it. TB is also stigmatised in this country because people are fearful of contracting it. Instead when people have TB, they tell others that they suffer from pneumonia.

Among the visible symptoms listed by my participants were the ‘chipping off’ of one’s skin, darkening complexion, lips turning pink and loss of weight. When people showed such indicators others tended to avoid contact with them for fear of contracting TB. Furthermore, because TB is associated with such symptoms; all of which are similar to that of HIV, these visible indicators of disease can reinforce stigma against TB patients (Abney 2011). This was also found by Abney (*ibid*) in Khayelitsha.

In Gugulethu as in nearby Khayelitsha, the largest township, there is a reluctance to disclose that one has TB and/or HIV. It could also be the reason why participants argued that TB can ‘transform’ into HIV. In this way the possible link to sexuality (and assumed immorality) is side-stepped. It is not necessarily because participants lacked information about HIV or TB but they were anxious that others might stigmatise them because of the perceptual link people make between the two.

4.4 Factors perceived to promote TB

In a study on TB and vulnerability in Cape Town Murray *et al.* (2013) concluded that if there is an understanding that there is collective vulnerability to TB there is less urgency to seek treatment. Murray *et al.*’s (2013) research indicates that in places such as townships, the living conditions result in people viewing TB as a disease that is unavoidable. ‘Collective

vulnerability’ suggests that perceptions of individual agency are low. One respondent in my study brought this perspective out when talking about the high TB prevalence in Gugulethu:

“Inhaling a lot of dust also causes TB. You can see here in Gugulethu, look around. All the rubbish in the streets. All that is the reason why we are sick with TB.” (32 year old male)

The streets are identified above as spaces that are ‘dirty’ and potential hubs of TB. Similar to Abney’s (2011) findings in Khayelitsha, participants perceive dirty places as harbouring TB. They also have an understanding idea that it is spread through the air, hence the necessity of covering one’s mouth when coughing.

Abney (2011) explores the idea of dirt in relation to how TB is contracted. She argues that cleanliness is associated with ‘proper’ and ‘good’ ways whereas being a ‘dirty’ person is linked to lower social status, social judgement and potential stigma. Research shows that in Khayelitsha people have ambiguous definitions of dirt, from being unhygienic to leading a poor lifestyle (*ibid*). Abney (2011) puts forward that if an individual deviates from social expectations, they become open to judgement: casting blame is aligned to personal habits or perceived hygiene. The spread of TB is therefore associated not only with unhygienic people and places but also with those whose habits are seen as ‘unclean’. It is this ideology that results in the stigmatization of those perceived as ‘dirty’ and potential TB carriers.

There was a sense among participants that some of the factors that drive TB in Gugulethu are beyond the people’s control. I noticed this during one of my visits to the township:

As one enters Gugulethu from Robert Sobukwe main-road they are welcomed by a shopping mall which conceals the realities of the living conditions beyond the structure. Further into the township one sees apparent dire living conditions that exist

in the township. The roads are different from the wide and tarred Robert Sobukwe. Here, the tar is degraded and distinguished by potholes. Sewage water runs parallel to the road in a number of streams whose sources are not clearly traceable. After every few metres there are clusters of mobile latrines which are communally owned. Land pollution is evident from the many garbage dumping sights wherever there is a clearing. (Field notes)

There is poor ventilation in dwellings and poor sanitation in Gugulethu with some families sharing common toilets. This makes it difficult to maintain hygiene. Due to the migration of people from the rural Eastern Cape to the township, there is overcrowding. In informal settlements there is no proper garbage disposal system and people have created dumping sites near their dwellings, adding to the pollution of the township. There are unpleasant smells coming from open sewage systems as well as garbage dumping sites and communal toilets.

Illness should be understood in relation to macro-social forces as a reflection of political neglect and economic deprivation, among other social forces (Kleinman 1988). Illness, as Kleinman points out, is more than just a biomedical condition. There are social factors that cannot be ignored as they contribute to the ill health of a population. In Gugulethu, like in Khayelitsha, the social injustices that are a legacy of apartheid paved the way for the political and social conditions in which TB still thrives (Abney 2011).

Participants expressed the need for intervention by the current democratic government to improve their living conditions:

“These ministers do not know how we live. Their houses are in Rondebosch and Claremont. How will they know? They should come here and live here so that they know what it is like.” (48 year old male)

The participant believed that government officials did not understand the situation because they lived in affluent areas and as a result Gugulethu's needs were not seen as a matter of urgency. These politicians also could not rightly represent Gugulethu residents. This highlights for political will to implement interventions that would benefit the people of Gugulethu.

Seventeen respondents included cold weather as a cause of TB and some of them brought it up as a key driver of the disease in Gugulethu. They stated that their dwellings were not appropriate for protection against the elements and the harsh Cape Town winter increased their vulnerability to TB. Murray *et al.* (2013) had similar findings in their research. They reported that TB patients expressed their inability to control the factors that cause TB and often attributed these causes to the harsh climate and poor living conditions. Lack of financial support and the added burden of a sick family member affected a whole household, participants said. Murray *et al.* (2013) argued that when patients shifted blame and placed it on external factors beyond their control, they feel disempowered and were less likely to be motivated to seek treatment or to fuel change in the community. In this Gugulethu study, the participants expressed the view that living in the township was in itself a driver of TB.

