Attitudes and perceptions towards TB in Grahamstown East in a time of HIV/AIDS

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ABSTRACT

Tuberculosis (TB) has become a serious South African health problem because it is the most common opportunistic disease that leads to death in people with HIV/AIDS. Due to the airborne nature of the disease it can easily be spread to anyone including healthy people. A lack of compliance to treatment by TB patients explains why prevalence rates of the disease are high and why there is an emergence of drug resistant strains such as XDR-TB and MDR-TB. Information on existing knowledge, attitudes and perceptions regarding TB can provide a crucial foundation for the development of educational programmes and interventions aimed at reducing the further spread of the disease.

This study aimed at understanding the knowledge, attitudes and perceptions towards TB and relating these to the current prevalence of HIV/AIDS. A face-to-face interview survey was conducted among adult Grahamstown East residents (n=1020). The Health Belief Model (Rosenstock et al., 1994) and Bandura's (1986) Social Cognitive Theory formed the theoretical framework of the data collection and analysis. The data generated from the field work was first descriptively analysed providing frequency tables. Thereafter cross tabulations were calculated for relevant items using independent variables, namely gender, level of education, and experience of dealing with TB.

The results of the study show that, in general, knowledge concerning TB was sufficient to provide a foundation for the adoption of healthier behaviours in the female respondents. Few of the respondents reported feeling personally susceptible although the majority of the respondents acknowledged the severity of the disease. The cues to action lacked the influence to persuade people to adopt positive health related behaviours. The perceived benefits of adopting preventative behaviour were not very influential in the adoption of healthier behavioural changes in the respondents. Disease stigma regarding the dual association of TB and HIV/AIDS was the main barrier for the adoption of healthier behavioural attitudes. Perceived self-efficacy in preventative behaviours was generally low in the less educated respondents. Recommendations regarding areas for future research and change interventions are provided.

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List of acronyms and abbreviations

AIDS	Acquired immunodeficiency syndrome
ARV	Antiretroviral
DOTS	Directly observed treatment short-course
DRA	Development Research Africa
HIV	Human immunodeficiency virus
ISER	Institute of Social and Economic Research
MDR-TB	Multidrug-resistant tuberculosis
NGO	Non-governmental organisation
NTP	National TB programme
PTB	Pulmonary tuberculosis
PTSD	Post traumatic stress disorder
SANTA	South African National Tuberculosis Association
SEL	Socio-economic levels
TB	Tuberculosis
VCT	Voluntary counselling and testing centres
WHO	World Health Organisation
XDR-TB	Extreme drug-resistant tuberculosis

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CHAPTER 1

INTRODUCTION

1.1 Chapter preview

This chapter covers TB as a disease followed by its effect on mental health, and incidence of the disease in South Africa. The effects of TB on the mental health of infected and affected persons are discussed within the chapter. A brief history of TB and the current incidence of the disease in South Africa are provided. After the relationship between TB and poverty has been discussed, an overview of the goals and rationale of the study are presented at the end of the chapter.

1.2 Tuberculosis

TB is a biphasic air-transmitted disease which mainly affects the lungs and when this happens it is called pulmonary TB (PTB). The disease may affect other parts of the body, such as the spine, bowel and brain. According to the World Health Organisation (WHO, 2007a) the tubercle bacillus is an infectious air-borne disease that is spread when infected people cough, spit, talk or sneeze. People who are in close proximity to infected persons for long periods are at risk of contracting the disease. If untreated, a person with active TB can infect an average of 10–15 people of any age each year (Deacon, 2005). People with compromised immune systems are at an increased risk of contracting TB. It has been estimated that someone becomes infected with the disease each second; thus approximately one percent of the world`s population is newly infected each year (Weiss, 2001). PTB is curable. Infected people do not necessarily become ill immediately as they can develop latent TB which is not infectious. The immune system protects the body against TB and the bacilli can lie dormant for many years. Ten percent of the people infected with latent TB, however, do develop active TB at some stage in their lifetime and, if latent TB is left untreated, it kills more than half of its victims (WHO, 2007b).

There are several drugs that can cure TB; of these, the most well known are isoniazid and rifampicin. In order for the drugs to work they have to be taken regularly for a long period of time, usually six to eight months. People with latent TB infection should be evaluated for a course of preventive therapy which usually includes taking anti-tuberculosis medications for several months. People with active TB, however, must complete a course of treatment for at least six months or more (Whalem & Semba, 2001).

