

**Exploring tuberculosis (TB) patient's adherence to treatment regimens and  
prevention programmes at a public health site**

**by**

**Pamela Naidoo**

**Student Number: NDXPAM003**

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## **ABSTRACT**

TB has re-emerged as a health threat to societies worldwide and is, consequently, a public health issue. In sub-Saharan Africa there is a high prevalence of TB and South Africa, specifically, the Western Cape Province is said to have one of the highest prevalence figures in the world. While it is well established that TB is a disease of poverty and it is expected that the prevalence of the disease will remain high in communities where the cycle of poverty persists, it is important to explore other factors that may help to reduce prevalence and incidence despite the relatively under-resourced living conditions of patients.

The aim of this study, therefore, was to explore the factors that contribute to TB patient's adherence to the Directly Observed Treatment Short-Course (DOTS) strategy and the factors that serve as barriers to adherence. The study was set in a historically disadvantaged township, Khayelitsha, a sub-district of the City of Cape Town in the Western Cape Province. A qualitative, phenomenological research design, which is part of an ethnographic tradition, was used. Fifteen male and female participants between the ages of 18 to 57 years were ethically recruited through purposive sampling at Kuyasa, a Cape Town City Health primary care clinic. In phase one, in-depth individual interviews were conducted in Xhosa, a predominantly used African language in the Western Cape. Issues around the core cognitive and social concepts linked to the study inquiry, namely, illness challenges, quality of health care received, adherence to the treatment regimen, level of awareness about the risk and dangers of infecting others, and reasons for participation or non-participation in voluntary counselling and testing (VCT)

for the human immunodeficiency virus (HIV) were probed. In the second phase, a focus group was conducted with the team of health care practitioners directly involved in the administration and management of TB treatment at the Kuyasa clinic, to ascertain their responses to the feedback given to them about the results obtained from the 15 individual interviews conducted. The interviews and the focus group discussion were tape recorded and transcribed for the purposes of the data analysis.

Theoretically this study is underpinned by a *relativist perspective*, which is one in which the value of theories and knowledge is determined by historical and cultural factors that are dynamic and change over time (Abraham, 2004). A hermeneutical phenomenological approach, which may be located within a relativist paradigm, was used to understand how the life circumstances and experiences of the participants influenced their choice to adhere to treatment for TB.

A qualitative data analysis method, which organizes phenomenological data as suggested by Moustakis (1994), was used to develop themes from the responses of the participants in phase one of the study and from the health care practitioners in phase two. Adherence to TB treatment in the public health sector must be understood within the individual characteristics of the TB patient including their social and economic resources, and the health care setting. The results indicated that six of the 15 participants were co-infected with HIV and no participants were 100 % adherent to TB treatment. Instead, a pattern of adherence and non-adherence to treatment co-existed. In general the participants were knowledgeable about the disease, its infectious nature, and the

effectiveness of drug therapy but nevertheless admitted to periods of non-adherence. Factors found to influence patterns of adherence either directly or indirectly were: social and economic resources prior to the onset of TB and during the course of the disease; the causal attributions assigned to TB; the social, cultural, economic, disease-related and psychological challenges faced as a consequence of having TB; quality of health care received; use of the traditional healing system; and the participants' HIV status. Factors that appear to be strongly associated with periods of non-adherence include poverty, HIV co-infection, stigma and unsupportive social and work environments. The prevalence of helplessness, hopelessness and depression among the participants of this study is possibly one of the most significant psychological contributors of non-adherence to TB treatment. The health care practitioners concurred with the findings from phase one but also provided significant additional input about the advantages and disadvantages of the World Health Organization's (WHO) recommended directly-observed treatment short-course (DOTS) strategy, and made suggestions about how to improve the health service to TB patients.

The findings will be conveyed to the most important stakeholder, which is the management team at the Cape Town City Health Department. The following recommendations regarding the implementation of the existing TB treatment and prevention programme will be made: the need for greater commitment to patient-and community-centred health promotion strategies, support groups for TB patients infected for the first time and for those with HIV and TB co-infection, and a more comprehensive community-based programme using a team of health professionals.

## **CHAPTER ONE**

### **INTRODUCTION**

#### **1.1 Background**

In 1993 the World Health Organization (WHO) declared tuberculosis (TB) as a global health emergency. Since this declaration by the WHO, there has been a serious effort to contain the TB epidemic (WHO, 1996, 2001, 2002). Yet this infectious disease remains a health threat and although it is a completely curable disease, it is the leading cause of young adult deaths (WHO, 2002). The spread of TB continues worldwide despite the widely available internationally recognized Directly Observed Treatment, Short-course (DOTS) strategy to control the epidemic (WHO, 2001).

TB is classified as a communicable disease. According to Beaglehole, Bonita and Kjellstrom (1993), a communicable or infectious disease is “an illness caused by transmission of a specific infectious agent or its toxic products from an infected person or animal to a susceptible host, either directly or indirectly (p 97). Berkow, Beers, and Fletcher (1997) provide a medically contextualized understanding of the disease. TB, they state “is a contagious, potentially fatal infection caused by the airborne bacterium *Mycobacterium tuberculosis*, *M. bovis*, or *M africanum*” (p 968). TB is spread when infected people cough, sneeze, or speak and those individuals who are exposed long enough to the infected person may breathe in bacteria and become infected.

To understand the pattern of TB infection over time, it is important to locate the disease in a social and historical context. Packard (1989) provides an informative and critical

account of the development of the disease in Europe and America and how, in his opinion, the disease was transported to Africa during the period of colonization. At the end of the nineteenth century, through the process of colonization, industrialization expanded into the so-called “third world”, including Africa. The increase and rapid spread of TB, commonly known as the “great white plague” in the late eighteenth to the early twentieth century in Europe and America caused high mortality rates, occurred at the beginning of the industrial revolution. A great number of people migrated to the cities to engage in paid employment but often lived in overcrowded conditions marked by squalor. TB has also been referred to as the “consumption of the poor” (Farmer, 1999). Farmer (1999) emphasizes the role of poverty in the spread of the disease and states that throughout history TB has been more prevalent among the poor. The decline in TB mortality in America and Europe is related to improved living and working conditions from the mid-nineteenth century (Packard, 1989; Farmer, 1999).

TB is completely curable through the intake of a strict anti-TB drug treatment regimen. The DOTS strategy, introduced in 1991 by the World Health Organization (WHO), is an inexpensive strategy that could prevent millions of TB cases and deaths. DOTS consists of five key elements: (1) government commitment to sustained TB control; (2) detection of TB cases through sputum smear microscopy among people with symptoms; (3) regular and uninterrupted supply of high-quality anti-TB drugs; (4) six to eight months of regularly supervised treatment (including direct observation of drug-taking for at least the first two months); and (5) reporting systems to monitor treatment progress and programme performance

(<http://www.who.int/mediacentre/factsheets/fs104/en/index.html>).

Once patients with infectious TB (bacilli visible in a sputum smear) have been identified using microscopy services, health and community workers or trained volunteers observe patients swallowing the full course of the correct dosage of anti-TB medicines. The most common anti-TB medicines are isoniazid, rifampicin, pyrazinamide, streptomycin and ethambutol.

Sputum smear testing is repeated after two months to check the patient's progress, and again at the end of treatment. The recording and reporting system ensures that the patient's progress can be followed throughout treatment. It also allows assessment of the proportion of patients who are successfully treated, giving an indication of the quality of the programme. The DOTS strategy produces cure rates of up to 95% even in the poorest countries (<http://www.who.int/mediacentre/factsheets/fs104/en/index.html>).

In developing countries especially the sub-Saharan region including South Africa (SA), where poverty is widespread, there is a high prevalence of infectious diseases, such as TB. About eight million people become sick with TB each year and in sub-Saharan Africa, about two million cases are reported (WHO, 2002). The WHO ranks South Africa as having the 10<sup>th</sup> highest TB rate in the world with a low treatment success rate of 68% in 2003. In 1999, SA registered a total of 118 686 newly diagnosed pulmonary TB cases. Of these only 60.3% of the new smear positive cases were eventually cured and 17.2% interrupted their treatment (WHO, 1997). At this point the cure rate was well below the WHO target for cure rate. WHO targets, ratified by the World Health Assembly in 1991 were to detect 70% of new infectious TB cases and to cure 85% of

those detected by 2005. While many countries have met these global targets, controlling the spread of TB remains a challenge, worldwide.

South Africa has one of the worst TB epidemics in the world, with disease rates double that found in other developing countries (Fourie, 2005). The role of poverty in the spread of TB is well illustrated in South Africa. Despite the advent of a democracy in South Africa in 1994, the quality of life of the average South African, particularly people who have been previously disadvantaged remains relatively poor, making them more susceptible to ill-health. In a recent edition of the Sunday Times, reporter Ntshingila (2006) published the findings of research conducted by “Eighty20”, described as a “financial think-tank”, about the poverty status in South Africa. It was found that more than 15% of South Africa’s 46.9 million people live well below the accepted poverty line of one United States Dollar (1USD).

The HIV and acquired immunodeficiency syndrome (AIDS) pandemic has, unfortunately, exacerbated the public health dimensions of TB because many individuals are co-infected with TB, and HIV and AIDS (WHO, 1996). Worldwide, an estimated one-third of the 40 million people living with HIV/AIDS are co-infected with TB, and up to thirty-five million people worldwide could die of TB over the next two decades unless greater action is taken to treat and prevent the disease. TB speeds up the progress of HIV and AIDS and vice versa. TB is the leading cause of death among people who are HIV-positive and accounts for about 13% of AIDS-related deaths worldwide (<http://www.globalhealthreporting.org/tb.asp>).

### *The importance of adherence behaviour of TB infected individuals*

In a condition such as TB a relatively strict adherence to the treatment programme is necessary for the patient to be cured. Given the high prevalence and incidence of TB in sub-Saharan Africa, including South Africa and the urgent need to contain the disease and prevent this life-threatening disease from spreading, it is essential that the afflicted individuals heed the advice and follow the treatment plan as suggested by health care practitioners.

A possible explanation for the low cure rates for TB in South Africa is poor adherence to the treatment programmes by the infected individuals. In addition, inconsistent adherence to the anti-TB prescribed drug regimens may lead to multiple drug resistance making it difficult to achieve high cure rates. Farmer (1999) argues that multiple-drug resistant TB (MDRTB) is more prevalent among the poor and should, therefore, be understood as a “biosocial” phenomenon. The emergence of MDRTB, according to Farmer (1999), is similar to the spread of HIV among certain populations because it is shaped by political, economic and cultural processes. If these barriers or issues of “structural violence” are not addressed by the health authorities and governments, the cost of health care to the state increases because more expensive drugs are needed to treat individuals who develop MDRTB (Farmer, 1999). The cost of treating MDRTB is 100 times as much as the cost of curing a TB patient infected with drug-sensitive bacteria (Fourie, 1995). Given the structural barriers that individuals infected with TB face, it is critical, therefore, to understand what factors influence the willingness or the

ability of patients to adhere to treatment and prevention programmes and to utilize this understanding to change the affected individual's behaviour to encourage higher adherence rates and to modify the existing programmes and/or devise new ones.

## **1.2 Rationale for this study**

TB is a serious public health concern given that in SA there was an estimated 419 per 100 000 of the total population infected with the disease in 1997 (Fourie, 2005). TB cases have increased from 349 per 100 000 people in the year 2000 to 550 in 2003, with the worst affected provinces being the Northern Cape, Western Cape and KwaZulu-Natal (<http://allafrica.com>). In the Cape region, the actual registration reports to the National Department of Health indicated smear positive rates as 285 per 100 000 of the total population for the Western Cape, 300 for the Eastern Cape, and 328 for the Northern Cape (Fourie, 2005). Although there is a reduction in the rate of TB in the Cape, until recently the Western Cape was regarded as one of the regions with the highest rates of the disease in the world (Fourie, 2005). This study was conducted in the Western Cape.

In keeping with the United Nations Millennium Development Goals, which includes reducing TB prevalence and death rates by half by 2015, it is vital to examine the factors that may help alleviate the burden of TB as a disease. This means that those patients who are already infected and present themselves for treatment must be willing to adhere to their treatment regimen to improve their health status, and in doing so will prevent

others from being infected. As already mentioned, in a condition such as TB a relatively strict adherence to the anti-TB treatment programme is essential for the patient to be cured.

Although this study is located within the discipline of public health, it interfaces with health psychology and public health because it explores the psychological factors that are pertinent to TB patient's adherence to treatment regimens and prevention programmes. Interfacing the fields of health psychology and public health is one way of achieving in-depth knowledge of both individual factors and factors external to the individual that impact adherence to anti-TB treatment. The term adherence implicitly implies that an individual has to be personally invested and motivated in cooperating with health care practitioners to follow and complete a treatment and/or prevention programme.

### **1.3 Aim and objectives of the study**

The aim and objectives of the study were achieved through the use of a qualitative research design. An interview guide (see Appendix Three) was prepared to ascertain, during the individual interviews, the factors that promote and hinder adherence to anti-TB treatment in an under-privileged group of TB patients attending a public health centre in Khayelitsha, a township in the Western Cape Province of South Africa.

The primary aim of the study was to explore individual factors and those factors external to the patient with TB, that contribute to his or her adherence to Directly Observed Treatment (DOT), with the purpose of empowering patients, improving health services and ultimately, increasing cure rates.

Questions for the interview guide were developed from the existing literature on the factors found to influence adherence and non-adherence. The types of questions asked helped to meet the objectives of the study, which were:

- (1) To ascertain the patient's knowledge of the disease.
- (2) To explore the patient's perception of the barriers or facilitating factors to adherence to TB treatment.
- (3) To explore the patient's perception of the quality of health care they receive.
- (4) To explore the reasons for agreeing to or refusing voluntary counselling and testing (VCT) for the HI virus.

A review of the literature on the factors pertinent to an individual's adherence to the treatment and health-promotive programmes recommended by health care practitioners is presented in Chapter Two.

## **CHAPTER TWO**

### **REVIEW OF THE LITERATURE**

#### **2.1 Adherence and non-adherence**

##### **2.1.1 Introduction**

Adherence to treatment regimens is critical in chronic diseases, particularly those that are potentially fatal and communicable, such as TB. Non-adherence, especially to medical treatment, is detrimental to patients because they may develop serious complications from their conditions. According to the WHO (2003), "Poor adherence is the primary reason for the suboptimal clinical benefit. It causes medical and psychosocial complications of the disease, reduces patients' quality of life and wastes health care resources" (p 25). Despite the information that patients have about the consequences of not cooperating with the treatment plan suggested by the health care professionals and the time that health professionals invest in attempting to improve the quality of life of these patients by addressing their health care needs, a high percentage of people in health-related treatment programmes do not comply (Becker & Maiman, 1980; DiMatteo & DiNicola, 1982; Kaplan & Simon, 1990; Trostle, 1997).

##### *Adherence and non-adherence: Developed and developing countries*

In developed countries there is a significant amount of literature on the various factors influencing behavioural and medical adherence and non-adherence in preventative,

maintenance and promotive health amongst individuals. A range of environmental, social and organizational, cultural, disease, treatment, and psychological factors associated with non-adherence have been identified (DiMatteo & DiNicola, 1982; Meichenbaum & Turk, 1987; Marks, Murray, Evans, & Willig, 2000). One may assume that individuals in developed countries are better re-resourced, socially, educationally and economically, and that largely individuals may adhere or not adhere to treatment regimens based on an informed personal choice. Marginalized groups of people, such as the poor and the homeless in developed countries, however, may face challenges which prevent them from adhering to treatment and prevention programmes. While similar factors influencing adherence may be operational in developing countries, the contextual features of these countries must be taken into account. In a country such as South Africa, the majority of citizens are still disadvantaged, which implies that there are certain economic, social, and cultural factors that may overwhelm the potential an individual has for decision-making about important life events, including health-related decisions.