Bheki, a 47 year old male contracted TB while he was incarcerated and at the time of the interview he was on treatment for MDR TB. He was released from prison on parole due to ailing health. Bheki attributed his illness to prison conditions and said even though he was aware that he would most likely become ill, he was not in a position to do anything about it.

“A hundred people in one cell sisi (chuckles). Sharing one sink, a few spoons and a few plates? All the dust caused by sweeping. There was no way I would not have been sick.” (Bheki 47 year old male)

From the participant's response, one can tell that there is an understanding that TB is a communicable disease due to his reference to overcrowding in the prison cell. He then draws attention to the dustiness and subsequently also referred to poor hygiene. This refers back to Abney's (2011) argument that people associate dirty places to the spread of TB. Being in confinement meant that Bheki had no choice and little chance to avoid TB infection. Bheki still struggles to adjust to life outside prison because when he was released he was very ill and could not look for a job. His friends and relatives provide minimal support but he pointed out that being an ex-convict also carried a stigma, therefore his family was not very forthcoming about assisting him. He said as soon as he was well enough he would search for piece-work in the suburbs.

Bheki's situation once again raises the issue of possible financial support of TB patients. Lutge *et al.* (2014) illustrated how economic support assisted those who were suffering from TB by supplementing their income. The vouchers given to the selected patients in the study meant that patients at least had a source of much needed food when taking their medication. Furthermore, Grande and Zumla (1999) argue that for one to recover from TB there is need for good nutrition and food security is therefore paramount. There is also a relationship between food and adherence to treatment. People often find it to take TB medication without eating first (Lutge *et al.* 2014).

Situations such as that of Bheki who is unemployed and suffering from MDR TB are not rare. There is need for government and/or community intervention to ensure food security among patients. The presence of a soup kitchen for TB patients in Gugulethu is one such initiative designed to ensure a basic intake of nutrients. That too comes with its own logistical challenges. Patients have to be able to get to the soup kitchen because there are no home delivery services. This becomes a struggle for patients who are too ill to make their way there. It raises the idea of the value of support from others such as friends and family

members. They become a fundamental factor that can determine TB patients' adherence to treatment and ultimately, their recovery.

Psychosocial support is one factor that came out as imperative in seeking treatment. A number of respondents were encouraged to seek treatment by family and friends, but some only did so when coerced. According to Munro *et al.* (2007), family support including financial assistance and emotional support encouraged patients to seek treatment and to adhere to it.

“My family made sure I sought treatment. They could tell that I wasn't myself and they made me go to the doctor.” (34 year old male)

Family support gives patients the means and support to deal with the diagnosis of their symptoms and as such. Most participants highlighted that they had family members who encouraged them to go to the clinic after noticing that they were unwell. In some cases, those relatives and family members even accompanied the patients to the clinic or hospital for moral support. The family unit or close relations with others cannot be ruled out as a factor that determines the outcome of TB treatment interventions.

4.5 Seeking treatment in Gugulethu

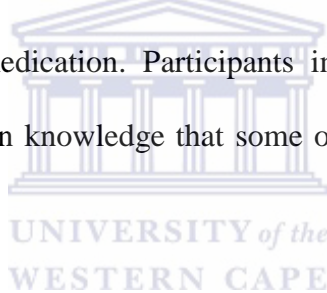
As indicated above, the participants indicated that TB symptoms were often initially self-diagnosed as flu or a common cold. As a result the participants treated these symptoms using flu medication that is commonly known and is easily accessible in shops and over the counter without any doctor's prescription. In a study done by Mavhu *et al.* (2010), patients waited and monitored the progress of, e.g. a cough, in order to determine its severity.

Most study participants in Gugulethu sought medical treatment after realising that their symptoms persisted. This indicates that in Gugulethu there is trust in the health care system.

In Zimbabwe however, the healthcare system is not trusted because of its malfunction during the time of economic recession (Mavhu *et al.* 2014) and as a result going to the hospital or clinic is usually the last resort.

Participants in Gugulethu did refer to e.g. bewitchment or spiritual pollution as causes for TB. They apparently also did not seek explanations for their illness other than biomedical ones. This is contrary to what Steen and Mazonde (1999) discovered in their research in Botswana where the majority of TB patients consulted prophets and traditional healers in their search for the reasons why they suffered from TB.

In Gugulethu study participants combined the use of pharmaceuticals prescribed and provided for TB treatment with the use of herbs and medicinal plants. Seeking treatment was often delayed due to self-medication. Participants indicated a strong faith in herbal medication and said it is common knowledge that some of these herbs can be used to treat various ailments:



“I used to take a herb called umhlonyane. You boil the leaves and drink. It cures almost everything. I also started jogging. It also helps. As you sweat, the TB comes out with the sweat and afterwards you instantly feel stronger.” (47 year old male)

Buwa and Afolayan (2009) describe *umhlonyane* (*Artemisia afra*) as a shrubby perennial herb with a leafy, hairy stem which is used for different purposes in many areas. They state that the herb has traditionally been used to treat a wide spectrum of respiratory disorders which include coughs, colds, whooping cough, fevers, bronchitis and asthma. According to Buwa and Afolayan (2009) research shows that *Artemisia afra* contains significant antibacterial activities and this may explain why it is used as a herbal remedy for respiratory disorders. It is this belief in its healing ability that makes people respond to respiratory TB symptoms by using the herb.