When a strain of TB is apparently incurable in a patient using the more common anti-TB drugs, it is known as drug-resistant TB. Drug-resistant TB was first reported in South Africa in 2005. Drug-resistant TB is caused by inconsistent or partial treatment of the disease. This occurs when TB patients default with treatment possibly because their health improved or the doctors and health workers prescribed incorrect treatment regimens. A particularly dangerous form of drug-resistant TB is multidrug-resistant type (MDR-TB), which is defined as the disease caused by the bacilli that are resistant to at least isoniazid and rifampicin. Four hundred and fifty thousand new MDR-TB cases are estimated to occur globally every year (WHO, 2007a).

While drug-resistant TB is generally treatable, it requires treatment of up to two years duration using second-line anti-TB drugs. These drugs are more costly than first-line drugs and they produce adverse drug reactions that are more severe, though manageable. The treatment of MDR-TB is very expensive and the prevention of MDR-TB is a serious challenge. The spread of MDR-TB could ultimately lead to an incurable epidemic. Extreme drug-resistant TB (XDR-TB) is a subset of MDR-TB in which the strains of TB are extremely resistant to several of the best second-line drugs. XDR-TB patients are difficult to treat and they make up approximately 10 percent of MDR-TB cases. If XDR-TB is not controlled in South Africa it is feared that it will spread to the rest of sub-Saharan Africa and will be very difficult and expensive to contain thereafter. XDR-TB is the most dangerous strain of TB in the world (WHO, 2007a).

1.3 The effect of TB on mental health of infected and affected persons

Research has shown that people infected with TB are more likely to develop mental and psychological problems than people not infected with the disease. TB infection usually results in a variety of psychological problems as it is stressful to be infected. Depression, post traumatic stress disorder (PTSD) and acute-stress disorder are the most common stress related conditions of TB patients (De la Rey, Duncan & Swartz, 2006).

TB, like other incapacitating conditions, can negatively affect an individual's ability to learn, to concentrate and to work. The main impact on the mental health of individuals mainly stems from social and economic disease related factors. Since TB has been viewed for a long time as a marker of poverty, many individuals infected with the disease carry the burden of shame within their respective communities. Many people in sub-Saharan Africa believe that individuals infected with TB also have HIV/AIDS. The existing stigma towards HIV/AIDS is believed as being passed on to TB and the internalisation of this association is becoming psychologically detrimental to TB patients (De la Rey et al., 2006).

The long duration of treatment, cost of the medication and the large volumes of medication have huge psychological effects on a patient. TB patients may lose their jobs because of poor health and the need to take treatment regularly. In an environment where jobs are scarce and incomes are low, this can have a negative effect on the mental health of a patient and family. The long duration of the treatment may cause TB patients to lose a sense of self-efficacy because of the delayed gratification. The ongoing TB pandemic in South African communities is having a negative impact on productivity and entrepreneurship thereby resulting in the demoralisation of affected families and communities. Having a family member infected with TB has a psychological impact on the rest of the family members as a result of the negative consequences that stigma and the expenses of caring for a patient pose for the family (De la Rey et al., 2006).

1.4 The history of TB in South Africa

TB was first spread to South Africa by the European settlers who came to South Africa in the beginning of the 19th century. The discovery of gold and diamonds resulted in an influx of Europeans in the 1800s and many miners who came from Europe were infected with TB. The mining magnate Cecil John Rhodes was sent to Africa because of his TB status. Europeans who were sick from TB were sent to South Africa because the European medical practitioners felt that the dry and sunny African climate would make the TB patients recover faster (Whalem & Semba, 2001). The TB infected Europeans located to various parts of South Africa thereby spreading the TB bacilli to the local inhabitants. The segregation policies implemented by the apartheid government of South Africa forced the majority of local inhabitants to live under poor and harsh conditions. Due to the repressive settlement policies implemented by the apartheid government there were acute housing shortages which contributed to the growth of slum conditions. Large numbers of black South Africans moved from the extreme poverty in rural areas to urban areas where they hoped to find employment as cheap labourers in mines and factories (Walker, Reid & Cornell, 2004). In the urban areas impoverished black South Africans lived in over-crowded single sex hostels or shacks. These over-crowded unsatisfactory living conditions resulted in the spread of TB through the poor native communities.