In reviewing the literature on behavioural and medical adherence and non-adherence to treatment and prevention programmes, it is clear that it is far too simplistic to make broad comparisons between the health behaviours of individuals in developed countries and those in developing countries. Poor adherence rates are reported worldwide (Sackett & Snow, 1979) despite the fact that in some countries there is a better quality of life, overall. In a synthesis of qualitative studies on individual's resistance to medicines, Pound, Britten, Morgan, Yardley, Pope, Daker-White and Campbell (2005) found that individual's were very reluctant to take medicine and prefer to take as little as possible.

In the next section a more detailed analysis of the factors that have an impact on whether individuals afflicted with a disease condition will cooperate with the suggested treatment plan of the health care practitioner. Applying this existing body of knowledge to the South African health care context in the face of the national health priorities, namely TB, HIV and AIDS, and malaria will help to reduce the burden of these diseases and improve the quality of life of individuals. Within the context of this study, exploring the environmental, social and psychological factors that may improve or impede a TB patient's ability to adhere to treatment and prevention programmes will ultimately improve cure rates.

#### 2.1.2 Environmental, social, cultural, disease and psychological factors influencing adherence and non-adherence

##### *Environmental factors*

Often environmental, social and cultural factors that are external to the individual may pose as barriers to adherence. Insufficient knowledge about the nature of a disease and the consequences of being afflicted may lead people to underestimate the importance of engaging in health-promotive and preventative behaviours; one of which is to cooperate with treatment and prevention programmes in order to maintain ones health status. The media has played a significant role in educating the public about the devastating consequences of becoming HIV positive, for example, through engaging in risky sexual behaviours; and the causative relationship between smoking and lung cancer. HIV and

AIDS, and lung cancer are but only two conditions, amongst several, that are life-style related.

The challenge for public health specialists and others working in the interest of promoting healthier nations is that often, despite the health messages that individuals gain through various sources they do not adhere, or in some instances are not able to adhere, to the behavioural and medical recommendations to live a reasonable quality of life, which includes good physical and mental health. In a country such as South Africa while serious attempts are being made to provide health messages to the public through various agencies, such as TV, the newspapers, radio, billboards and so on, these messages are not accessible to all. Many individuals who live in rural areas or in abject poverty do not have the resources that enable them to become empowered through the informal education provided by the various agencies mentioned. Health messages are unlikely to reach those that are at the greatest health risk, such as the poor and the uneducated (DiMatteo & DiNicola, 1982). This of course means that the vicious cycle of individuals infecting each other through a lack of health knowledge will perhaps continue.

Another factor associated with poor adherence is health literacy (Sullivan, Dukes, Harris, & Dittus, 1995). Often patients do not understand the treatment instructions and suggestions given to them by the health service providers. Lower levels of education are expected to be associated with poor health literacy. In a study conducted by William, Parker, Baker, Parikh, Pitkin, Coates, and Nurss (1995) among a sample of patients of low socio-economic status, it was found that 42% were unable to understand what the

treatment direction for taking medication, “on an empty stomach”, meant and at least a quarter of the patients were unable to understand information about their follow-up appointment. The relationship between poor adherence and health literacy may contribute towards lower cure rates of TB in South Africa, where a large proportion of individuals attending public health sites are disadvantaged and have minimal levels of formal education.

The quality of the communication between the patients and the health service practitioner may also pose a barrier to adherence. The way the patient perceives the attitude of the health service provider also affects adherence. Adherence is usually better when the health practitioner displays the capacity to be human, that is, the practitioner is warm, caring, listens intently not only to the reporting of the patients symptoms but also to what is happening in the patients social life. DiNicola and DiMatteo (1982) found that patients are more compliant if their doctor is warm, caring, friendly and interested. A person-centred approach by the health care practitioner enhances adherence as compared to an authoritarian style, which appears to give the practitioner too much control in the patient-practitioner relationship. Patients' are less likely to adhere to treatment regimens if they perceive the doctor to be judgemental, infantilizes him/her by 'scolding', and conveys the message that the patient is in a powerless position relative to the doctor (Roberson, 1992; Rogers, Day, Williams, Randall, Wood, Healy, & Bentall, 1998).

Another factor affecting adherence is the patient's perception of the nature and quality of the health care setting. If patients perceive that the health care setting has good

infrastructure then it is more likely that they will comply with treatment. Waiting times, availability of health care staff, perceived efficacy of drugs, perceived competence of health care staff and so on, contribute to the overall infrastructure of a facility (Meichenbaum & Turk, 1987).

An individual's limited economic resources may also influence adherence patterns (Farmer, 1999). This is especially true in communities that are served by the public health sector. Often patients have limited resources with many competing demands and often cannot meet the cost of their individual and their family's health care needs. The life conditions and quality of life of these individuals were compromised prior to the onset of the disease and their socio-economic status is worsened as a consequence of having an illness condition. Brainard, Hyslop, Mera, and Churchill (1997) found in an outpatient treatment facility for TB, the only predictor of poor compliance was homelessness. This finding confirms the strong relationship between adverse living conditions and the motivation (or the lack of it) to engage in health promoting behaviours, such as adhering to treatment programmes.

### *Social factors*

Adherence to treatment programmes that require the person affected by the illness condition to be disciplined and consistent about following the suggested behavioural and medical (including drug therapy) therapy appears to be more successful with good social support from family and friends (Berg & Lipson, 1999; Rhodes, Martin, & Taunton,

2001). Family and friends not only provide relevant health information to the patient but also encourage the patient to cooperate with and follow through on the recommendations of the health care practitioners. A higher rate of adherence to appointments was found in chronically ill patients with good social support (Tanner & Feldman, 1997). Compliance to a recommended diet was found among men whose wives were very supportive as opposed to wives that offered little support (Bovbjerg, McCann, Brief, Follette, Retzlaff, Dowdy, Walden, & Knopp, 1995). On the other hand, poor compliance to medical treatment was found in individuals from unstable families (Bender, Milgrom, & Rand, 1997).

### *Cultural Factors*

Cultural and religious factors may also affect the way and the extent to which an individual cooperates with a treatment or prevention programme (Kato & Mann, 1996; Nall & Speilberg, 1967). An individual's behaviour is often guided by the cultural context within which he/she lives and may, therefore, not adhere to all or some components of the treatment programme for fear of being rejected by significant others. Additionally, the individual may not be able to endure the guilty feelings for going against the grain of expected behaviours associated with health care in his/her community.

The relationship between culture and health is complex. Culture shapes all aspects of our behaviour, including, for example, the type of food one eats; and when, where and how

certain ritualistic acts may be performed. Of course, most cultural prescriptions are underpinned by a sense of meaningfulness within various groups of people. Difficulties arise when certain disease conditions require as part of a treatment plan, for example, a restricted diet or the use of drugs that may contain substances that are taboo, such as alcohol. Kagee (2005) found that in a sample of disadvantaged hypertensive and diabetic patients in South Africa, prescribed treatment regimens affected family functioning. Participants in his study reported that the prescribed change in their diet set them apart from their families.

Finally, the use of alternate or indigenous healing methods may also influence the way in which an individual complies with treatment. Pound et al (2005) report in an article based on a review of qualitative studies on resistance to medicine taking, the widespread use of “non-pharmacological” treatments. In Africa and Asia there is widespread use of culturally endorsed treatment methods that has been used for centuries. Consulting with a traditional healer in times of ill-health is commonly reported in South Africa (Bengu, 1989). The Ayurvedic system of health and healing, which originated in India, is also extensively used. It is estimated that 70% of the population in India and indeed many people throughout the world use Ayurveda as a treatment method of choice (Schober, 1997). Traditional medicines given to patients may not always, however, compliment the prescribed mainstream treatment methods.

*Psychological Factors: Patient characteristics*

Efforts have been made to identify the “non-compliant” personality. The evidence for the relationship between personality characteristics and compliance among patients is unconvincing. There appears to be no consistent relationship between age, sex, marital status, education, the number of people in a household, social class and compliance (Hulka, 1979). The relationships between adherence, age and gender are fairly complex. Depending on the type of illness, the nature of the illness, the illness course, and the adherence regimen, studies show that treatment cooperation can either increase or decrease with age; and that men and women may adhere differently to recommendations (Brannon & Feist, 2000).

Certain sub-groups of people have been found to be more non-compliant to medically prescribed treatment. There are sub-groups of “non-compliers” who are described as being more dependent, more irrational, and tend to rebel against the authority of the physician (Gillum & Barsky, 1974; Christensen, Moran, & Wiebe, 1999). Individuals who have very low or very high levels of anxiety also seem to represent another sub-group of “non-compliers” (Ley & Spelman, 1967). Patients who are low in anxiety may not remember what the health care practitioner has recommended and those high in anxiety may be so overwhelmed by their mood state that they cannot process what was said by the health care practitioner.

According to Marks et al (2000) evidence suggests that the more the prescribed medication is congruent with the patient's belief systems, the more likely they are to comply with the suggested treatment. Social cognitive models, in particular the *Health Belief Model (HBM)* (Rosenstock, 1974), have been popularly used to explain the relationship between a patient's health beliefs and compliance. The HBM proposes that there are two major factors that underpin whether an individual performs a particular health behaviour. These factors are: (a) the degree to which the disease is perceived as threatening, and (b) the degree to which the health behaviour is believed to be effective in reducing the risk of a negative health outcome. According to the HBM the degree to which an individual complies with treatment programmes rest on the perceived disease severity, susceptibility to the disease, benefits of the treatment recommended and barriers to taking the treatment. Support for the HBM seems to depend on the type of disease condition an individual has. Masek (1982), for example, found that the more patient's perceived their disease to be serious, the more likely they are to adhere to treatment recommendations. Glasgow, Hampson, Strycker, and Ruggiero (1997), however, did not find perceived seriousness of diabetes predictive of adherence.

#### *Disease factors*

Disease characteristics, such as the severity of the disease and whether or not the patient is symptomatic have been found to be associated with treatment compliance (Marks et al, 2000). Individuals with chronic diseases, which are not symptomatic, or are in remission, are less likely to adhere to treatment regimens (Miller, 1997). Individuals afflicted with a

disease, which has a poor prognosis and is terminal, such as cancer, may be less likely to comply as they may not see compliance as making a difference to their disease outcome (Dolgin, Katz, Doctors, & Siegal, 1986).

### 2.1.3 Measuring non-adherence

It is rather difficult to measure non-adherence because both patients and health care providers appear to provide inaccurate estimates. According to Friedman (2002), there appears to be a lower rate of adherence if measured objectively and a higher rate if self-reports are taken from patients' or the health-service provider. Patients tend to over-estimate their compliance to treatment regimens and health care practitioners, such as doctors and nurse practitioners, often do not detect lower rates of compliance. Patients do not often report their non-adherence or inconsistent adherence for fear of being reprimanded by the health care practitioner and therefore provide responses expected of them.

According to Friedman (2002) more objective measures of adherence to medication, include checking medical records to see if patients are attending follow-up medical visits, checking pharmacy records, and pill counts. Of course none of these measures are fool proof because patient's may still not be taking medication despite the pharmacy records showing that they have collected their drugs and the pill counts indicating that they have indeed taken their medication. The best objective measure of compliance to

drug taking is a direct measure of the medication in the patient's body by means of a tracer or the medications metabolic by-product (through urine testing).

In this study, the measure of non-adherence is relatively uncomplicated because the TB treatment programme requires that the individual on the programme visit the health care setting consistently for a specified period of time to receive the anti-TB drugs under the direct supervision of the nurse practitioner(s). Failure by the TB patient on TB medication to attend the health clinic as prescribed by the health service providers would constitute non-cooperation to the treatment. The WHO DOTS strategy for TB was discussed in Chapter One, section 1.1.

The literature review shows that adherence and non-adherence to treatment and prevention programmes should be understood from both the patient's and the health care practitioner's perspectives. Patients in developing and developed countries using public health services are usually marginalized individuals from the under-privileged class and are, consequently, severely under-resourced and not able to control the factors that may influence whether they are able to co-operate with the treatment recommended and/or provided by the health care practitioners. The complex array of factors that contribute to adherence behaviour must, therefore, ultimately be understood from a patient-centred approach, which is the approach used in this study.

## **CHAPTER THREE**

### **METHOD**

#### **3.1 Study Design**

Methodologically, this qualitative study is framed within phenomenology, which is considered to be an ethnographic approach (Payne, 2004). Colman (2001) describes phenomenology as “A philosophical method of inquiry, introduced in 1901 by Edmund Husserl, that concentrates on the detailed description of conscious experience while suspending or bracketing all the preconceptions, interpretations, and explanations” (p 533). In the human sciences accessing meaning must be done through examining and exploring individual’s perceptions, cognitions, and language. Consequently, concrete descriptions of the lived experience of individual’s become an important source of data (Von Eckartsberg in Valle, 1998). In this study the lived experience of the participants who were diagnosed with TB was the main reference point in attempting to understand why some patients adhere to TB medication and others do not. The subjective experience articulated through the participant’s own ‘voice’ became the study data. In-depth individual interviews, the focus group and field notes were used to collect data in the study.

In the first phase of the study, in-depth individual interviews of the participants were conducted. In the second phase of the study, immediately following feedback to the health care practitioners of the findings of the first phase of the study, a focus group was

conducted to ascertain the level of receptivity and understanding of the various themes that emerged from the data analysis of the in-depth interviews.

### **3.2 Study setting**

The study was conducted in Khayelitsha, a sub-district in the Cape Town Metro Region of the Western Cape Province. Khayelitsha, was established in 1983 during the Nationalist Party's apartheid rule, and is a "large peri-urban" area situated 32km from central Cape Town (Cooper, 1995). The 2001 population census estimated that the City of Cape Town had 2 893 246 people and the Western Cape had 4.5 million people of which 51.5% were females (Western Cape Population Profile, 2001). The population of Khayelitsha is about 340 000, made up of predominantly black South Africans (Western Cape Population Profile, 2001). The area was seriously under-funded during apartheid rule, and despite democratic governance in South Africa since 1994, is still marked by poverty, high rates of unemployment and poor infra-structure. A mixture of formal and informal housing, and of formal and informal trading, is characteristic of Khayelitsha. It is indeed visible that there are "pockets" of areas that are better serviced than others with respect to public transportation, public health sites, local government maintenance of public spaces, businesses, and so on.

Public health services in Khayelitsha are provided by the Provincial Government of the Western Cape (PGWC) and Cape Town City Health. The study was confined to only one City Health clinic, namely the Kuyasa clinic, which is one of several City Health clinics

in Khayelitsha. The City Health management requested that the study is conducted in the sub-district of Khayelitsha because of the low cure rate for TB in this area, as compared to the other seven sub-districts making up the Metro Region. In the 2<sup>nd</sup> quarter of 2005, there was a 51% cure and success rate for new smear positive cases for TB in Khayelitsha and a cure rate of 62% to 80% in the other seven sub-districts for the same period (Azevedo, 2006).