I was shown the *Artemisia afra* herb by a participant who grew the shrub in his yard. He said that it is a common herb that most households grow and often make use of when treating various diseases. This knowledge of herbal medicines seems to be passed down through oral tradition. The fact that herbal treatment worked in past generations fortifies the faith people have in herbal remedies regardless of social dynamics that have taken place over time and the evolving trends of diseases. Research done in Namibia also shows a strong belief in the use of medicinal plants as treatment for TB (Gibson 2010). Gibson (2010) also proposes that some medicinal plants have anti-bacterial traits and this could account for some of their healing abilities. This however requires further research and it is one more reason why healthcare personnel should fully explain TB disease to patients so that they understand why it is necessary to take TB treatment and adhere to it despite their belief in ‘alternative’ treatment.

Similarly in Kenya, people who experienced TB symptoms used self-medication in the form of herbs or medicines – often acquired from friends and relatives who have experienced similar symptoms (Liefoghe *et al.* 1997). Liefoghe *et al.* (1997) reported that in Kenya, traditional healers were consulted by patients at some stage of illness. Some Kenyans preferred traditional medicine to biomedicine because they found biomedical treatment regimens cumbersome. People with TB have to take a lot of pills. Patients also saw no harm in using a variety of methods of treatment. When there was little improvement after using modern medicine, traditional medicine became the alternative. This is common especially in rural Kenya where there is a strongly-rooted belief in traditional healers.

The setting in Gugulethu is somewhat different from that in Kenya because it is an urban area. Study participants did not go to traditional healers for TB treatment – this disease was seen as the main knowledge and treatment of the formal health care system. Instead

participants consulted traditional healers for social and ‘cultural’ matters such as problems in relationships, bad luck, to explain dreams, do rituals and such.

A number of participants used treatment methods that were common among the community members and were used as treatment for various symptoms:

“I used to treat myself. I would pour hot water in a bucket and cover myself with a blanket so that I would breathe in the steam and sweat. That sweating cures many things especially when you are coughing. Sometimes I would drink a lot of water and make myself vomit so that I clean my insides and the illness would come out with the vomit.” (43 year old male)

These participants who tried self-medication and other treatment methods prior to seeking medical attention did so due to a mistaken perception of the seriousness of the symptoms because of their similarity to flu. There is deep-rooted faith in these alternative methods and this suggests that in some instances there have been successful treatment for some ailments. When these alternative methods fail to treat TB symptoms it indicates that the symptoms may be more serious than previously contemplated. Biomedical interventions are then sought and often the assistance of others is needed for this journey of TB suffering

4.6 Experience on TB stigma and discrimination

Most participants stated that revealing to others that they suffer from TB was not an easy thing to do but they did it for fear of stigma and gossip which is encouraged by its perceived contagiousness especially in an area where people are prone to TB infection:

“You have to disclose because even if you don’t, people can tell sisi. After some time it begins to show. You become dark and thin and people begin to think you are suffering from other things. It’s better to tell them before they start talking.”

Participants highlighted that making others aware that one has TB makes it easier for one to deal with, e.g. an employer in times when they are very ill and need sick leave or when they need to take time off for their visits to the clinic. Thirteen participants said it was better to tell others when you had TB so that you can get assistance from friends and relatives: when one has TB every bit of support helps if one is to survive the illness. Munro *et al.* (2007), in their research findings refer to the importance of family in disclosure of TB. Abney (2011) argues that there is anxiety and fear that is experienced by people who have TB because of their uncertainty on how people will react to their illness. For reasons similar to those found in Khayelitsha, my participants said that they found it easier to tell a family member:

“I preferred to be alone in the house because I easily became angry and I did not want people to notice and start asking questions. It is not easy to disclose. You can tell one person who can help you when you are very sick.”(34 year old female)

Many participants said that they felt compelled to make it known that they had TB. They foresaw stigmatization if they failed to do so, fearing speculation on their illness (as HIV for instance). For this reason, alerting others to their TB was used as a protective mechanism and a means to avoid the stigmatization related to HIV, which they constantly referred to as ‘another disease’ or ‘other diseases’:

“If they see you in hospital they talk. It’s better to tell them you have TB before they see you because they will ask themselves what are you doing in the hospital and when they start talking they will even start looking at you with a different eye. They can say you are suffering from other diseases.”(42 year old male)

Clearly there is a need for study participants disassociate themselves from HIV and to rather clarify that they have TB (cf Wood *et al.* 2011). Patients are always conscious of being watched or being under surveillance due to their illness. As such their movements are

reduced and they try to behave in a manner that is acceptable to society in order to retain the acceptance of other community members, or to keep their positions in social circles (Abney 2011).

There is a general consensus by participants that stigma and discrimination exists in Gugulethu, although people experience it with varying intensity. It is issues such as these that Kleinman (1988) suggests should be given supremacy; the experiences that patients have when suffering from a disease because these in turn determine their treatment-seeking behaviour (Kleinman and Kleinman 1991). Many participants said that their families were supportive during their illness and therefore discrimination emerged as something unintended and rather as part of a TB control measures in the home, e.g. when household members try not to share eating utensils, or avoid close proximity to the sick person.

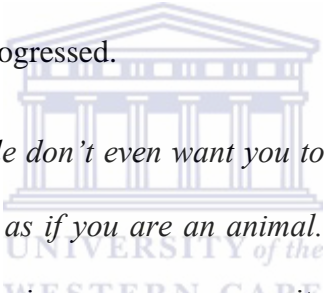
In research conducted in the Eastern Cape, Cramm *et al.* (2010) found that perceived stigma for TB was one reason for non-adherence to treatment. Although some patients experienced 'discrimination' in the home, there was no malice intended by their families. Some actually stressed that they could not share certain things with family members because they also did not want to spread the disease to their families. Nonetheless they felt somewhat isolated as a result.