### **3.3 Participants**

In phase one of the study, medically confirmed adult male and female registered TB patients that tested smear positive and who were already enrolled into treatment programme at the clinic were eligible to participate. Purposive sampling techniques (Bless & Higson-Smith, 1995) were used to recruit respondents. Saturation of data occurred with a sample of 15 respondents. Participants were carefully or 'purposively' selected to ensure that there was a reasonable 'spread' or range of patients with respect to age, sex, and consistent, inconsistent or failed attendance at the clinic for treatment. The participants were Xhosa-speaking, which is the predominant language used in the area of Khayelitsha and generally by black Africans in the province of the Western Cape.

Patients with a psychotic disorder were excluded from the study. TB patients on treatment regimens for other co-conditions, such as HIV and AIDS, were also excluded. Only those TB patients who were exclusively on the TB treatment programme were

included in the study because of the study's focus on the factors that influence adherence, specifically to this treatment programme.

In phase two of the study, health care practitioners involved in the management of TB at the Kuyasa clinic were invited to participate. The staff that participated in this phase of the study was engaged in the research process in the most ethical way possible. Special emphasis was placed on ensuring that the health care workers understood and trusted the fact that their participation in the project will not adversely affect the quality and the nature of their relationship with their seniors (health managers). This was done through open and transparent communication with the TB health care team at Kuyasa from the planning phase of the project until its completion.

### **3.4 Procedure**

During the preparatory stage of the first phase of the study, prior to the selection of the participants, the health care practitioners that assisted in selecting the participants were advised by the principal investigator (PI) and the research assistant on what the eligibility and exclusion criteria were. The health practitioners were also requested to select a range of registered TB patients, i.e. young and older adult male and female patients on TB treatment who attended the clinic consistently; and young and older adult male and female patients on TB treatment who were inconsistent and irregular in their attendance.

The TB patients who participated in the study and who attended the clinic consistently were interviewed by the research assistant at the clinic in a specially designated room. The participants who were on TB treatment but were not attending the clinic consistently or had not attended the clinic for some time were interviewed in their homes or other places of abode. In some instances arrangements were made to interview them at the Kuyasa clinic. Access to these patients, who were potential participants for the study, was possible because the research assistant accompanied the community TB workers on their field visits.

The community TB workers were responsible for trying to locate the registered patients who were not adhering consistently to the TB treatment programme and to re-emphasize to them the importance of attending the clinic for treatment. In addition, the community workers are able to ascertain the possible barriers experienced by those TB patients not adhering to treatment and assist the patient to overcome them where possible. The services provided by the community worker is one component of the regular health service rendered by the clinic as part of the DOTS strategy. Of course in some cases it is found that the patients listed on the clinic records as not adhering to the programme, have in fact passed away. Their death could be a consequence of poor adherence to TB treatment, or from being co-infected with other disease conditions, such as AIDS, which could have led to their premature death.

Once a potential participant was identified and recruited for the study and if they agreed to participate, they signed an informed consent form in Xhosa (see Appendix One),

which included their right to withdraw from the study at any time. During the period of 'briefing' (Kvale, 1996) it was ensured that they understood the various aspects of their rights, and the researcher's obligations as stated in the informed consent form. In the pre-interview stage, the research assistant administered a short biographical questionnaire just prior to conducting the interview to obtain background demographic information (see Appendix Two). In addition a few semi-structured questions were asked in order to contextualize the life circumstances of each of the participants. The pre-interview phase served two purposes. Firstly, it facilitated in a non-threatening way, the development of rapport between the participant and the interviewer and allowed for the necessary psychological distancing on initial contact. Secondly, the characteristics of the data collected in the pre-interview phase, such as the demographic information, was common to all the participants. Consequently, each participant's subjective experience of the TB treatment programme and the difficulties they encounter in adhering to TB medication was framed within their individual characteristics, such as age, sex, marital/partnership status, and so on. The in-depth interview, conducted in Xhosa, followed.

### **The in- depth interview**

The semi-structured in-depth interviews were conducted by a trained research assistant who is also a clinical psychologist well trained in qualitative interviewing techniques. Each of the 15 participants was interviewed for one session for the duration of between 90 and 120 minutes. A set of guiding questions was developed for the interview. The questions were as follows: (1) Tell me about the time you were first told that you have

TB. How do you think you got infected? (2) Tell me how much you know about TB?; (3) What was happening in your life at the time you were diagnosed with TB?; (4) What is your experience of being a person with TB?; (5) What is your experience of taking the treatment that the nurses in the clinic give you? Have you been able to take your treatment exactly the way the nurses have advised you to? Are you getting advice and/or treatment from anyone else besides the nurses and doctors that treat you in the clinic? and (6) Have you been asked by the nurses whether you would like to have an HIV test? Would you mind telling me if you agreed to have the test?

The questions were framed within a time sequence, i.e. participant's experience of their disease condition was explored from just prior to being diagnosed with TB until the point that the interview was conducted. Interviews were tape recorded and later transcribed for analysis. The interview data was translated into English for the following reasons: Firstly, it allowed the PI to make sense of the data because she is not proficient in Xhosa, and secondly it facilitates the dissemination of the study findings to a wider audience.

The interview process was guided by Moustakis' (1994) concept of the *Epoche*, which involves "setting aside prejudgements and opening the research interview with an unbiased, receptive presence" (p 180). This meant that the interviewer tried to maintain a non-judgemental presence throughout the interview and did not allow her prior knowledge about the participant, influence the interviewing process. The participant's 'voice' was of paramount importance and the interviewer was, in a sense, also guided by the participant's responses in deciding when and how to probe the emergent themes. This

process was a completely non-invasive one. A period of debriefing followed the interview (Kvale, 1996), after the tape recorder was switched off, to allow the participants to express any emotional conflicts or anxieties they had that may have arisen out of their disclosure about their lived experience of being infected with TB, and about other significant life events, such as discovering their HIV positive status.

To maintain a high ethical standard the tapes have been locked in a cabinet that only the PI has access to in order to ensure confidentiality of the participant's identity and responses. The tapes are not marked with the patients names.

### **Focus group**

A single focus group was conducted, in English, with three health care practitioners and one supporting TB health worker assistant involved in the management of TB at the Kuyasa health clinic. The PI acted in the capacity of the focus group facilitator and the research assistant was the co-facilitator. All the members of the focus group were women and comprised of the nurse manager, the sister-in charge, a professional nurse, and a TB health worker assistant. There was one male in the health worker team who was, unfortunately, unavailable on the day the focus group was conducted. The duration of the focus group was 120 minutes. The focus group discussion was tape recorded and later transcribed for analysis. These tapes are also locked in a cabinet to ensure the focus group member's identities are protected and their responses are kept confidential. Only the PI has had access to the tapes since the transcriptions were done.

Using a focus group is one way of generating qualitative data. The choice of using a focus group as a data collection technique, instead of individual interviews, in this study, rested on the fact that this particular health-care setting is based on a team approach to health management. It made practical sense, therefore, to allow the nurse practitioners to have a collective voice about the themes that emerged from the in-depth interviews of the 15 participants. Individual interviews with the health care practitioners would not have facilitated collective agreement regarding the possible recommendations that can be made to the Senior Management of the Cape Town City Health Department with respect to the existing TB treatment programme, namely DOT.

#### **Field Notes**

A constant monitoring process was part of the research plan and formed an integral part of the data collection. This was done through keeping field notes about every component of the project including the study setting, the patients who utilize the health setting, the field visits into the community, and the logistics of carrying out the research. The research assistant also recorded in her study journal the verbal and non-verbal communication that played out during her interaction with the following: the health care workers at the study site, the community workers and the participants during the interviews. She also recorded her observations on the nature of the following: the health practitioner-patient interaction at the clinic, the community worker-patient interaction in the community setting, and the interpersonal relationships between health care practitioners.

The Principal Investigator (PI) was also intimately involved in the monitoring process and met regularly with the research assistant to ensure that the latter developed a high degree of reflexivity. Reflexivity is, according to Malterud (2001), “An attitude of attending systematically to the context of knowledge construction, especially to the effect of the researcher, at every step of the research process” (p 484).

### **Standards for qualitative inquiry**

Malterud (2001) proposes that relevance, validity, and reflexivity should be used as overall standards for qualitative inquiry, although simultaneously warning that achieving standards is not simple because invariably judgements are made in the process. To ensure standards for the study the PI scheduled regular meetings with the research assistant to ensure that she understood what has to be done to achieve relevance, validity and reflexivity. During the meetings the PI and the research assistant (RA) reported the difficulties they experienced and the observations made. The RA was very receptive to the guidance provided by the PI.

Relevance was enhanced in the study by using detailed reports and a good sampling technique and validity was improved by using procedures suggested by Mays and Pope (1995) such as triangulation, respondent validation, thorough methods of data collection and analysis, reflexivity, and attention to negative cases.

## **Ethical statement**

This project was conducted using the national and international ethical code for research in the social and health sciences. Ethical approval was obtained, separately, from UCT's and Cape Town City Health Departments ethics committees' for phases one and two. The study is also registered with the University of the Western Cape's Research and Development Committee, who provided ethical approval for the first stage of the study, namely in-depth interviews with the TB patients (participants of the study).

## **3.5 Analysis of the data**

Qualitative data analysis, which organizes phenomenological data, as suggested by Moustakis (1994), was used. The data was analyzed in two phases. In the first phase, the data obtained from the individual interviews conducted with the 15 participants was analyzed, and in the second phase, the data obtained from the focus group conducted with the health care staff was analysed. A preliminary analysis of the in-depth interview data was conducted and when themes began to recur it meant that data saturation was reached. At this point the sampling process was considered to be complete.

The first step in phenomenal analysis, according to Moustakis (1994), involves the horizontalizing of the data. This meant that each statement made by the participants of the study was treated with equal value. "Meaning units" were then listed out of the horizontalized statements. The meaning units were then clustered into themes and used to

develop textural descriptions of the experiences. Finally, from the textural descriptions, structural descriptions and an integration of textures and structures into the meanings of the phenomenon were constructed.

In this study, two sets of structural descriptions were constructed. Firstly, structural descriptions were developed based on the meanings that TB patients assigned to their adherent behaviour of the treatment and prevention programmes. Secondly, within the framework of the phenomenological approach, structural descriptions were developed from the responses of the focus group members who reflected on the structural descriptions that arose out of the emergent themes of the 15 individual interviews conducted with the TB patients that agreed to participate in this study. The outcome of the analyses is presented in Chapter Four.

## **CHAPTER FOUR**

### **FINDINGS**

#### **4.1 Introduction**

In this chapter, the core themes that emerged from the data, which captures the essence of what participants said and implied during the illness narrative, is presented. A demographic profile, period since onset of TB infection, and the HIV status of each of the 15 participants are presented in Table 4.1. The information was obtained from each participant in the pre-interview phase as discussed in section 3.4

**Table 4.1** Demographic profile, duration of TB infective status, and the HIV status of study sample

<b>P</b>	<b>Age</b>	<b>Sex</b>	<b>Educational Level</b>	<b>Gainfully Employed</b>	<b>Marital Status</b>	<b>Duration of TB infective Status</b>	<b>HIV Status</b>
1	50	F	Between grade 4-7	No	Married	5 months	negative
2	45	F	Between grade 8-10	No	Married	3 months	negative
3	18	F	Between grade 8-10	No	Single	3 months	positive
4	20	M	Between grade 8-10	No	Single	5 months	negative
5	42	M	Completed grade 12	Yes	Widowed	1 month	negative
6	36	M	Below grade 4	Yes	Single	1 month	positive
7	49	M	Between grade 4-7	No	Divorced	2 months	positive
8	48	F	Between grade 4-7	No	Married	4 months	positive
9	27	M	Between grade 8-10	Yes	Single	5 months	positive
10	57	M	Between grade 8-10	Yes	Single	6 months	unknown
11	24	F	Between grade 8-10	Yes	Single	4 months	unknown
12	25	F	Between grade 8-10	No	Single	12 months	positive
13	30	M	Between grade 8-10	No	Single	6 months	positive
14	29	F	Between grade 8-10	No	Single	5 months	negative
15	27	M	Between grade 4-7	Yes	Single	3 months	negative

P = Participant; M = Male; F = female

An analysis of the demographic data revealed the following: the mean age of the 15 participants was 35.13 years (range 18 to 57 years); there were seven female and eight male participants; the mean duration of the disease was 4.3 months; seven participants were co-infected with the HI virus; six participants tested negative for the HI virus; and the HIV status of two participants was unknown. Most of the participant's were single (10), three were married, one was divorced, and one widowed. The educational status of the participants were as follows: A large proportion of the participants (8) had secondary schooling qualifications between grades 8 to 10, four participants had primary schooling qualifications between grades 2 to 4, one participant had a below grade 2 qualification, and only one completed grade 12 (matriculation). Finally, the majority of the participants, 10 out of 15 participants, were not in gainful employment.

In order to capture as accurately as possible the voice of each participant, the quotations provided in English in this research report do not follow the technical rules of the English language, but rather try to capture the exact meaning of the interview data. The same principle regarding the use of the English language in presenting the quotes of the members of the focus group is applicable to phase two of the study. The focus group members, comprised of the health care providers at Kuyasa clinic, preferred that the group session is conducted in English despite the fact that English is their second language.

The Xhosa-speaking, female, research assistant who conducted the individual interviews in phase one of the study also recorded significant non-verbal responses of the

participants, such as pauses, silences, and facial expressions depicting a range of emotions including helplessness, hopelessness and depression. Significant non-verbal responses of the members of the focus group were also recorded by the facilitator and co-facilitator. Significant non-verbal responses of the 15 participants and the focus group members are noted in the presentation of the findings.

#### **4.2 Findings: Phase one**

Two core themes emerged from the stories narrated by the 15 participants about their lived experience as an individual infected with TB. The subjective or lived experience of illness reflected contextual, individual and disease factors that influence, directly or indirectly, whether they are willing and able to adhere to TB treatment. The emergent themes are: (1) Contextual, individual and disease factors associated with the illness experience; and (2) Psychosocial factors promoting and hindering adherence to TB treatment.

The corresponding identity of the participants whose narratives highlight the theme being presented can be found in Table 4.1.

**Theme One: Contextual, individual and disease factors associated with the illness experience**

***Life Conditions***

Many participants alluded to the fact that they have severe financial constraints. The challenging, often competing financial demands that participants face is illustrated by the statements made by a 45 year old married female co-infected with HIV and diagnosed with TB four months prior to the interview (P2):

*Recently I've been stressing a lot because of the financial difficulties that my husband and I are faced with. I don't work and my husband also doesn't work. He lost his job in the mines in 1994. The children are now growing and they have more needs which at times we cannot meet.*

***Illness challenges***

The illness challenges that participants faced were associated with contextual, disease-related and psychological factors. The challenges were essentially four-fold: Participants perceived that they: (1) were living in poorly resourced social environments, (2) had to endure disease-related symptoms, (3) experienced feelings of hopelessness and depression, and (4) lived with the stigma of being infected with TB.

All four components of the perception of the illness challenges are reflected in the following response of a 25 year old HIV positive female participant (P12) who was infected with TB one year ago:

*The biggest challenge that I had to live with was having to bear with my aunt who each time when she got drunk would swear at me about my illness. This got to a point where I couldn't take it anymore and I left and went to my partner again. She made me feel like dirt. After I left home I didn't come back to the clinic for my treatment. I just gave up on myself and didn't find the need to care for myself or live. (Participant paused for a long while). At times when I cooked she would often come at home and say that she won't eat food that has been cooked by me. She would accuse me that I have spit on the food. She really made me angry. (Again participant paused for a long while).*

Feelings of helplessness and depression were associated with disease-related symptoms in this 45 year old female participant (P2) diagnosed with TB three months prior to the interview:

*I was always tired, I didn't feel like doing anything, I didn't want people around me and I was irritable. (Pause, looking down) I couldn't even wash myself and my sister had to help me to get washed and this made me feel very angry because I felt helpless.*

Of all the reported illness challenges reported by the participants, stigma associated with being infected with TB was the easiest to delineate. There were reports of: a lived experience of stigma, self-imposed stigma, and anticipated stigma.

A 20 year old male participant (P4) who was diagnosed with TB five months ago talked about his actual experience of being stigmatized by people that he knew well following the disclosure of being afflicted with TB:

*Yho! (Participants head facing downwards) I was coughing a lot. This is when I started to realize that I need to start dressing warm when I go out. At school my friends kept on asking me what was wrong with me. When I told them that I have TB they teased me everyday.*

A co-infected 18 year old HIV positive participant (P3) diagnosed with TB three months ago illustrates self-imposed stigma:

*I was coughing a lot, I lost weight and I became ashamed and embarrassed to be together with my friends. I didn't know what were they thinking about me honestly. I then withdrew myself from them. (Participant paused for a few minutes) Sometimes I was irritable and didn't feel like talking to anyone even at home.*

This 30 year old HIV positive male (P13) diagnosed with TB six months ago illustrates anticipated stigma:

*I was ashamed. Often when a guy has TB he is always teased by others. It's like there's something really wrong or funny with you.*

### ***Causal Attribution***

There were essentially two main types of causal attributions made by participants about the onset of their illness condition. Firstly, many participants saw that external factors such as the climate, which is out of their locus of control, as causing them to become infected with TB. A 42 year old male participant (P5) who was diagnosed with TB one month prior to the interview stated:

*I don't know. But what happened I became very sick coughed a lot and at night I would sweat. I guess it could also be due to the cold weather that we have here in this area because we are quite close to the beach. Well, I've never been ill before and ever since I've been in this area I have been becoming sick. What I've noticed is that there are a lot of other people in the area who also complain about their health and they also have TB.*

A 48 year old female participant (P8) who was co-infected with HIV and diagnosed with TB four months ago expressed the following:

*I don't know. I'm not a person of poor health although I have had TB once in 1999. Also in my family no one has had TB before. Perhaps then it's due to cold weather.*

Secondly, some participants stated that they believe they became infected with TB because they were living in an 'infected' environment. Family infected with TB were living or came to live with them. According to the participants, some family members were in denial and refused to attend the clinic for treatment, and some were aware that they were infected with TB but were not adhering to the treatment programme.

According to an 18 year old female (P3) co-infected with HIV and diagnosed with TB three months prior to being interviewed:

*I got infected from my uncle whom I was staying with at my maternal grandmother's house at the Eastern Cape, in the homelands. My uncle was refusing to eat his treatment and I tried getting the assistants from the clinic to come and give him his treatment at home. He only ate his treatment for one week and thereafter he stopped again. So when I started getting sick and my mother heard about it she said that I must rather come and stay with her here in Cape Town. I then had to organize with the clinic to give a referral letter that states that I am a TB patient so that I could get treatment here.*

A 29 year old female HIV negative participant (P14) talked about how she believed that she became infected with TB five months ago:

*I got infected from my father. During that time I was staying with my parents at the Eastern Cape. My father had been suffering from TB and refused to eat his treatment properly. Even when the TB workers came to visit him at home and tried to encourage him to take his treatment, he refused.*

Another young 24 year old female participant whose HIV status was unknown (P11) explained in an angry tone about how she believed she became infected with TB four months ago:

*I think that I got TB from my cousin brother who also has TB. Every weekend last year he use to come and sleep over by our house. My mother and I knew that he had TB but it wasn't a big deal because he said that he takes treatment. You know the funny thing is that although he claimed to be taking treatment he never seemed to be getting better. He use to cough a lot but we never thought of anything. In October when I started getting sick I decided to go to the doctor thinking that maybe I had flu. I was then told to do a sputum test and the results came out positive for TB. After that my mother then found out from my cousin's mother that he has been sleeping around in other people's houses because he refuses to take his treatment for TB which seems to be something that he and his mother have been fighting about. One weekend when he came to visit, my mother*

*spoke to him about what we heard and told him that if he is not prepared to take his treatment then he should not come to visit. But after that day my cousin never came back again.*

The third type of causal attribution made was life-style related and commonly reported by the male participants. These participants disclosed during the interview that they engaged in high-risk behaviours, which they believed caused them to become infected with TB. It is clear that they reflected, introspectively on their behaviour. A 20 year old, HIV negative participant (P4) who was diagnosed with TB five months ago stated:

*Aish! Sister I think I got TB from roaming around at night in cold weather and not wearing warm clothes. Like most of the weekends my friends and I have a shebeen that we usually like to go to and (pause) things really happen there. We have lots of fun, we drink alcohol, smoke and mix ourselves with nice girls. So most of the time ones temperature is always on its peak. Ja! By the time we go home it's early in morning round about one, two and it's like freezing cold. So, Ja! I believe that's how I ended up being sick.*

Another 49 year old participant (P7) co-infected with HIV and re-infected with TB two months ago disclosed the following:

*Mmm! Firstly I'm a person who use to enjoy having a good time. I use to be a guy who just didn't want to let any woman pass me by and smoked a lot. I*

*smoked dagga and I also drank a lot of alcohol. When the day came that I was told by the doctor at Grootte Schuur that I have TB in 1995, I knew that it must have been from the smoking and drinking. But after my diagnosis I never smoked nor drank again.*

### ***Reaction to being diagnosed with TB***

The initial response of the participants to being told that they were infected with TB was one of being “ok” or “upset”. Participants stated further that they overcame their feeling of “upset” very quickly because they realized that TB is curable, and that they know of one or more people who are or were infected with the disease.

A 50 year old female HIV negative participant (P1) who was diagnosed with TB five months ago stated:

*I was fine because the doctor had told me that TB is curable. So at least I had the hope that I was going to get better. I also remembered the time my daughter once had TB that through eating her medication she became better.*

A HIV co-infected, 27 year old male participant (P9) who was found to be infected with TB five months ago expressed his reaction to his TB status:

*I was shocked sister but at least I knew that this was something that could be treated.*

### ***Participation in VCT***

Registered TB patients at Kuyasa clinic are advised by the health care providers to participate in VCT because of the high prevalence of TB/HIV co-infection nationally and in sub-Saharan Africa. Once it is established whether the patient is co-infected, an effective and appropriate treatment management plan, in addition to anti-TB treatment, can be decided on. In the study there was a high degree of willingness to participate in VCT for the HI virus as illustrated by the following responses by following three participants:

Participant 14: A 29 year old female living with TB for the past five months:

*Yes. I did do the test and my results came out negative. I was then told to come back after three months.*

Participant 12: A 25 year old female diagnosed with TB 12 months ago:

*Yes and when I tested my results came out positive.*

Participant 10: A 57 year old male living with TB for the past six months:

*Yes I did. After I tested I was told to come back for another test after three months.*

## **Theme Two: Psychosocial factors promoting and hindering adherence to TB medication**

Individual factors and factors external to the individual are associated with adherence behaviour. It was evident that even those participants', who were adhering to the DOTS programme at the time of the interview, also had periods of non-adherence. Whether a participant took their TB medication or not at any particular point in time is largely influenced by the characteristics of the individual, the social and economic resources available to him/her, and the social and cultural milieu of his/her family and community.

### ***Factors promoting adherence to TB medication***

In the study the participants adhering to the TB treatment, including those that have been re-infected with TB stated that it was not really difficult to follow the treatment regimen. Adherence to the programme rested on a few factors, such as experiencing relief of the symptoms of the disease, the knowledge that another known person recovered from TB by taking the medication and the hope that they will be cured by taking the treatment as

prescribed. Reasons commonly given for adhering to the TB medication are illustrated by the following responses:

A 50 year old female participant (P1) who readily took the treatment five months ago at the onset of the infection and continues to take the drugs because of the symptom relief she experiences stated:

*I took my treatment frequently just like I'm doing right now. I didn't have any problems. Instead since I have been taking my treatment I feel a big relief even from the stiffness and the pain I always felt.*

A 20 year old participant (P4) who was diagnosed with TB five months ago related how the fact that his family member was cured from the disease made him hopeful that he would be cured if he adhered to the treatment programme:

*You see my older brother once had TB and he used to cough a lot when it started. But then he got better again because he was eating treatment. So like when I was told that I have TB it wasn't a big deal because I knew that it can be cured.*

The positive experience of the quality of health care received by the participants also influenced the adherence to the TB treatment. In the study when participants were asked about their perception of the quality of the health care they received, their responses

clustered only around one theme, namely, the attitude of the health care team at the clinic. Not a single participant commented on the positive or negative structural and other components of care, such as the waiting and/or treatment room(s) or the time spent waiting to receive treatment, and so on.

A 50 year old female participant (P1) who was diagnosed with TB five months ago expressed her satisfaction with the attitude of the health care team as follows:

*The assistance that I get at the clinic is very good. The nurses are understanding and they have done the best that they can for me. Sometimes even when you have another problem they are willing to listen to you and they'll make follow up.*

Another overwhelmingly positive response was from a 45 year old female participant (P2) diagnosed with TB three months ago:

*My experience at this clinic is good. I find the nurses being good at what they do and they are very helpful especially Sister X (name withheld). I have no complaints honestly. This is where I have found real help.*

### ***Factors hindering adherence to TB medication***

Periods of non-adherence to the TB treatment programme was associated with: participants stopping the treatment when they felt they “better”, when they had work or school commitments, and after discovering they were HIV positive.

The following statement was made by a 49 year old male, HIV positive participant (P7) who stopped taking his treatment when he felt better:

*The first time I ate treatment when I saw myself getting better I decide to stop eating treatment. But from having done that I have learned a lesson because I feel now that I need to take serious responsibility over my health. I definitely do not want to loose my life.*

The statements made by the following participants illustrate the periods of non-adherence because of school or work commitments:

Response of a 20 year old HIV negative male participant (P4) diagnosed with TB five months ago:

*Well I didn't have a problem with taking treatment. The only time I had a problem coming for treatment was at the time I was writing exams in September for matric. But after that I came back again for my treatment.*

Response of a 27 year old HIV positive male participant (P7) diagnosed with TB five months ago:

*Since I have been working I haven't been able to take my treatment regularly. After three months I was diagnosed with TB I found myself a job. I came to the clinic to report my problem and I requested to be given a weekly treatment but the nurses refused. They stated that they need to be sure that I am going to take my treatment and that they need to see whether there is progress regarding my health. The nurses then suggested that I should rather inform my boss so that he can also assist me by reminding me to take my medication. I didn't like that idea because once my boss knows about my status then everyone at work will know.*

It is clear that in the case of the 27 year male participant that non-adherence to the treatment programme is more complex than simply because of work commitments. The participant also evidently feared that disclosing that he was infected with TB would jeopardize his job and he was in a double-bind because the health care providers refused to provide him with weekly treatment. This reported non-cooperation by the health care staff was only reported by this particular participant.

The use of traditional healing systems was not uncommonly reported in the study.

A 45 year old HIV negative female participant (P2) who was diagnosed with TB three months prior to the interview responded to the interviewer's prompt about being on anti-TB drugs and using an alternate healing system in the following way:

*I use them in the same amount because to me both treatments are strong and they can help me. The only extra thing with the water I get from the spiritual healer is that it also helps in keeping away evil spirits.*

A 45 year old HIV negative female participant (P2) diagnosed with TB three months ago reported on the periods during which she made use of alternate healing systems:

*I did feel better after the treatment but then in the middle of 2000 I started becoming sick again. Since then I was on and off. I drank some herbal medication from different herbalists. Then in 2003 my mother heard about a witchdoctor who said he'll be to help me. My family then had to give a sheep plus fifty rand to him. He also gave herbal medication to drink. It didn't really help but I continued to use it with the hope that I was going to get better. But what I've noticed since I have been using the medication from the clinic my health has improved a lot.*

Poor living conditions are known to also contribute to the spread of TB, a disease which is often referred to as a disease of poverty. Participants reported that their state of poverty was most certainly a barrier to adhering to TB medication. A 42 year HIV

negative male participant (P5) diagnosed with TB one month ago reported having limited financial constraints as one reason for not maximizing the benefits of treatment:

*One of the challenges that I have faced is not being able to maintain a healthy diet consistently. At the clinic the nurses tell us that we need to try and eat more vegetables and the money is not always there to buy such things. Most of the time I eat bread and tea or coffee.*

The same participant stated: *Well I feel that it would be wonderful if the TB patients especially those that have financial constraints to be provided with food parcels. Even if one day we could get an egg and perhaps on some days get soup. That would be very helpful.* This statement illustrates that this particular participant was seriously financially challenged.

An 18 year old HIV positive, female participant (P3) diagnosed with TB three months ago further illustrates the seriousness of the level of poverty experienced by the participants in this study. She stated (tearfully):

*It has been very hard sometimes for me to take treatment because sometimes I don't have something to eat. There are days that I need to go to a friend's house just to ask for something to eat so that I can be able to take my treatment. Sometimes I ask one of the nurses then she will give me from the packet of porridges from the clinic. The problem is that my mother doesn't work and*

*sometimes it can become really difficult because I have two younger siblings and all three of us go to school. We depend on the fish that my mother sells and sometimes business doesn't go so well at all.*

***Field Notes: Findings***

The research assistant, who also carried out the individual interviews and co-facilitated the focus group, noted that the patients who utilized the Kuyasa health care facility were indeed disadvantaged and were grateful for the care provided by the health workers. Verbal communication between the patients and the health care providers took place in Xhosa, which appeared to facilitate the patient-health provider alliance. Although patients had to wait to receive their treatment, they did not seem to complain.

Despite living in Khayelitsha, the research assistant found that she was very affected, during the community visits, by the level of poverty that the TB patients were confronted with. She shared the feelings of helplessness with the clinic and the community health workers about the patients' disadvantaged status. She was also witness to the challenges that the community workers faced in trying to locate the patients that were not attending the clinic for their TB treatment. These workers were not provided with transport to carry out their duties and had to, consequently, brave difficult weather conditions and work in unsafe areas.

Other significant observations, such as the non-verbal behaviour of the participants and the health providers during the individual interviews and the focus group respectively, made by the PI and the research assistant are incorporated into the body of the findings of phases one and two of the study.

### **4.3 Findings: Phase two**

The themes that emerged from the first phase of the study were presented for discussion in the focus group with health care providers. While every attempt was made to systematically work through each of the themes, it was not entirely possible to keep the focus group discussion highly structured because the health care workers offered opinions, personal perceptions and their understanding of TB patients' adherent and non-adherent behaviour to the TB treatment programme linking various components of each of the themes presented. For this reason the themes that emerged from the focus group are broadly clustered around the member's perceptions of adherence and non-adherence by the participants, in phase one, to the TB treatment programme.

It is also important to note that the members of the focus group did not confine themselves solely to the responses of the participants in the first phase of the study. Instead the themes presented to them by the facilitator formed a springboard for the discussion of their own understanding of the adherent and non-adherent behaviour of the TB clinic patient population. Hence, they expressed disagreement when they felt that a

particular theme that emerged from patient interviews did not coincide with their own views about the general TB patient population at Kuyasa clinic.