In Gugulethu stigma was mostly experienced outside the home from other community members. Nonetheless 'precautions' were taken in the home and this resulted in a feeling of 'otherness' and a loss of commensality with family, as shown by one respondent:

"TB shows. One who has TB becomes dark and their lips change. People can usually tell when somebody has TB and they do not want to share things with them. At home you have your own cup and plate so that you do not spread the disease to the others."(32 year old male)

For others, their experience of stigma from TB was more intense. Bheki is one patient who says he is often stigmatised against and says it is probably because he is ill looking and has been ill for a while and people fear contracting a disease from him. Although Bheki had MDR TB, he did not wear the M95 mask described and discussed by Abney (2011) in Khayelitsha (cross refer here to the section where this is discussed). The mask becomes a sign that the wearer is suffering from a serious illness. Not wearing it therefore becomes an attempt to blend in with the rest of the people and not 'other' oneself with the burden and connotations that come with wearing this distinctive mask.

Bheki cannot hide (with his mask) in the house because he has no source of income and has to visit the soup kitchen in the area. He walks to it daily: it is during these walks that people see him and how his illness has progressed.



“When you have TB people don’t even want you to look at them. They ask ‘what are you looking at? Foetsek!’ as if you are an animal. They don’t even want to be near you. You become a stranger in your own community” (Bheki)

The five participants who found it easier to deal with their TB came from close-knit families and also had a better understanding of TB disease than others. They understood that TB can be treated and they had supportive families who eased the burden of their illness.

“For me it was easy. When I came home from the clinic I told people that I had TB. Some may find it hard to tell people because they are afraid of being treated badly but I had a lot of support so I disclosed. Those who understand TB and how it is spread do not stigmatise but those who don’t are afraid of catching it and avoid those who are sick.” (36 year old female)

This participant (and her family) understands that TB is a disease independent of HIV. They all dealt with TB as they would with any other ailment that would not necessarily bring stigma.

For four participants, TB was a biomedical disease that simply required biomedical treatment and if medication was taken correctly it could be treated. They found it easy to tell the people around them that they were suffering from TB and did not express fear, risk and anxiety like those who struggled with disclosure. This showed some participants had a good support system that helped give them the courage to deal with the illness the way they would with any other.

TB nevertheless affects peoples' lives: One respondent said:

"You cannot work. You cannot go out and interact with others. Your life changes"

Unlike female participants men found it difficult to participate in social activities that they would normally enjoyed as part of living in the community:

"It is difficult. You have to stop drinking because when you are on treatment you cannot drink. You cannot go to the tavern because some people are not comfortable with having someone with TB around them. Most days you just stay at home. It is easy to lose friends." (32 year old male)

Alcohol is frequently mentioned in relation to non-adherence to treatment. Alcohol consumption and smoking are reasons for people to frequent places that put them at risk of coming into close contact with individuals who have TB. It is also where TB patients are likely to spread TB to others because of sharing beer and passing cigarettes around. These behavioural factors are a form of entertainment in the community and some patients

experience stigma whilst others self-stigmatise and discontinue sharing, which eventually means losing touch with friends.

4.7 Experience with TB treatment

In Gugulethu, TB treatment is available at the clinics and in hospital. It is administered as part of the DOT strategy where a TB patient needs to be observed when taking medication. Some TB patients are required to make daily visits to the clinic whereas others can be observed by a friend or relative with whom they go to the clinic to collect their medication. This is a way to ensure that patients have someone who can monitor and observe them during the duration of treatment. There are also community health workers who make home visits to TB patients and assist them in any possible way in order to make their experience with TB less of a burden. Support groups in various parts of the township also assist patients so they can meet and encourage each other.

None of the people who were interviewed were familiar with the term Directly Observed Treatment but understood that the treatment they were taking was administered as a TB treatment strategy. In Gugulethu DOT was administered in different ways. Some patients were required to go to the clinic daily for their treatment for a certain prescribed duration and others were asked to go to the clinic with somebody who would monitor how they took their medication and who would also ensure that the patient adhered to treatment. According to one participant:

“I told the doctor that I cannot go to the clinic every day and I asked him to give me pills for the whole month and he refused and said I should come to the clinic every day for the pills. These people don’t understand. What could I do? I’m the one who was sick and needed the pills.”(42 year old female)

While DOT allows the patient to have their own treatment observer some health personnel did not make this option available to the patients, who in turn interpreted this as a lack of understanding on the part of the doctors and nurses. In this regard the study participants expressed negative attitudes towards healthcare personnel, even though, as indicated earlier (cross refer here), they trusted them. The DOT strategy offers psycho-social support and in Gugulethu there were counsellors and health workers who paid visits to patients and checked on them and their progress. Although this service existed, most participants did not participate in it:

“Health workers visit you in your home and check if the place where you stay is clean and if your clothes are clean and whether you are eating well or not. If not, they take you with them to their place here in Gugulethu where they take care of you for three months as you recover.” (33 year old male)

Two participants said they were reluctant to remain at Vuyani clinic, which offered TB/HIV services to patients. Here they were closely monitored and given treatment under observation. The clinic has facilities for very ill patients where they can be observed for a stipulated period of time. They are also provided with basic needs for the duration of their stay there. This includes food: for patients who are very ill, there are food supplements that are available to them in the form of shakes with balanced nutrients. These shakes are easier to take especially for patients who have no appetite and have difficulties in food intake. The researcher established that reluctance was caused by two factors. One reason was that the clinic was primarily an ARV access point and TB patients were hesitant to be mistaken for HIV patients, as one participant stated:

“Vuyani is not far. People at Vuyani are very sick and when you go there people know what you have. Sometimes they say it’s HIV when it’s not. When they see you at the clinic they start talking, so I go to the hospital.”