In the final analysis the following themes emerged from the data: (1) Perceptions regarding the pattern of TB patients' adherence to TB medication, (2) Opinions of the DOTS strategy, (3) Recommendations to improve health service to patients, and (4) Additional observations about TB patients and the quality of the health care provided by Cape Town City Health department.

#### **Theme one: Perceptions of the factors hindering TB patients' adherence to TB medication**

The feedback given to the focus group members regarding the adherence behaviour of the TB patients who participated in the study, focussed on both adherence and non-adherence to TB medication. Group members, however, did not really engage with the pattern of adherence but did offer an extensive understanding of the reasons why TB patients often do not comply with the treatment programmes offered at the clinic.

The health care practitioner's perceptions regarding the reasons why TB patients do not adhere to the treatment programme can essentially be categorized into five components of non-adherence: (a) Socio-economic status of the patients, (b) Individual characteristics of the patients, (c) Nature of the DOTS strategy, (d) HIV and TB co-infection, and (e) Stigma.

### ***Component One: Socio-economic status of the patients***

There was overwhelming agreement by the focus group members that one of the main barriers to adherence to the TB treatment programme is the limited social and economic resources that TB patients endure. It was evident that the health care team felt helpless in the face of the patient's poverty and because it was a factor beyond their control, they could not address this barrier to adherence. According to the focus group members many patients often report that they are not able to meet their basic needs for food and adequate shelter. The patients also reported that there was a lack of an adequate transport infra-structure and that they found it difficult to get to the clinic because their places of abode and the clinic were not in close proximity to each other. Of course, the patients also found travelling long distances in poor weather conditions hindered their attendance at the clinic. The following statements reflect these perceptions of the health care team regarding the social and economic status of the patients at the clinic:

*It is true but also it's because some of them say they don't have something to eat and that is why they don't take their treatment. Sometimes for some of the clients it's far for them to get to the clinic everyday and its worse in winter when it's raining. Sometimes we can understand as most of them are poor and if they get wet and must return to a house with no heater then we can't do anything. (Said with a sense of helplessness).*

### ***Component Two: Individual characteristics of the patients***

The individual characteristics that posed a barrier to adherence were the negative attitudes patients had regarding the recommended treatment programme to combat TB. Faced with unemployment and low household income, patients were dependant on others for survival. This dependency made them vulnerable and decreased their capacity for self-control and self-efficacy.

However, in addition the health care team perceived many patients to be “ignorant” as illustrated by the statement made by one of the focus group members, which served as a basis for discussion as one of the reasons for non-compliance to TB treatment: *“And sometimes its also ignorance and not wanting to take care of themselves, where you just get someone who decides that they won’t take their treatment”*. They perceived patients not wanting to “take care of themselves” despite being give information about the nature of TB and the consequences of not adhering to the treatment programme.

The focus group members were also of the opinion that patients’ were often resistant to taking their medication and made a conscious decision not to take their treatment. The following statement illustrates this: *you just get someone who decides that they won’t take their treatment.*

The heath care team saw that there was a gender dimension to adherence, with a higher frequency of non-adherence amongst males. They related this to risk-taking health

behaviour, reflective of the perceived general risk-taking behaviour usually displayed by males.

Finally, they reported that there is a sub-group of patients that experienced side-effects from the medication and may, therefore, voluntarily stop taking the treatment as a result. There was general agreement to the explanation offered by one of the focus group members in this regard: *“Another factor that would also affect adherence is the reactions some of the people get from the medication and by that I mean being allergic. Because if you react to a specific medication then you don't want to use it again.”*

### ***Component Three: Nature of the DOTS strategy***

The members of the focus group expressed many opinions regarding the DOTS strategy. They were in general agreement that the length of the programme served as a barrier to adherence. Many patients comply with the treatment in the first two months and default as soon as they experience some relief from the physical symptoms of the disease. Consequently many patients become re-infected.

A senior member of the health care team stated that there is an alarming increase in the rate of multiple drug resistance (MDR) because patients do not adhere to treatment consistently. When the focus group was given the feedback that that the re-infection rate among the participants was high, they confirmed that this pattern was also reflective of the general TB patient population that attended the clinic. One of the more experienced

members of the focus group stated: *"Now regarding the re-infection part that you mentioned it is true what you were saying because we have a lot of MDRs. because our clients take their treatment and then they stop. Our scale of MDRs is very high now and before it wasn't. (Pause) In so much that we had one doctor at the time and he could manage all our cases and I'm talking about Khayelitsha alone not other places."*

The health care team also felt that daily visits to the clinic proved too demanding for patients. They compared DOT to other treatment programmes, such as the anti-retroviral (ARV) roll-out where patients were given a weekly dosage of medication. A member of the focus group stated: *Also when they get their ARVs they receive a packet for the whole week and as time goes on they get a months supply as compared to having to come everyday for their TB treatment.* Another comparative advantage of the ARV programme they expressed is that *"the ones who get ARVs have a support system where there needs to be someone who reminds the patient to take medication, showing that they care."* Clearly, members of the focus group that have experienced other areas of health service delivery outside of TB care, recognize the importance of a social support system in improving adherence rates.

#### ***Component Four: HIV and TB co-infection***

Patients who are co-infected tended to take their HIV status more seriously than they did their TB status. There was general consensus among the focus group members to the

following statement offered by one of them: *“What you also find is that they take HIV more seriously than TB.”* Patients who were both on ARVs and DOT also took the treatment for their HIV positive status more seriously. This referred to patients who were on treatment for both the HI virus and TB, and does not refer to the participants.

### ***Component Five: Stigma***

There was general agreement that many TB patients experienced actual stigmatization or perceived stigmatization at home, in the community and at the work place. Stigma was experienced as especially problematic in the work place and many patients have reported to health care providers of stigmatization by employers. There was consensus on the following statement made by a senior member: *“That’s true as some of our patients have reported incidents even at work. But what happens TB care does go to the workplaces of our patients to conduct talks about TB and issues around stigma so that those who are infected are not victimised.”*

### **Theme Two: Opinion of the DOTS strategy**

The health care practitioners’ opinions about the DOTS strategy related to the reasons they thought the programme often failed. Many of these factors have already been presented under theme one, component three entitled ‘Nature of the DOTS programme’. These include the fact that (1) the programme is too long, (2) daily visits to the clinic are

too demanding for patients, and (3) some patients experience side-effects from the anti-TB drugs and as a result interrupt or stop treatment.

The health care team provided additional valuable opinions regarding the TB treatment programme. They believed there was too much focus on the medication regimen and insufficient attention given to other socially supportive elements that could improve adherence by being built into the programme. These included support from significant family members, friends and health care workers who are specifically assigned to the task of monitoring and reminding the patient to take his/her medication.

Finally, the health care team felt that the TB treatment programme did not consider in a substantial way contextual factors, especially with respect to the role of traditional healers. Our data supports the fact that many individuals straddle mainstream and alternate healing systems. Despite this the treatment for TB is not tailored to these cultural practices of the affected communities. Focus group members did not, however, discourage patients who wished to see a traditional healer whilst they were on the TB treatment programme. Instead they emphasized the importance of continuing to take TB medication, especially at the beginning of treatment, even in the event that they decided to seek alternate methods of health care. This is illustrated in the following statement related to medication usage: *“Ja and what we usually do is to discourage them from taking both medications. We often tell them that for the first few days they must only use clinic medication as to see whether it works for them.”*

### **Theme Three: Recommendations to improve health service to TB patients**

The main recommendation made by providers was the establishment of a support group for the TB patients' attending the clinic. They felt that as most of the education about the disease is provided on the day the patient is told that they have tested positive for TB, patients are often overwhelmed by this knowledge at the same time as being informed of their diagnosis. They are, therefore, unable to process and absorb all the information about the disease. An on-going educational support group may improve adherence rates to TB treatment. The following opinion offered by a senior member of the focus group received support from the other members and captures the essence of the critical need for an "on-going" support group for the TB patients: *"I think on their first day after given their diagnosis that in itself is overwhelming for them and it's asking a bit too much to expect them to be able to hold all that information on education. That's why I feel that there needs to be an ongoing support educational group."*

### **Theme Four: Additional observations regarding TB patients and the health care provided by Cape Town City Health.**

A few important observations made by various members of the focus group regarding TB patients adherence to DOT and the health care provided by Cape Town City Health were discussed by the focus group participants. The observations that achieved group consensus are discussed.

One of the factors believed to contribute to poor TB cure rates is the fact that it is common for those individuals who are infected with the disease for the first time to adhere to their anti-TB drug treatment for two months initially and then stop the treatment once they were feeling well again. These are the patients who often get re-infected.

A critically important issue raised by the focus group participants related to the ineffectiveness of support staff. Paid community support staff were meant to monitor, especially those TB patients that do not attend the clinic for treatment as regularly as they should and motivate them to adhere to TB treatment. However, there was consensus that the support staff were ineffective and had a low work ethic as illustrated in the following statement: *“Just to add something regarding the DOT programme, the community supporters who are suppose to monitor the TB patient’s who can’t come to the clinic and take sputums are not doing their job. And they do get paid R30 per patient.”*

A factor felt to promote higher levels of adherence was the provision of food incentives to patients. The health care team reported that *“in winter when there are soup kitchens that are done by community members then you find that the level of adherence goes up because then the patients go for soup and bread.”* As part of the health service patients receive porridge and powdered milk if they request for a food parcel or if the health care worker thinks it is warranted.

## CHAPTER FIVE

### DISCUSSION

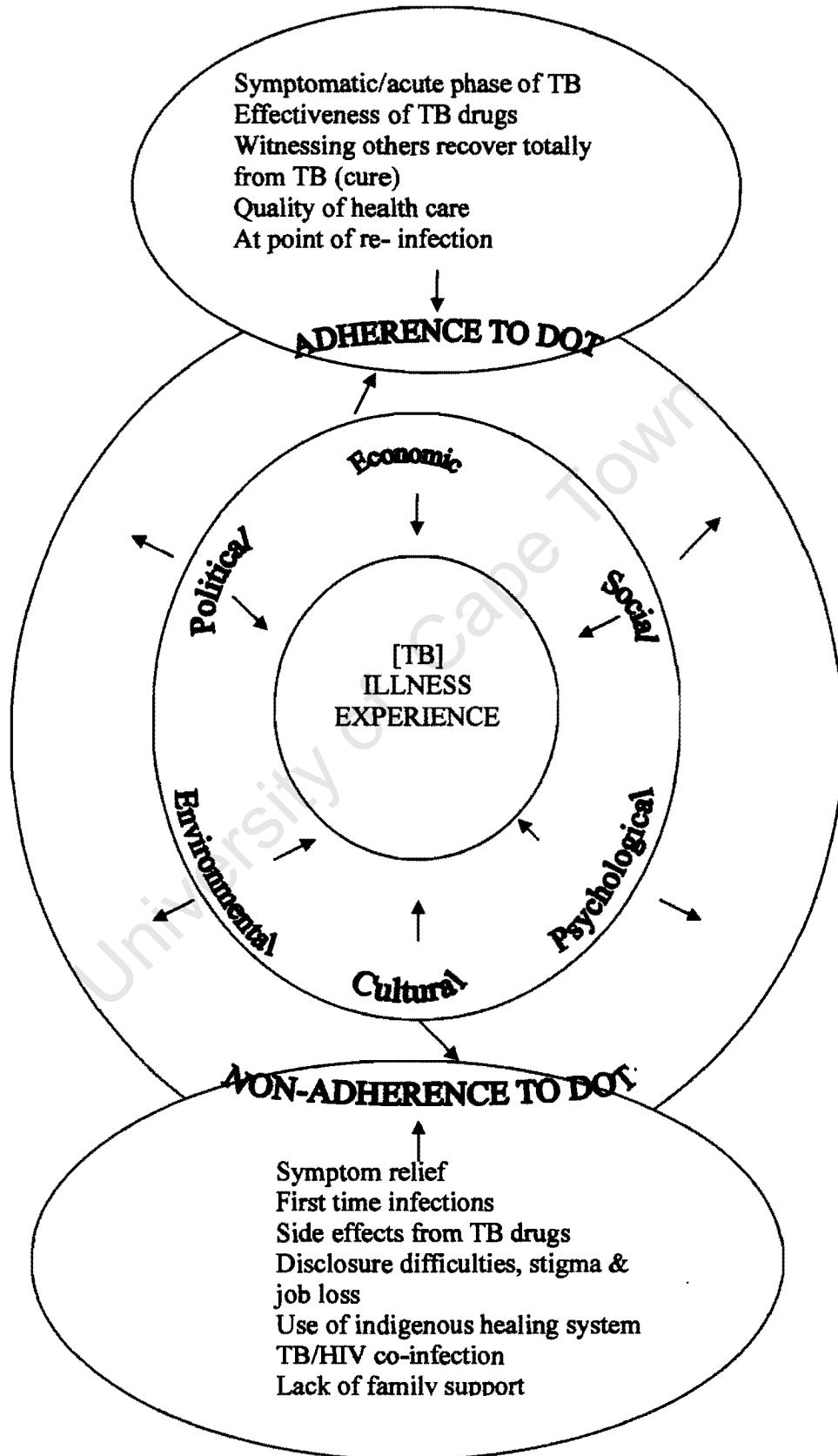
#### 5.1 Introduction

A *relativist perspective* as opposed to a *rationalist perspective* underpins this study. A rationalist approach demands that knowledge development is based on observation and experimentation. A relativist position, according to Abraham (2004), is one in which the value of theories and knowledge is determined by historical and cultural factors that are dynamic and change over time. A relativist position, therefore, is not researcher or theorist-focussed as is the case in a rationalist position, but participant-focussed in that the historical and other contextual features of the person or group being studied forms an important component of academic knowledge construction. The findings of this study are discussed within a hermeneutical phenomenological approach, which may be located in a relativist paradigm. Within a hermeneutical phenomenological perspective health and illness are considered to be *experiences* that “occurs in a concrete situation involving me and others living within a historical, cultural and social setting” (Kugelmann, 2004, p 44). In this study the life circumstances and the life experiences of the participants were explored to understand the factors that influenced their ability to adhere to a TB treatment programme. The researcher endeavoured to set aside any pre-conceptions about participant’s adherence and instead, made every effort to allow the participant’s construction of the factors that enhance or serve as barriers to be ascertained. The findings of the study, based on the integration of the patient’s and

health care provider's perspectives, revealed that the factors that have an impact on the participant's willingness or ability to adhere to TB treatment reflects a complex array of economic, social, environmental, cultural and psychological components. Figure 5.1 depicts this complexity.

University of Cape Town

**Figure 5.1** Factors influencing adherence and non-adherence to TB medication



## **5.2 The economic, social, cultural and psychological factors influencing adherence to TB medication**

### *The social, economic and political context of TB*

A sense of helplessness prevailed among the participants and the health care providers in the face of the poor social and environmental context of the participant. Factors that could contribute to improving the quality of life of the participants appear to be out of reach for the participants and health practitioners. Unfortunately, the health profile of the general patient population at Kuyasa clinic, in which the study was conducted, is consistent with the national disease burden profile with respect to TB, and HIV and AIDS. Six of the 15 participants were co-infected with the HI virus at the time the study interviews were conducted. Personal communication with the senior management at the Kuyasa clinic confirmed that the almost 50% TB/HIV co-infection rate of the study sample was reflective of the clinic's co-infection rate.

Health authorities are experiencing difficulty in improving the cure rate for TB in the historically disadvantaged community of Khayelitsha and are often challenged by the rate of re-infection of the disease. Individuals who are committed to better health outcomes for themselves often face social and economic constraints that are beyond their control and prevent them from making health-enhancing choices. They are confronted with unemployment because they lack skills consistent with current labour demands and have low levels of formal education.

The fact that TB is considered to be a disease of poverty is clearly reflected in this study. All the participants endured the experience of being poor and had a lived experience of the consequences of poverty, namely crowded and often dangerous living conditions, unemployment, limited formal education, limited social support and a narrowly defined social network, poor infra-structure, and general ill-health in their families and the community. The brutal level of poverty that participants in this study faced often meant that they were living below the breadline and unable to meet theirs' and their families' basic need for food, clothing and decent housing. The health care practitioners and the research assistant that carried out the individual interviews in the study also experienced, through the voice of the participants, the extent of poverty that patients are confronted with. The research assistant was also "witness" to the poverty when she accompanied the community health workers to locate TB patients who were non-adherent to the TB treatment programme. This is confirmed by the findings of the South African burden of disease study conducted by the Medical Research Council, which indicates that mortality due to diarrhoeal disease, TB and nutritional deficiencies, is significantly greater in the poorer provinces and rural regions (Bradshaw, Nannan, Laubscher, Groenewald, Joubert, Nojilana, Norman, Pieterse, & Schneider, 2004). Political will towards the progressive realization of rights for all South African citizens is critical within a health care context because good physical and emotional well-being clearly rests on an acceptable standard of living. Historically, individuals higher on a social stratum have enjoyed better health than those below (Farmer, 1999).

Participant's feeling of impotence within the context of such poor living conditions is illustrated by the fact that they have the information that anti-TB drug treatment is more effective if an individual is well-nourished but had to often confront the fact they sometimes could not afford to buy basic food items, let alone the "nourishing" food recommended by the health care workers. Thus the vicious cycle of poverty and ill-health continues.

It was evident during the research process that individuals born into sprawling, overcrowded and poor townships, such as Khayelitsha, during the apartheid years continue to face hardships. The cycle of poverty persists in South Africa despite the changing face of politics to one of democratic governance.

### *Causal Attribution*

Ascertaining the causal attributions made by the participants about how they became infected with TB provided a deeper understanding of their adherence to treatment for TB. Attribution theory, according to Kelly and Michela (1980), is "the study of perceived causation ....., the term attribution referring to the perception or inference of cause" (p. 458). Attribution, which is essentially a cognitive process, involves systematic assessment and/or manipulation of the information an individual gathers and his/her beliefs. Causal explanations are centrally linked to the attributional process. Attribution theory is widely used within a health psychology context in order to

understand some of the factors that contribute to health enhancing behaviour(s) and hindering health behaviours of individuals.

Kleinman and Kleinman (1991), within an ethnographic paradigm, state that social, cultural, and political factors act as a mediator to an individual's illness experience and will contribute to the way in which an individual constructs explanations for his/her illness. The causal attributions that individuals assign to their illness condition will affect their way of coping with it. If a treatment regimen recommended by a health practitioner is consistent with an individual's understanding of what caused his or her illness, then the individual is more likely to adhere. An individual who ascribes external factors that are out of his/her control as causing the illness, is less likely to be self-motivated to improve his/her health status as compared to an individual who rates highly on self-efficacy. Those high in self-efficacy believe that they are able to carry out tasks and engage in behaviours that matter and provide direction in their lives. Increased levels of self-efficacy has also been associated with better disease management, such as adhering to prescribed medicines, managing stress and following a recommended nutrition programme (Clark & Dodge, 1999). The reality is, however, that in socially and economically under-resourced communities there may well be factors that individuals have very little control over. This presents as an immense challenge for many individuals in these communities who rate high on self-efficacy and have the personal will to improve their quality of life but are overwhelmed by their currently adverse life conditions and are unable to effect changes in the short-to-medium term.

In this study the complex interrelationships between environmental, social, cultural, and personality factors are evident in the way participants' constructed causal explanations for TB. The inability to control the factors that contributed to the cause of the onset of TB was one of the dominant themes that emerged from the individual interviews with the participants in phase one of the study. Cold and damp weather conditions as a causal explanation for the onset of TB was common among the participants (e.g. P5, P8).

Assigning climatic and poor living conditions as causes for the disease possibly render people helpless in the face of ill-health because they do not have control over both these factors. Health practitioners' concurred with this because they were also reduced to a state of psychological helplessness in the face of the patient's extreme level of poverty.

Certain social and cultural influences, which were beyond the participants' control, were also considered to have caused the onset of TB. In particular, participants (e.g.P14, P11) alluded to the fact that they lived within a patriarchal family system with men having relatively more power around decision-making. The participants perceived that, the fact that male members of the family did not want to present themselves for treatment fuelled their TB infection rate. It was evident that participants who believed that they were infected by close family members felt betrayed by their irresponsible behaviour and their lack of due consideration for others. Ultimately, participants felt devalued in the family home. Women in patriarchal families perhaps do not feel sufficiently empowered to assert their rights, needs or desires and, in fact may not be permitted to articulate their opinions (Doyal, 1995). These findings alert us to the fact that health in South Africa

should be looked at critically and the health experience of individuals should also be located within the discourse of gender, class and ethnicity/race (Naidoo, 2004).

The fact that participants believed that they were infected with TB by significant others, mostly family members, who were indeed non-adherent to treatment, provides good insight into one of the possible mechanisms in recurring infections within families and communities. The challenge that health authorities face, with respect to improving the cure rate for TB, therefore, is that many infected individuals do not present themselves for treatment despite knowing their diagnosis and the consequences of failing to take treatment. One may also surmise that these individuals do not believe that adhering to the recommended treatment of the local health authorities will cure their illness condition and possibly view the treatment methods with skepticism and mistrust. Of course the individual characteristic of having an “optimistic bias” within a health context may also explain why these individuals refuse to take treatment. “Optimistic bias” refers to “the belief that other people but not one’s self will develop a disease, have an accident, or experience other negative events” (Brannon & Feist, 2000, p 106).

Perhaps another reason for the resistance towards health promoting behaviour on the part of the male members of the families concerned is reflective of a fear of disclosure of their infected status and the associated stigma. If they are labelled as an individual who is afflicted with a disease condition, their power within the family decreases. The fear of being co-infected with HIV is yet another reason that some individuals may not present

themselves for treatment. This is based on the assumption that they have the information that there is a high TB/HIV co-infection rate in the community.

A subgroup of both younger (e.g. P4) and older male participants (e.g. P7) in this study were fairly introspective in that they made the causative link between their high-risk lifestyle and the onset of TB. The disclosure on the part of the older males, in particular, helps to challenge the commonly held expectation that it is predominantly the youth and young adults that engage in risky behaviour that is detrimental to their physical and mental well-being.

*TB infection: a norm in the community?*

It was evident in the study that the participants did not appear to experience psychological distress to any great extent after knowing that they tested positive for TB (e.g. P1). Their response to being diagnosed with TB was, however, significantly different to being told they were HIV positive. This is true for those participants that agreed to take the HIV test following VCT at Kuyasa clinic. The participants who tested HIV positive reacted with “shock” (Ross & Deverell, 2004) and dismay and in many instances stopped adhering to the TB medication.

Perhaps the participants did not react with ‘shock’ when they were informed by the health care provider that they had TB because of the fact that they were aware of the high prevalence of TB in the community. Further, their knowledge that TB is curable

possibly led them to take this disease status less seriously than they would HIV and AIDS. This opinion is also shared by the health care workers who stated that TB patients who are co-infected with HIV tend to take their HIV status more seriously than their TB status. This may imply that patients' do not fully comprehend the relationship between TB and HIV, and the importance of adhering to the TB treatment regimen when having a compromised immune system due to HIV. Perhaps a clearer message needs to be conveyed to these patients, through a health education process, that in order to contain the spread of these co-infectious diseases, such as TB, and maintain an optimum level of physical health, those who are HIV infected have to adhere to TB treatment. A culture of optimism needs to be created by the health care team to encourage the affected individuals to see that the overall improvement in their quality of life rests on being disease free (in the case of an infectious disease, such as TB).

The apparent normalization of their TB infected status may also reflect the participant's attempt at achieving equilibrium in their lives by maintaining their self-identity. This psychological process allows individuals to maintain an internal balance and appear "normal" to others. The process of normalization also allows the individual to be just like the "other" because being different places them in a marginalized position. This may be especially true in stigmatizing illness conditions, such as TB which is infectious and can be transmitted from one individual to another (Friedman, 2002).

### *Illness challenges*

The illness challenges that participants in this study faced, clustered around social and economic, disease-related and psychological factors. The economic factors and the social factors have been discussed, to some extent, earlier in the chapter. However, due to the complexity of the participants' illness experience and the interrelationships between the social, economic, cultural, disease-related and psychological factors, these factors as they relate to the challenges of having TB merit further examination.

### **Social Support**

The social and familial environments of the participants were not unquestionably supportive (e.g. P12). In fact, family support, or lack thereof, appears to be gendered. Women in the families of those infected with TB played a more supportive role. This is consistent with research, which indicates that women tend to fulfil nurturing roles and are more emotionally "giving" because it is what society in general and certain cultures, in particular, expect of them (Mark et al, 2000). Males in the families of the participants were seen to be contributing to the spread of TB because they did not adhere to recommended treatment programmes for the disease and were, consequently, perceived as unsupportive. Moreover, there was an implication that the patriarchal nature of these families allowed the men to make unilateral decisions even if these decisions did not serve the interest of other family members. The men did not appear to consciously consider the consequences of their non-compliant behaviour with respect to the risk and

dangers of infecting others. This lack of 'critical consciousness' contributes to the perpetuation of the vicious cycle of disempowerment, particularly of women, in certain communities (Campbell, 2004).

#### Emotions associated with the illness experience

A sense of hopelessness and depression, with underlying anger, prevailed among the participants in this study (e.g. P2, P12). This is especially true during the initial phase of the disease. At the time the diagnosis of TB is made, many patients are in the acute phase of the disease and are therefore symptomatic. Symptoms experienced during this period often render patients functionally impaired and dependant on others in order to manage their activities of daily living (e.g. P2). Essentially, patients feel they have limited control of their lives and may develop a sense of helplessness. According to Seligman (1975) people who are in an adverse situation, which they feel they cannot control may develop *learned helplessness*. Most participants reported that they found being in a perpetual state of exhaustion and incapacity for self-care, especially with respect to their personal hygiene, very challenging. Often this resulted in self-imposed isolation and feelings of loneliness. Studies have shown that an individual with a serious illness, who loses their independence and is forced to endure limited mobility because of the nature of the illness, becomes depressed (Koenig & George, 1998; Williamson, 1998, Newman & Mulligan, 2000).

The associated feelings of anger experienced by participants was directed towards close family members who were perceived to have TB and were not on treatment, or have had TB and did not take treatment at the time they were infected. Participants believe that they have been infected by irresponsible adult family members who were in denial of their own diminished health status.

### Stigma

Participants perceived being stigmatized as another major challenge of being infected with TB. It was evident that many participants withdrew from the members of their close social network because they felt “ashamed” and “embarrassed”. In this instance the stigma was self-imposed. Participants (e.g. P4, P12) reported being directly stigmatized within their families and in the community. This actual experience of facing prejudice, discrimination and disadvantage is termed “enacted stigma” by Kelly (Porter, 1999). By and large most of the participants anticipated that they would be stigmatized if they disclosed their TB infected status. This fear of anticipated discrimination is referred to as “felt stigma” by Kelly (Porter, 1999). In this study “felt stigma” is likely to be complicated because of the 50% HIV co-infection rate of the sample, as HIV remains a highly stigmatized illness in many South African communities (Ross & Deverell, 2004). Participants who were co-infected with the HI virus perhaps experienced increased levels of anxiety and avoided disclosing their health status for fear of both enacted and felt stigmas. Disclosure of their TB infected status and HIV positive status could possibly lead to double stigma. Goffman (1963) suggested that when individuals try to

preserve their identities they present themselves to others in a certain way, which may not be consistent with the “true self”. Participants in this study, therefore, may have increased levels of anxiety and depression because they are not able to freely express their individual identity, which is partly constituted by their state of health.

### *Patterns of adherence*

The complexity between adherence and non-adherence behaviour to the same treatment programme by the same individual poses a huge challenge to health practitioners who are striving to improve the cure rates for TB. The findings in the study revealed that neither adherence nor non-adherence were absolute. There were clearly periods in which the participants adhered to the TB treatment and there were periods in which they were non-adherent.

Factors favouring adherence: symptom relief, effectiveness of drugs, and total recovery from TB

Adherence to the treatment programme appeared to be better during the initial, acute phase of the illness when the participants were more symptomatic. They experienced symptom relief by complying with the recommended drug therapy for TB (e.g. P1). Those participants who continued to adhere to the treatment programme for TB were hopeful that they will recover fully because they were aware of the effectiveness of the drug. Many participants reported that the TB medication cured members of their family

and friends who were infected with the disease (e.g. P4). This finding is consistent with other research, which suggests that compliance to medication is positively associated with the patient's beliefs about the benefits of taking the drug (Marks et al, 2000). This study also lends support to the Health Belief Model (Becker & Rosenstock, 1984) in that the participants that adhered consistently to the TB medication believed in the effectiveness of the drug and its ability to cure them.

#### Factors favouring non-adherence

##### (1) Symptom relief/"Feeling better"

The reasons for the periods of non-adherence reported by the participants were many. Participants reported that they stopped attending the clinic for treatment as soon as their symptoms improved and they were "feeling better" (e.g. P7). This pattern of non-adherence has been found in other conditions as well. Patients who are taking medication to lower their cholesterol level, for example, may stop taking their medication because they have no symptoms. According to Jaret (2001), becoming symptomless may lead to the inconvenience of taking the drugs on a daily basis outweighing the benefit of remaining on the drug.

## (2) First time infections

A fair number of participants, in this study, who were re-infected with TB, admitted that they had been non-adherent the first time they were diagnosed. At the point of re-infection they made a more concerted effort to take the prescribed treatment, possibly because they finally acknowledged and accepted the extent of their vulnerability to ill health. Perceived susceptibility to the negative consequences of non-compliance and the perceived severity of these consequences play an important role in influencing compliance to health-related behaviours as suggested by the Health Belief Model (Becker & Rosenstock, 1984). Patients who do not cooperate during the first episode of being infected with TB may underestimate the seriousness of a communicable disease, such as TB, and the reasons for having a regimented treatment programme. Fogarty (1997) uses the theory of *psychological reactance* to explain this form of non-cooperation. The more extensive and complex the treatment is, he argues, the more likely patients will perceive the treatment repertoire as a threat to their personal freedom. In this context, non-adherence may be viewed as a means of resisting medical dominance (Fogarty, 1997; Trostle, 1988).

## (3) Side-effects

The health practitioners' at the Kuyasa TB clinic stated that the side-effects of the anti-TB drugs should not be under-estimated. Many TB patients attending the clinic stopped taking their medication because they experienced severe side-effects. Ill-health caused

by a health care practitioner, sometimes by virtue of the pharmacological drugs he/she prescribes, is called *iatrogenic illness* (Friedman, 2002). Non-adherence because the patient is unable to tolerate the drug therapy may, therefore, be beneficial to the patient at times. In America, it is estimated that 100 000 deaths occur as a result of medical errors, which range from poorly performed surgery to unsuitable drug therapy (Kohn, Corrigan, & Donaldson, 2000). However, despite the information provided by the health care providers, none of the participants in the study enlisted medication side-effects as one of the reasons for not cooperating with DOT.