The other reason why TB patients were reluctant to be cared for at Vuyani was that they preferred being with their families when they were not well. Patients felt that being admitted for long periods of time made them feel lonely. They said that healthcare personnel would only be ‘doing their job’ and would therefore not be as caring as friends and family would be. Munro *et al.* (2007) argues that patients on treatment become increasingly demoralised and more likely to default as family support weakens.

One issue that was raised by most participants is how badly the healthcare workers treated them at the clinic. Dingi, a 42 year old male, said that he preferred to go to Mitchell’s Plain for treatment and did not use the healthcare facilities in Gugulethu. Although the services there were within close proximity, the attitudes of the nurses had driven the participant to seek treatment further away from his home.

“Yes they are supportive but they are rude. We accept because we know nurses are rough. That is how they are. In Mitchell’s Plain they are better. Coloured people don’t shout as much as our nurses here. They say few words in English because they know I am Xhosa and they don’t know Xhosa so they only say what they have to say.”(Dingi)

Another participant shared the same sentiments:

“They are very aggressive. They should be more patient and understand that one does not ask for sickness. It just comes. I did not ask for it so they should still treat me like any other human being.” (39 year old male)

Participants say that it is common knowledge in Gugulethu that nurses are ‘rough’. It is such social dynamics that require further investigation of TB treatment because they have an impact on the experience of ill-health and treatment. DOT may also require frequent interaction between health care providers and patients.

In Zimbabwe Mavhu *et al.* (2010) found that stigmatisation by nurses and other clinic personnel were reasons why TB patients delayed seeking treatment. On a similar note, Lutge *et al.* (2014) propose that nurses are not passive agents therefore their role in TB intervention strategies should not be taken for granted. Their behaviour towards patients and how they deliver the required services have implications for the success of a project or initiative. The mere availability of treatment at the clinic does not guarantee its uptake. Participants in Gugulethu said their relationship with the nurses did have a part to play in whether they visited the clinics or not.

For some patients being on DOT does not affect their lives drastically. They have no denial of their illness and they handle it well, adhere to treatment and recover.

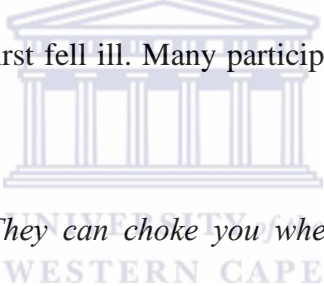
“Life goes on as usual. You can continue working. You just have to tell your boss if you have to go to the clinic.” (38 year old female)

Things are more difficult for patients who depend on others for care-giving and visits to the clinic. According to the philosophy of DOT they need somebody close to them who can monitor their treatment and ensure that they adhere to it. Otherwise it means a daily trip to the clinic to have the medication administered there. This usually involves money for transport as well as making time to go to the clinic on a daily basis. According to study participants in Gugulethu this becomes a burden to patients and chances of defaulting may increase. The challenges with DOT may not only be financial but also emotional and physical as a participant remarked in relation to his treatment:

“Walking is difficult. The clinic is not far, but the energy to walk there is just not there. Some days you cannot even eat but you have to go to the clinic. You run out of breath and you have to rest often. Since I chose to go to the clinic in Mitchell’s Plain it meant extra costs for transport. Somehow I just had to find the money.”

A caregiver or observer also has to make adjustments to accommodate the needs of the patient. This requires good relations between observer and patient and participants say that in most instances it is either a family member or a close friend who is willing to oblige.

The long-term treatment required for TB is one issue that most participants raised as a challenge they faced when taking TB medication. They understood the importance of adherence, especially those who suffered from MDR TB, and expressed regret at not having adhered to treatment when they first fell ill. Many participants had problems with the actual pills and injections:



“The pills are too big. They can choke you when they are stuck in your throat. Sometimes you have to take them with a piece of bread that will push them down. What I do is I crush them and turn them into a powder that I can dissolve in water. That way the medication is easier to take.” (47 year old male)

Patients come up with ways of handling treatment which make it somewhat easier for them to take the medication and avoid defaulting

“I prefer going to Mitchell’s plain. There you are given one pill to take per day. Here at Gugulethu clinic the pills are too big and too many. They make you vomit so I would rather get treatment at Mitchell’s plain.” (39 year old male)

Participants also stated that they faced challenges with the immediate effects of medication. Most of them said that the pills caused them to become weak and to vomit especially if taken on an empty stomach:

“The pills are heavy on the body. They should stop changing them. Every time they do many tests and give you different pills. If those pills do not work they do more tests and keep trying other pills. They should know what pills to use. It is not easy to keep changing pills. They make you sick.”(42 year old male)

4.8 Conclusion

This chapter has explored the ways in which people in Gugulethu deal with TB and how they understand it. People in Gugulethu understand the symptoms of TB but at its onset, they try home remedies before consulting medical practitioners. There is evidence that TB is stigmatised in the township due to its symptoms which are similar to those of HIV, a disease that carries stigma because of the perceived lack of morality attached to it. The chapter has explored how people interact with DOT and outlined the various challenges that come with being on TB treatment. Despite awareness of TB, there are various socio-economic factors that pose a barrier to TB interventions and these have also been drawn out.