#### (4) Disclosure, stigma and associated job loss

Another reason for non-adherence among the participants in gainful employment was their commitment to their work and their fear of losing their jobs if they disclosed their health status (e.g. P15). Perhaps for these individuals the knowledge of the devastating consequences of not treating an infectious disease, such as TB, poses a double-edged sword. On the one hand, work is what defines their individuality, provides purpose in their lives, helps shape their identity as a productive member of their family and provides their material means to support. Therefore, to lose their job would reduce them to the extreme poverty experienced by the majority of people in the impoverished township of Khayelitsha. On the other hand, knowing that non-adherence to the recommended treatment regimen for TB not only endangers their own health but the health of the members of their close social network, and may also lead to losing the

dignified existence that being in employment offers. Hence they find adherence being influenced by conflicting factors.

In the case of the employed participants, disclosure of their TB status may also lead to stigmatization, victimization and marginalization because the disease is viewed by others as a “contagious” disease, thereby implying that the infected person is “contaminated”. In a study conducted in Vietnam it was found that the reluctance of individuals to seek treatment for TB was associated with fear of stigmatization and the (mis)perception that TB is a “dirty” and incurable disease (Johansson, Diwan, Huong & Ahlberg, 1996). Moreover, the participants in this study who were co-infected with HIV were perhaps fearful of “double” stigmatization if their health status was discovered. Fear of disclosure of ill-health and associated stigma has been found among individuals afflicted with various conditions. People with HIV, for example, were reluctant to disclose their illness and often did not take their medication in public because others will become aware of their illness (Johnstone Roberts & Mann, 2000; Segal, Schrimshaw & Raveis, 2000). Similarly, Smith, Francis and Rowley (2000) found that individuals with mental health problems reported feeling stigmatized because of their drug treatment regimen. In South Africa there is an increasing awareness of TB and HIV co-infection in the workplace because of the pressure placed on private and public institutions, by the government, to progressively realize the health rights of workers.

##### **(5) Use of an indigenous/alternate healing system**

The use of an African indigenous healing system was also associated with periods of non-adherence to the TB treatment programme among the participants in this study (e.g. P2). Consulting with a traditional healer during times of ill-health is deeply embedded in the psyche of African people and forms part of the African cultural identity. Bengu (1989) found that one of the reasons that black psychiatric patients did not adhere to mainstream treatment is that they opted to consult traditional healers because they received individualised care. In addition traditional healers were perceived to provide psychological support to the patients and their families without labelling or stigmatizing them. Many studies (e.g. Roberson, 1992; Lumme-Sandt, Hervonen, & Jylha, 2000) have found that alternative or “non-pharmacological” treatments are widely used by individuals diagnosed with illness conditions, such as asthma and hypertension. In developed countries it is estimated that about half the general population uses complimentary and alternative medicine (Ernst, 2003). In this study, participants generally stopped adhering to TB treatment after the initial contact with the traditional healer. They soon learned, however, that the indigenous system of healing and the treatment programmes suggested by health care practitioners’, who served as agents for the mainstream health system, could be used in a complimentary fashion, and may have, therefore, used both simultaneously.

#### (6) TB/HIV co-infection

Non-adherence to TB treatment also occurred after participants discovered that they were co-infected with the HI virus. The emotional reaction to the news of their HIV positive status was probably one of shock, psychological numbness and disbelief (Ross & Deverell, 2004). This feeling of being overwhelmed with this news hampered the participants from psychologically integrating and accepting their TB infected and HIV positive status. Instead they needed time to process the fact that they were also afflicted with HIV, an incurable disease.

#### (7) Lack of family support

Family instability and unsupportive family members were associated with the disruption of treatment. There is evidence to show that when individuals suffering ill-health are faced with disharmony in their families, experience family instability or social isolation, they are less likely to comply with medical treatment (Baekeland & Lundwall, 1975; Porter, 1969).

#### *Quality of health care*

Participant's equated "nursing" care with the quality of health care received. They were very positive about the attitude of the health care practitioners (e.g. P1, P2). All the participants, except one, expressed their appreciation that the TB clinic staff often went

beyond their call of duty by listening to them about the difficulties they were experiencing in their personal lives. The relationship that the health care practitioner's and the participants shared is indicative of a good "therapeutic alliance", a process in which the practitioner effectively communicates the patient's problem and formulates a management plan that is conducive to patient compliance (Brock & Salinsky, 1993). This demonstrates a patient-centred approach to health management because the biological, psychological, social and cultural aspects of a patients' life are considered. A good therapeutic alliance is underpinned by trust, empathy and positive regard (Rogers, 1961). Additionally, the participants who were gainfully employed at the time the interviews were conducted stated that the "nurses" were often "sympathetic" and provided the prescribed drugs for the days they were unable to attend the clinic because of work-related reasons. There is evidence that good communication between the health practitioner and patient is the most powerful predictor of adherence or more appropriately, concordance. Weiss and Britten (2003) state: "Crucially, concordance advocates a sharing of power in the professional-patient interaction" (p 493).

The willingness of participants to agree to be part of the VCT programme for the HI virus was encouraging because this meant that they were keen to know their HIV status. This may imply that the clinic health care staff readily gained the trust of the participants by imparting knowledge of TB, HIV and AIDS as transparently and honestly as possible in order to influence the patient's decision to take the HIV test. Willingness to be tested for the HI virus at Kuyasa clinic is a reflection of both the quality of health care received and the personal motivation of the individual taking the test to know their HIV status.

The patient-practitioner alliance is critical to good health outcomes because it fosters a mutually agreeable health management plan for the patient.

The health care practitioner's provided their perspective on some of the reasons they felt the quality of health care provided, in the context of TB, has not reached an optimum level. In particular, they believed that community support staff were not fully committed to the TB prevention drive despite receiving remuneration for the work they do. The support staff were meant to specifically target those individuals not adhering to the TB treatment programme and motivate them to attend the clinic for the treatment and prevention programmes. Perhaps the support staff in the community face challenges that they are unable to meet and, therefore, appear ineffective in carrying out their responsibilities. The research assistant in this study gained insight into some of the reasons why community workers were not motivated. These reasons include the fact that it is often difficult to trace patients who are not adhering to the TB treatment programme because they do not live in the same abode long enough, have died or are simply resistant and avoidant. Working conditions are also hazardous for community health workers because they carry out their duties "on foot" even in adverse winter weather conditions and of course their personal safety is often threatened in certain high crime areas of Khayelitsha. In a similar community-based model using volunteer health workers to improve adherence of notified TB patients to anti-TB treatment in an under-resourced area called Elsies River in the Western Cape, Dick, Schoeman, Mohammed and Lombard (1996) found that the supervision and support of the volunteer workers did not significantly increase cooperation in adult patients. Both paid and volunteer

community health workers perhaps have difficulty in influencing the health-seeking and health-enhancing behaviours of the adults in the affected communities.

#### Limitations of the study

The results of the study cannot be generalized to the TB patient population at Kuyasa primary health care clinic because of the small sample size. An understanding of the factors that enhance adherence and the factors that serve as barriers to adherence to TB treatment may only be applied to the 15 participants in the study. Perspectives on adherence provided by the health care practitioners is only applicable to the setting in which the study was carried out. While the “richness” of the data collected in a qualitative study is undoubted, the data does not always reflect the phenomenological dynamics of the individuals participating. Individual in-depth interviews, which captured the participants’ “voice” and subjective experience, may not be an entirely accurate reflection of what they feel, think and do within a self-regulatory health-enhancing context. Participants may articulate mostly what they think the interviewer wants to hear and may not disclose some of their or the health providers, what they perceive to be, socially undesirable qualities. Similarly, the health care practitioner’s may not have disclosed un-reservedly about what they perceive to be the flaws in the health care system that may serve as barriers to adherence because an important stake-holder in the process was their senior management.

## Significance and recommendations

### *Significance*

The Principal Investigator (PI) did not impose a research agenda on the Cape Town City Health Department (CTCHD). Instead she collaborated with the Director and his management colleagues to ascertain their need with a view to improving the public health care service they provide. In this study the complex array of social, economic, cultural and psychological factors that influence whether an individual adheres to the TB treatment programme, is explored from the patient's and the health care practitioner's perspectives. This approach to the study of adherence to medical care deconstructs the prevailing literature, which commonly conceptualizes adherence from the medical profession's worldview (Trostle, 1988). The integration of results from the patient's and the health care practitioner's perspectives allowed, albeit, in a limited way to gain a deeper knowledge of the nature of the TB patient population at the clinic. The approach adopted by the researcher in interfacing psychology and public health is consistent with the current demand for more in-depth knowledge of the behavioural correlates of health and health behaviour so that individual health outcomes may improve. Wilkinson and Marmot (2003), in a World Health Organization publication, highlight the importance of having a thorough understanding of the social determinants of health.

The richness of the data captured in this study and the subsequent interpretation of the findings was enhanced by the fact that the interviewer was Xhosa-speaking and

understood, without prejudice, the challenges that the participants faced because she lives in the same township. This meant that there was a relatively equal power relation between the interviewer and the participants. The fact that the interviewer was equipped with the qualifications of a clinical psychologist meant that she was able to skilfully guide the interviewer-participant alliance.

### *Recommendations*

It is recommended that:

- (1) there is greater commitment by the public health sector, in particular the (CTCHD), to patient-centred and community-centred health promotion strategies (Campbell, 2004).
- (2) support groups are run at the clinic for TB patients, especially those infected for the first time. TB patients who are co-infected with HIV would also benefit from a support group process, which may focus on the broader illness experience and the 'triple-stigma' experienced by co-infected patients. The concept of 'triple stigma' arises out of the fact that TB is a contagious disease, and HIV is both sexually-transmitted and is terminal.
- (3) a more comprehensive TB treatment programme should be adopted in the Khayelitsha community. The TB treatment package should include: food parcels, social work services to facilitate family stability and family involvement, a dedicated staff

member to liaise with employers, and mental health professionals to assist patients who are depressed, marginalized and stigmatized.

(4) the merits of “importing” the components of other models of treatment and health-promotion, such as the HIV and AIDS health management model, into anti-TB care, should be explored. Getting a family member, friend or community member to play a supportive role during the treatment period is widely used, for example, in the ARV roll-out. Developing community resources and increasing social capital are effective avenues towards maintaining the health and well-being of a society (Campbell, 2004).

(5) there should be greater efforts for collaboration with religious and traditional healing institutions to highlight the health care needs of the Khayelitsha community and to explore the potential for a ‘combined mainstream, traditional and religious health care system’. It is evident from the study that many patients straddle traditional healing systems and mainstream health care.

### **5.3 Conclusion**

Adherence to TB treatment in the Public Health sector must be understood within the context of the individual characteristics of the TB patient, their social, cultural and economic situation and resources, and the health care setting. While some factors that influence adherence to the treatment for TB may be under the personal control of the afflicted individuals, many patients appear to experience barriers to adherence that are

out of their personal locus of control. Participants were, in general, knowledgeable about the disease, its infectious nature, and the effectiveness of drug therapy but nevertheless acknowledged that they had periods of non-adherence. Non-adherent behaviour in this public health context is complex. Factors that appear to be strongly associated with periods of non-adherence include poverty, HIV co-infection, stigma and unsupportive social and work environments.

Factors that underpin the association between non-adherent behaviour and a fear of being stigmatized are complex. While on the one hand in the Khayelitsha area the prevalence of TB is high and becoming infected appears to be somewhat “normalized” in this community. On the other, despite this participants still report actual or perceived stigmatization. Stigmatization in the work place may occur as employers are focused on maximum productivity, which is dependant on a “healthy” work-force and may, therefore, not take kindly to employees being ill. This apparently contradictory situation that in which community stigmatisation of individuals with TB within a high prevalence setting such as this one occurs, needs further exploration.

The prevalence of helplessness, hopelessness and depression among the participants of this study is possibly one of the most significant psychological contributors of non-adherence to TB treatment. Having an infectious disease such as TB is burdensome and to be part of a treatment programme for at least six months is taxing. Moreover, these individuals have social and economic constraints. This combination of factors may lead to a sense of helplessness and hopelessness because those afflicted with TB may

genuinely not have any control over their circumstances, which consequently reduces their ability to improving their health status by adhering to the treatment programme.

An integration of the participants and the health care provider's perspectives indicate that adherence to TB treatment in a public health service must be understood within the context of poverty, the health belief system of the individual, cultural beliefs and practices, social support, stigma, the high rate of TB and HIV co-infection, the health practitioner-patient alliance, and the nature of the DOTS strategy. Non-adherence to TB treatment clearly poses a challenge to the already over-burdened public health system in South Africa.

University of Cape Town

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## **APPENDICES**

**Appendix One: Informed Consent Forms**

**Appendix Two: Background Information Questionnaire**

**Appendix Three: Interview schedule**

University of Cape Town

## Appendix One

University of Cape Town

UNIVERSITY OF CAPE TOWN  
DEPARTMENT OF PUBLIC HEALTH  
INFORMED CONSENT FORM

Dear Participant

You have already been informed by the nurse in charge of the TB clinic that I am carrying out a study which looks at why some patients with TB are able to follow the treatment programme given to them by health care workers (including doctors and nurses), and some TB patients are not able to. Thank you for allowing the person who is helping me to carry out the study talk a little more about the details of the study and also answer any questions you may have about the study. If you decide to participate then the responses you give us, combined with what other TB patients tell us, will help health care workers gain a better understanding of your experiences as a TB patient. The results of the study will, therefore, assist health care workers to develop a better way of treating TB, which is more suitable to the needs of the patient.

If you decide to take part in this study, you will be involved in two ways. Firstly, you will be requested to complete a questionnaire which asks you about yourself. Other information that we need, such as the details of your treatment, will be obtained from your file at the clinic. Secondly, you will be interviewed for about an hour and a half to two hours. A specially trained research assistant will interview you in the language of your choice. I will supervise each and every step of the study. You have a chance to ask questions about the research project at any point before, during, and after the interview. To make certain that what you say during the interview is properly recorded, the interview will be taped and these tapes will only be used for the purpose of this study. I would also like to ask you to allow us to do this.

Please be assured that your participation is entirely your choice and that any information gathered from you, and other TB patients, during your involvement in the study will be kept in the strictest confidence. Your real name will not be used in any public document including written reports. Your real name will also not be used in any public talks that may be given based on the results of the study. Instead, you and any other person and places names involved in your case will be changed so that no one will know who you are.

You also have the right to withdraw from the study at any point and if you decide that you do not want to continue taking part in the study, you may do so and you will continue to receive the same treatment at the clinic.

Permission to conduct this study was obtained from the University of Cape Town, through the Department of Public Health. Permission was also granted by the relevant authorities of Cape Town City Health. The University of Cape Town, Cape Town City Health, and the two funders for the project, the University of the Western Cape (UWC)

and the National Research Foundation (NRF). They are also aware that the results of this study will be published. Feedback will be given to the Cape Town City Health management and staff, and suggestions will be made about how to strengthen the existing TB treatment and prevention programme. The clinic staff is also fully informed about this study and will treat the TB patient's in the same way whether or not they are involved in the study.

Finally, please feel free to ask questions at any time during the interview. You may also call me, Pamela Naidoo, on the number(s) indicated below if you would like to discuss anything to do with the study. Once again, thank you for considering being part of this study. Kindly sign the Informed Consent Agreement Form if your final decision is to take part in the study.