Chapter 5: Conclusions and Recommendations

This chapter summarizes the study findings and draws conclusions based on the objectives that guided the research. The limitations of the study are highlighted and recommendations outlined, with some suggestions for further research.

Participants in Gugulethu have knowledge of the symptoms of TB and an idea of how it is spread, although there are some blurred lines in their understanding of how contagious it is. Symptoms such as continuous coughing, fever, loss of appetite and loss of weight were most commonly mentioned by the participants. They strongly believed that factors such as alcohol intake, cold weather and smoking caused TB. Their observation of the connection of these factors to TB is vital because they could contribute towards compromising health and immune systems, thereby catalyzing already latent TB and driving it to develop into active disease. One issue that stood out was that knowledge of TB increased greatly when participants became were diagnosed and began treatment. Those who were more knowledgeable about TB prior to their illness acquired this knowledge from a friend or relative who had TB and not through awareness campaigns.

The link between HIV and TB is not clearly understood by most participants. There is an idea that the two diseases go hand in hand but no clear knowledge of how the Human Immune Virus compromises one's immune system, making the person vulnerable to TB, which is an opportunistic disease that the compromised system cannot control. There is a mistaken belief that TB somehow develops into HIV at some point during illness.

There is also an awareness of Multi Drug Resistant TB but there is insufficient medical knowledge of what it is. People however are aware that TB is curable but it can become

severe and result in death. This fear of dying of from TB encourages people to adhere to TB treatment.

Apart from the behavioral factors driving TB in Gugulethu, there is a strong feeling that TB is also determined by the prevailing living conditions and the community places the responsibility for these conditions on the government and its leadership. In their view, regardless of all the knowledge that can be attained on TB as well as the advance in treatment and medication, if poor living conditions persist, efforts to eradicate TB are futile. The number of people per dwelling and the type of dwelling itself makes it difficult for people to exercise TB prevention control measures.

In relation to the stigmatization of TB in an area burdened with a high HIV burden, participants understand that TB is a disease that can be cured by taking the treatment according to prescription. There is an understanding that non adherence to treatment regimens causes difficulty in treating TB. The presence of MDR TB, for instance, suggests that people do not always adhere to treatment. From the research it appears that this is not because they have no access to medication but because of inadequate psychosocial support to encourage and enable them to keep taking their medication.

Compared with similar research done in Botswana (Steen and Mazonde 1999) the people of Gugulethu do not attach any supernatural etiology to TB. Some feel that contracting TB is almost inevitable given the poor state of the environment.

There is a wide tendency to self-medicate when participants first experience TB symptoms, which are often mistaken as indicative of common cold or flu. Self-medication can be in the form of herbal medication or other practices known to assist in disease treatment. Even after diagnosis, patients continue to administer such treatment together with their medication for TB, the idea being that they boost the ability of one's body to fight disease and they can

‘work together’ with TB pills. Liefoghe *et al.* (1997) reported similar findings in research in Kenya where participants used *muti* prescribed by traditional healers in conjunction with biomedicine because they saw no harm in doing so. Some abandoned biomedicine if they found it too onerous to deal with, and used traditional medicine as an alternative.

The study indicates that participants feel that TB is stigmatised in Gugulethu. In this regard the three types of stigma that Naidoo, Dick and Cooper (2008) discuss are all present in the township. There is anticipated stigma which results from patients’ observation of how other TB patients are treated and observations of how HIV sufferers are treated. The two diseases are seen as related, therefore TB patients anticipate being stigmatised when they look ill and are thought by others to be HIV positive (Abney 2011). They also anticipate stigmatization resulting from being seen at the clinic taking medication because the clinic in Gugulethu is an ARV administration center that also caters for TB patients. By simply observing people walking into the building, one cannot tell who is suffering from what. In an attempt to keep their TB status a secret patients end up preferring to go to the hospital where there are people suffering from various diseases (Abney 2011).

Self-imposed stigma is common among female participants in Gugulethu. Upon discovering that they have TB, they disassociate themselves from other community members and prefer to remain indoors. They state that women gossip a lot therefore they would rather not be seen until they feel and look well. In cases where men self-stigmatise, they cease going to social gatherings to interact with other men or join in leisure activities such as drinking and smoking. These men are aware of how TB is spread and they fear being discriminated against by other men by being excluded from drinking and smoking circles and as a result, they keep to themselves.

Lived experience of stigma was not reported by many participants but those who did say it was experienced outside their homes, in the community. This stigma was in the form of actions and words. Hurtful words were spoken and they were often driven away by others who feared contracting TB from them. They attributed these reactions to their sickly appearance and the fear of community members that they would get TB and look like the patients. There was some practical discrimination in their homes, mostly involving arrangements like TB patients having their own bedding and cutlery in order to avoid spreading the disease to other family members. This discrimination was enacted in good faith as a TB control mechanism and participants did not appear to be hurt by these actions. Some actually encouraged it as necessary precautions.

In relation to participants understanding of DOT, it became apparent that participants were initially not aware of what the term DOT means, but were aware that there is a treatment strategy that is being implemented in their community. Most of the patients do not make use of certain components of the DOT strategy such as the counselling services or the quarantine centre for those who are too ill to travel from home for treatment and require close monitoring by healthcare personnel.

A number of patients had a problem with the actual medication. They said the pills were too big and difficult to swallow. Many of them also had problems with the side effects of the medication but the knowledge that TB could kill, made them persevere in most cases. Those who defaulted took medication for a longer period of time and some had to be given injections after developing MDR TB. They found this to be a burden and more cumbersome than taking treatment for active TB.

DOT involves a number of interactions with healthcare personnel and for many patients this was reportedly not a pleasant experience in Gugulethu. Some even opted to get their

treatment from a hospital in a different area even though it was further away from home. Those who had their treatment at the clinic on a daily basis faced financial challenges as well as emotional and physical problems. When they were very ill, walking became difficult even if the clinic was close by.

Although Gugulethu, like any typical township, is beset by hardships in most spheres of life, there is relative faith in biomedicine as a way of treating TB. Other treatment methods are used to 'boost' biomedicine rather than as an alternative. People associate TB with poverty as well as a dirty environment. They feel that if their environment were cleaner and if they had better housing, water and sanitation services then they would not be as vulnerable to TB as they currently are. For this reason, people feel that TB control is out of their hands. They do practice some control measures such as covering their mouths when they cough and using separate blankets and utensils in their homes but beyond that, all other efforts are perceived to be beyond their control.

There is stigma attached to TB in Gugulethu and this is fueled by its association with HIV and the clouded understanding of how the two diseases are related. This stigma varies, with some being discriminated against by community members and other patients not having experienced it. Those who had experienced instances of stigmatization attributed this to their physical appearance which made others fear them, exclude them or call them names. A limited knowledge of how TB is spread at times resulted in staying out of circulation in an effort to protect others from contracting the disease.

The high HIV/Aids prevalence in Gugulethu has led to an acute awareness of HIV and a fear of this co-infection in the community, which has led to people to react to TB in a similar way as their response to HIV. Often, the driving force behind their attitude towards TB is fear of a grueling illness, stigmatization and dying. HIV is still so stigmatised that people still cannot

bluntly refer to it as HIV but use innuendos instead. There is difficulty in disclosing that one has TB because people do not want their illness to be mistaken for HIV.

In Gugulethu participants faced difficulties once they became sick. Poverty is exacerbated when they are unable to work. Most participants who were part of the study were unemployed at the time of the research but said that TB made it difficult to even do their daily chores and thus they need assistance from others. There is dire need for financial and psycho-social support. TB is not a disease that one can easily survive without having close support from others who understand the situation. People's experiences with TB have shown the importance of family and friends who can be counted on when one disclosing your TB status. Because of the level of trust that exists in these relationships it encourages patients to be honest about their ill health with the guarantee that support will continue even after disclosure.

Those who have MDR-TB or TB/HIV co-infection appear to have the heaviest burdens in dealing with TB. Their appearance instills fear and causes stigma yet they are among those who need assistance the most. Although the community provides support in terms of soup kitchens and support groups, the issue is one of access rather than availability, because those who are seriously ill are often unable to reach these services. They do have the option to be admitted to a clinic until they feel better although many are reluctant to be separated from their families and therefore this service is often not used. Access to treatment is available to all regardless of gender, but gender appears to determine people's decisions to make use of these services.

Gugulethu township has embraced TB treatment compared to other communities such as those studied in Kenya and Botswana (Steen and Mazonde 1999; Liefoghe *et al.* 1997). People still make use of herbs and other treatment practices either at the onset of symptoms

or together with biomedicine. Often treatment seeking is involuntary. Patients who display symptoms are encouraged or even at times forced by family members and close friends to seek treatment. Most times they do not perceive TB symptoms as serious because of its likeness to flu or cold symptoms.

After being diagnosed people in Gugulethu take their medication despite exhausting side-effects for fear of becoming worse, especially when sufferers have seen examples of other community members who defaulted. There is an awareness that TB kills and that the illness is grueling, thus people try to adhere to treatment. Those who admit to defaulting and have developed MDR-TB express regret at not adhering: they have become examples of the effects of TB in the community. There is also awareness that treatment for MDR-TB is considerably worse than that for active TB, so those with active TB dread relapsing and consequently take their medication.

Scant knowledge of TB and its symptoms contributes to the factors that lead to delays in seeking treatment. This is because upon experiencing TB symptoms, patients hardly suspect that they could be suffering from TB. Those who do suspect so may be in denial and prefer not to acknowledge this reality. Late treatment-seeking further complicates TB treatment.

Recommendations

1. There is need for TB care and treatment providers to provide patients with detailed information on their illness and treatment in order to improve their understanding on what is going on in their bodies. That way they will be able to identify the types of TB and clearly understand the need to adhere to treatment.
2. TB awareness strategies could encompass edutainment where community members are educated through entertainment, especially if the entertainment is participatory. Community

members could be given the opportunity to act in community plays that raise awareness of TB. This would also be a good way of conveying an interesting message in order to capture the attention of people.

3. Equal attention should be given to HIV and TB awareness to avoid an imbalance in knowledge of the diseases. This would assist people in their understanding of the relationship between HIV and TB and reduce misconceptions that lead to speculation and stigmatization of patients.