Sincerely

**ASSOCIATE PROFESSOR PAMELA NAIDOO**  
**PRINCIPAL INVESTIGATOR**

Cell: 083 776 11 44  
Office: 959 2835/9595 2283

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### INFORMED CONSENT AGREEMENT FORM

I, \_\_\_\_\_, understand the reason why the study is being conducted and exactly how the study will be done. My participation is entirely my own choice. Further, I am fully aware that I have a right to refuse to continue to take part in the study at any point during the study period.

PARTIPANT'S SIGNATURE

DATE

SIGNATURE OF RESEARCH ASSISTANT:

DATE

## IYUNIVESITI YASE NTSHONA KOLONI

### IFOMU YEMVUMELWANO EYAZISIWEYO

#### Mthathi-nxaxheba Obekekileyo

Enkosi ngokuvuma ukuthatha inxaxheba koluphando, olunjongo yokuhlola izizathu ezibangela okokuba izigulana ezinesifo sephepha (TB) ziyilandele inkqubo yonyango enikwa zona ngonompilo, ukuquka (oogqirha kunye nabongikazi), zize ezinye izigulana ezinesifo sephepha zingayilandeli.

Inxaxheba oyakuthi uyithathe iyakuthi incede onompilo ukufumana ulwazi olungcono ngamava okuba ngumntu ofunyaniswe enesifo esosulelayo. Iziphumo zoluphando ziyakwazisa indlela yokuphuhlisa unyango lwesifo sephepha, eyakuthi ihambelane ncakasana neemfuno zezigulana.

Kukho amabakala amabini ayimfuneko kwinxaxheba oyakuyithabatha koluphando. Okokuqala, uyacelwa ukuba uphendule ngokupheleleyo uluhlu lwemibuzo eyakuthi ibuzwe ngawe kwaye kunye naluphina ulwazi olungezelelekileyo oluyakuthi lufuneke luyakuthatyathwa kwifayile yakho yasekliniki. Okwesibini, uyakuthi uthatyathwe udliwano-ndlebe oluyakuthabatha iyure enesiqingatha ukuya kwi yure ezimbini. Oludliwano-ndlebe luyakwenziwa ngumncedisi ofumane uqeqesho olugqibeleleyo malunga nezophando, eyakulwenza ngolwimi othe walukhetha. Intloko yoluphando yiyo eyakulawula yongamele koluphando. Uyakunikwa ithuba lokubuzwa imibuzo phambi kokuba luqhutywe udliwano-ndlebe, nangelixesha luqhutwayo naxa sele lugqityiwe. Ukuncedisa koluphando, nokuqinisekisa okokuba impendulo oyakuthi uzinike ziyashicilelwa ngendlela efanelekileyo kuma cwecwe ayakuthi asetyenziswe kuphela kwiinjongo zoluphando.

Nceda wazi ukuba inxaxheba oyithabathayo uyenza ngokuzithadela kwaye naluphina ulwazi esilufumeneyo kuwe nakwezinye izigulana ezinesifo sephepha ngelixesha loluphando luyakubayimfihlelo eqinisekisiweyo. Ukungafuni kwakho ukwaziwa kuyakukhuselwa. Ngako oko, igama lakho lokwenyani alisayi kusetyenziswa nanini na koluqokelelo lolwazi okanye kwingxelo ebhaliweyo, endaweni yoko wena kunye nawuphina umntu nendawo zokuhlala ezibandakanyekayo ziyakunikwa amagama angengawo la anikiweyo aze asetyenziswe kuzo zonke ingxelo ezenziwa ngomlomo nezibhaliweyo zashicilelwa.

Ukwanalo nelungelo lokurhoxa koluphando nangaliphina ixesha, kwaye ukurhoxa kwakho akusayi kuchaphazela ngendlela engeyiyo uncedo olufumanayo ekliniki. Kwangokunjalo abasebenzi base kliniki bazisiwe ngokupheleleyo ngoluphando kwaye balindeleke oko kuba babeyinxalenye yoluphando ngeyona ndlela esemthethweni nesesikweni.

Imvume yokuqhuba oluphando ifumaneke kwi Yunivesityi yase Kapa (UCT) kwisebe lezempilo. Kwakhona imvume yoluphando iphinde yanikezelwa ngabasemagunyeni abaphathelele kwicala lezempilo kwi dolophu yase Kapa. IYunivesityi yase Kapa, icandelo lezempilo kwidolophu yase Kapa kwakunye naba xhasi-mali ababini abangaba, IYunivesityi yase Ntshona Koloni (UWC), kunye nesiseko sophando lwamazwe jikelele (National Research Foundation) bayaqonda ukuba iziphumo zoluphando nezinto ezithi zilukuze ziyakushicilelwa kuma phepha ndaba (journals)

obuchule nobugcisa. Impendulo ngokubanzi iyakunikezelwa kubaphathi becandelo lezempilo besixeko sase Kapa nabasebenzi abaphathelele kweze mpilo, nengcebiso ziyakunikwa ngoku phathelele kwizinto ezilungileyo nezingamasolotya enkqubo yonyango nokhuselo lwesifo sephepha.

Okokugqibela, ndiyathemba okokuba niyakuziva nikhululekile ukubuza imibuzo yengcaciso nangaliphi na ixesha lale ntsebenziswano. Ungatsalela intloko yezophando kwezinqwaba zingezantsi xa ufuna ukuxoxa nokuba ngowuphina umba wenkqubo yezophando.

Ozithobileyo

ASSOCIATE PROFESSOR PAMELA NAIDOO  
PRINCIPAL INVESTIGATOR

Cell: 083 776 11 44  
Office: 959 2835/959 2283

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#### IFOMU YEMVUMELWANO EYAZISIWEYO

Mna, -----, ndiyasiqonda isizathu sokwenziwa koluphando namanqanaba alo.

Ndivumile ukuthatha inxaxheba ngokuzithandela. Ngaphaya koko, ndiyaqonda kakuhle ukuba ndinalo ilungelo lokurhoxa koluphando nangaliphi ixesha.

Umtyikityo womthathi-nxaxheba:

Umhla:

Umtyikityo womncedisi phando:

Umhla:

## Appendix Two

University of Cape Town

**BACKGROUND INFORMATION QUESTIONNAIRE**

Please note that all information contained in this questionnaire will solely be used for the purposes of this research project and will remain strictly confidential.

Please tick ✓ the box containing the correct information.

**Part A**

A1. What is your sex?

Male	1
Female	2

A2. What is your age in years?

A3. What are your contact details?

A4. What is your home language?

English	1
Afrikaans	2
Xhosa	3
isiZulu	4

If other (Please specify): \_\_\_\_\_

A5. In which residential area do you live?

\_\_\_\_\_

A6. What type of transport did you take to get to the clinic?

Public

Private

A7. Who lives with you? Where applicable please fill in the number of members per category.

Example: If you have two brothers living with you.

Brother/s	2
-----------	---

Participant Number: \_\_\_\_\_

Mother	Wife	Mother-in-law
Father	Partner	Father-in-law
Sister/s	Son/s	Cousin/s
Brother/s	Daughter/s	Friends
Husband	Grandmother	If other please specify: _____

A8. What is your relationship status?

Single	1
Married	2
Divorced	3
Widowed	4
Living with a partner	5

If other (Please specify): \_\_\_\_\_

A9. Do you have dependant children living in your home?

Yes	1
No	2

If yes, please specify the number of dependant children

Do you have any other dependants?

Yes	1
No	2

If yes, please specify the number of dependants

A10. What is your highest educational qualification?

Below Grade 4 (Std 2)	1	Technikon diploma	6
Between Grade 4-7 (Std 2-5)	2	Technikon degree	7
Between Grade 8- 10(Std 6-9)	3	Postgraduate diploma/degree	8
Completed Matric	4	Masters degree	9
Undergraduate degree	5	Doctoral degree	10

If other (Please specify): \_\_\_\_\_

Participant Number: \_\_\_\_\_

A11. Are you currently employed/working?

Yes	1
No	2

A12. If you are employed, what is your employment status?

Full-time	1
Part-time	2

A13. What is your total household income after deductions?

Less than R 2 500	1
Between R 2 500- R5 000	2
Between R 5 000 – R 7 500	3
Between R 7 500 – R10 000	4
Between R10 000– R12 500	5
Between R12 500– R15 000	6
Between R 15 000 and over	7

A14. Do you practice a particular religion? If yes, are you:

Moslem  
Christian  
African Traditional  
Other

A15. Have you converted from another religion? If yes, please state when did this happen, and why you decided to convert?

A16. Do you receive any financial aid from the government? If yes, please specify.

**Part B**

How long have you been living with Tuberculosis (TB)?

Does anyone else living in your home also have TB?

Did they have TB in the past? \_\_\_\_\_ If yes, how long ago was this? \_\_\_\_\_

Other than TB, do you have any other existing physical or mental health problems?

Yes	1
No	2

If yes, please specify: \_\_\_\_\_

What medication has been prescribed to you since your diagnosis?

Please specify: \_\_\_\_\_

Other than your prescribed medication, what other medication/substance do you use?

Alcohol	1	Painkillers	4
Marijuana	2	Cocaine	5
Tik	3	Heroin	6

If other (Please specify): \_\_\_\_\_

Have you been for any other form of health care, such as traditional healing? \_\_\_\_\_

If yes, were you given medication by the healer? \_\_\_\_\_

How much did you pay the healer? \_\_\_\_\_

What do you do in your leisure/spare time?

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**IMIBUZO NGEMIVULAVULI YAKHO**

Lonke ulwazi olakuthi lufumaneke ngalemibuzo ozakuthi uyiphendule luyakusetyenziswa kuphela kwiinjongo zoluphando, futhi luyakuba yimfihlelo eqinisekisiweyo.

Fakela uphawu ✓ ebhokisini.

**Isahlulo A**

A1. Chaza isini sakho?

Indoda	1
Umfazi	2

A2. Buthini ubudala bakho ngeminyaka?

A3. Chaza inkcukacha zakho zonxibelelwano?

A4. Chaza ulwimi lakho lwenkobe?

English	1
Afrikaans	2
Xhosa	3
isiZulu	4

Ukuba kokho olunye nceda uchaze \_\_\_\_\_

A5. Uhlala kowuphi ummandla?

\_\_\_\_\_

A6. Chaza uhlobo lwesithuthi othe wasisebezisa ukuza kwakho ekliniki?

Esika wonke-wonke

Esabucala okanye esakho

A7. Uhlala nabani? Fakela inani lamalungu kuluhlu ngalinye.

Umzekelo: Ukuba uhlala nabantakwenu ababini.

Um/aba/ntakwenu	2
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Participant Number: \_\_\_\_\_

Mama		Umfazi		Mazala/Mkhwezi	
Tata		Umlingane		Bawozala/Mkhwe	
U/oo/dade		U/oo/nyana		Um/aba/zala	
Um/aba/ntakwethu		I/ii/intombi		Isi/izi/hlobo	
Umyeni		Makhulu		Ukuba kukho abangabanye nceda uchaze:	

A8. Sithini isimo sakho?

Uwukatshati	1
Utshatile	2
Ubutshatile wohlukana	3
Umhlolo/mhlolokazi	4
Uhlala nomlingane	5

Ukuba kukho engenye nceda uchaze: \_\_\_\_\_

A9. Ingaba kuhko abantwana abaxhomekeke kuwe ohlala nabo ?

Ewe	1
Hayi	2

Ukuba kunjalo chaza inani labantwana abaxhomekeke kuwe

Unabo abanye abantu abaxhomekeke kuwe?

Ewe	1
Hayi	2

Ukuba kunjalo chaza inani labantu abaxhomekeke kuwe

A10. Chaza ibanga eliphezulu lemfundo oliphumeleleyo?

Ngaphantsi ko Greyidi 4(Ibanga 2)	1	Techinikon diploma	6
Ngaphantsi kuka Greyidi 4-7 (Ibanga 2-5)	2	Techinikon degree	7
Ngaphantsi kuka Greyidi 8- 10(Ibanga 6-9)	3	Postgraduate diploma/degree	8
Uphumelele Imatriki	4	Masters degree	9
Undergraduate degree	5	Doctoral degree	10

Ukuba kukho engenye nceda uchaze \_\_\_\_\_

**A11. Ingaba uqashiwe/ uyasebenza?**

Ewe	1
Hayi	2

**A12. Ukuba uqashiwe ingaba uqeshwe njani ?**

Isigxina	1
Isingxungxo	2

**A13. Uthini umvuzo wekhaya uwonke emva kokutsalelwa?**

Ngaphantsi R 2 500	1
Phakathi R 2 500- R5 000	2
Phakathi R 5 000 – R 7 500	3
Phakathi R 7 500 – R10 000	4
Phakathi R10 000– R12 500	5
Phakathi R12 500– R15 000	6
Phakathi R 15 000 and over	7

**A14. Unalo uhlobo oluthile lwenkolo olulandelayo? Ukuba unalo ingaba ulandela:**

Muslimu  
Ubukristu  
Inkolo yakwantu  
Engenye

**A15. Ingaba uguqukele kwenye inkolo? Ukuba kunjalo yenzeka nini, kutheni wagqiba ekubeni uguquke ?**

**A16. Ingaba uyalufumana uncedo lwemali oluvela kurhulumente? Ukuba kunjalo chaza ucacise.**

**Isahlulo B**

Uhleli ixesha elingakanani uphila nesifo sephepha (TB)?

Wawukhe wanaso esisifo kwilixa elidlulileyo?

Ingaba kukho omnye umntu ohlala ekhayeni lakho onesifo sephepha?

Babekhe banayo iTB kwilixa elidlulileyo? \_\_\_\_\_ Ukuba kunjalo kwakunini?

\_\_\_\_\_

Ngaphandle kwe TB ingaba unazo ezinye izifo emzimbeni okanye ingxaki zempilo engqondweni?

Ewe	1
Hayi	2

Ukuba kunjalo nceda uchaze \_\_\_\_\_

Ngawaphi amayeza owanikwayo oko wafunyaniswa unesi sigulo?

Nceda uchaze \_\_\_\_\_

Ngaphandle kwamayeza owanikwayo ngawaphi amanye amayeza/ into oyisebenzisayo?

Utywala	1	Izibulala-ntlungu	4
Intsango	2	Cocaine	5
Tik	3	Heroin	6

Ukuba kukho enye nceda uchaze \_\_\_\_\_

Ingaba wakhe wakolunye ulondolozo lwezempilo, olunje ngonyango lwesintu? \_\_\_\_\_

Ukuba kunjalo, ingaba wanikwa amayeza yinyangi? \_\_\_\_\_

Wayihlawula malini inyangi? \_\_\_\_\_

**Appendix Three**

University of Cape Town

## **APPENDIX THREE**

### **INTERVIEW GUIDE**

- 1. Tell me about the time you were first told that you have TB. How do you get think you got infected?**
- 2. Tell me how much you know about TB?**
- 3. What was happening in your life at the time you were diagnosed with TB?**
- 4. What is your experience of being a person with TB?**
- 5. What is your experience of taking the treatment that the nurses in the clinic give you? Have you been able to take your treatment exactly the way the nurses have advised you to? Are you getting advice and/or treatment from anyone else besides the nurses and doctors that treat you in the clinic?**
- 6. Have you been asked by the nurses whether you would like to have an HIV test? Would you mind telling me if you agreed to have the test?**