4. Efforts to improve TB awareness should be age-specific. Children and illiterate individuals should be given simplified information for easier understanding. The youth should be engaged in interesting projects to encourage participation. Messages can be spread through sport or by using local celebrities to attract this particular age group and to pose as ambassadors and role models.

5. There is need for economic support for TB patients who are too ill to work or take care of their families. This would ensure availability of food not only for the patient but for the household. Since it has been established that the availability of good nutrition is important in the recovery of TB patients, the government should consider ensuring the food security of patients in an inclusive manner that would include all patients.

6. Having identified the various factors that drive TB in Gugulethu, there should be co-operation among stakeholders in order to reduce TB disease. Communities should come together and assist each other in making the environment cleaner. They should also be encouraged to make changes in their behaviour and lifestyle by drinking and smoking less, if at all.

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Appendices



UNIVERSITY of the
WESTERN CAPE

OFFICE OF THE DEAN DEPARTMENT OF RESEARCH DEVELOPMENT

14 November 2014

To Whom It May Concern

I hereby certify that the Senate Research Committee of the University of the Western Cape approved the methodology and ethics of the following research project by: Ms WS Ncube (Institute for Social Development)

Research Project: Peoples understanding of TB in a setting of high HIV/TB prevalence: Case study of Gugulethu Township, Cape Town.

Registration no: 13/9/9

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

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

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

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

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Letter of Consent:

I....., have had the opportunity to ask any questions related to this study, and received satisfactory answers to my questions, and any additional details I wanted.

I agree to take part in this research.

I understand that my participation in this study is voluntary. I am free not to participate and have the right to withdraw from the study at any time, without having to explain myself.

I am aware that this interview might result in research which may be published, but my name may **be/not** be used. (Circle appropriate).

I understand that my name will not be used and that this will be ensured by the researcher.

I may also refuse to answer any questions that I don't want to answer.

Date: _____

Participant Name: _____

Participant Signature: _____

Interviewer Name: _____

Interviewer Signature: _____

If you have any questions concerning this research, feel free to call Wenzokuhle S. Ncube on (+2783273488) or by email on wenzokuhle@gmail.com. Alternatively, you may write to my supervisor Professor Diana Gibson on gibson.diana@gmail.com for any further questions.



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INFORMATION SHEET

Project Title: People's Understanding of TB in a setting of high HIV/TB prevalence: Case Study of Gugulethu Township Cape Town.

What is this study about?

This is a research project being conducted by Wenzokuhle S. Ncube at the University of the Western Cape. We are inviting you to participate in this research project because you have knowledge on tuberculosis (TB) illness experience. The purpose of this research project is to investigate the meanings that people attach to tuberculosis. It will explore the illness experiences of TB patients and bring out how they deal with the burden of the disease in an environment that is TB endemic. The research intends to contribute to existing knowledge on TB and people's own understanding and experience of living with it for the duration of their treatment. The findings will highlight the areas where public policy can be improved in order to reflect the needs of TB patients and assist them in coping with the burden of the disease.

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

You will be asked to share information, opinions and experiences on the tuberculosis and how it is understood in your community. The interview will take about 30-45 minutes and will take place in Gugulethu Township where the participants live. The interview will involve answering questions on one's knowledge on TB. Those who have experience with TB disease will be asked to narrate their experiences. Interviewees will be asked questions such as; what does TB mean to you? Is TB stigmatised and if so, why and how?

Would my participation in this study be kept confidential?

Your personal information will be kept confidential and participants will remain anonymous. You will be required to sign a consent form to protect your confidentiality and privacy whilst taking part in this study. The information contributed by participants will be kept safe and only used for the purpose of this research project. In the research report, your name will not be used and your identity will be protected to the maximum extent possible.

In accordance with legal requirements and/or professional standards, we will disclose to the appropriate individuals and/or authorities information that comes to our attention concerning potential harm to you or others. Confidentiality of information provided by participant is guaranteed.

As the researcher I am bound by the university ethics policy which provides ethical and legal obligations regarding my conduct. The policy makes provision for ethical conduct in the collection and use of information gathered during this research.

What are the risks of this research?

There may be some risks from participating in this research study. The subject matter may bring out unpleasant emotions during narrations of experiences. You will not be forced to answer questions that you are not comfortable with and the researcher will not persist. From the onset the aims and objectives will be made clear with all participants so that no unrealistic expectations are created through participation.

What are the benefits of this research?

This research is not designed to help you personally, but the results may help the investigator learn more about the socio-medical aspect of TB. We hope that, in the future, other people might benefit from this study through improved understanding of TB and that interventions will be designed in such a way that they cater for the needs of patients in all aspects. It is hoped that policy makers will pay more attention to the effects of TB on other dimensions of one's life and not only the medical side of it.

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

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

Is any assistance available if I am negatively affected by participating in this study?

There are no likely or anticipated negative effects that could arise from participating in this study.

What if I have questions?

This research is being conducted by Wenzokuhle S. Ncube (078 327 3488), a student at the University of the Western Cape. If you have any questions about the research study itself, please contact Professor Diana Gibson at the University of the Western Cape, telephone number 021 959 3349, email: gibson.diana@gmail.com

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

Head of Department:
Director of Institute of Social Development
University of the Western Cape
Private Bag X17
Bellville 7535

This research has been approved by the University of the Western Cape's Senate Research Committee and Ethics Committee.