The social capital, binding the African communities and their culture, was broken by the policies of the apartheid government. Social capital in a community is associated with positive enduring outcomes of social support (Walker et al., 2004). According to Putnam, Leornadi and Nanetti (1993, p. 46), "social capital is defined as the existence of community networks, participation in community activities, local identity and a sense of solidarity with other community members". TB patients who feel that they are supported by their community are confident in revealing their disease status and are willing to receive help and support from the community and health care institutions (Kelly, 1999). According to Walker et al. (2004, p. 36), "in a context where violence, substance abuse and social divisions are eminent, social cohesion and a sense of identity are widely unable to gain a sense of acceptance". A lack of social cohesion allows for negative

attitudes and perceptions to develop towards an infectious disease such as TB. As a result of the lack of community support in some areas in South Africa it is very difficult for TB patients to cope with the disease in their communities which results in the tendency of infected people in such communities to not disclose their disease status (Kelly, 1999).

In South Africa extreme drug resistant TB was first identified in 2005 in the town of Tugela Ferry in KwaZulu-Natal Province. This type of TB is resistant to all major anti-TB drugs (South African Institute of Race Relations, 2008). In research conducted in South Africa, the non-adherence to TB medication by patients was a major cause of the development of drug resistant TB in South Africa. In South Africa the mortality among MDR-TB defaulters is high owing to substance abuse and the supposed lack of social support from the community and health care workers (South African TB Vaccine Initiative, 2006).

1.5 The incidence of TB in South Africa

According to the South African Institute of Race Relations (2008) the incidence rate of TB in South Africa is approximately 718 cases per 100,000 people, a rate that is classified by the WHO (2007a) as a serious epidemic. In South Africa in 2006 there was a 48% increase in the cases of TB reported nationally. South Africa has the fifth largest number of TB cases of any country in the world and it has the most dangerous strain of TB (XDR-TB) in the world. A study conducted by the South African TB Vaccine Initiative (2006) found that three per cent of South African infants had TB, an incidence rate of 3,000 per 100,000. It was found that among all age groups there were 1,400 cases of TB per 100,000 which is double the global average making South Africa one of the worst affected countries. According to the WHO (2007a), TB rates in most developed countries are well under 20 per 100,000.

Apart from the alarmingly high incidence of TB in South Africa, its close relationship to HIV/AIDS is another source of concern because TB is the most prevalent cause of death of people living with HIV/AIDS. In 2005 there was a 66% co-infection rate of TB and

HIV/AIDS. It is estimated that over 5 million South Africans living with HIV/AIDS are likely to contract and die from TB in the course of their lifetime (South African Institute of Race Relations, 2008). The outbreak of extreme drug-resistant TB in Tugela Ferry killed 53 victims of which 52 victims were also infected with HIV/AIDS (South African TB Vaccine Initiative, 2006).

South African health practitioners are concerned that too few individuals with TB symptoms present themselves for treatment (Cramm, 2006). The reasons why TB patients in South Africa resist treatment are not yet fully understood. However, Kelly (1999) suggested that the link between HIV/AIDS and TB contributes to stigmatisation and prevents TB sufferers from presenting themselves for treatment and thus results in avoidable infection of other people. More specifically the results obtained from community studies conducted on urban black South Africans in the Eastern Cape identified social rejection and disease stigma as the most common reactions towards TB. These findings are supported by two further studies. Cassie (2002) found that the stigma associated with TB, which was due to its association with HIV/AIDS in both urban and rural South African communities, played an important role in the spread or non-containment of the epidemic. Based on their findings, Edginton, Sekatane, and Goldstein (2002) concluded that the stigma attached to TB was responsible for the delay and unwillingness of infected people to continue treatment over their recommended course and this led to the development of drug-resistant TB such as MDR-TB and XDR-TB.

1.6 TB and poverty

TB is a physical disease which is understood medically although the factors that promote its continuous spread are economic, social and political (Gandy & Zumla, 2002). Poor people are often malnourished and often exposed to unhealthy working conditions which increase their risk of contracting TB (Packard, 1989). According to Farmer (1997, p. 78), "poverty not only increases the chances of TB infection, it also limits the likelihood that medical treatment will be accessed". The prevalence of TB is twice as high in areas of lower socio-economic levels (SEL) than in areas with higher SEL. In South Africa

poverty and TB have been divided unequally along racial lines caused by apartheid and as a result of this, previously disadvantaged groups that include black workers are the hardest hit by the disease. Periods of economic recession created shortages of employment, and this in turn contributed to the development of overcrowded peri-urban slums with poor living conditions (Saraiya & Binkin, 2000). According to Metcalf, Bradshaw and Stindt (1991, p. 48), "migration, urbanisation and overcrowding have been factors that promoted the spread of TB throughout history, causing a direct link between TB and poverty". Migration is believed to make the access of health care and the adherence of long-term treatment difficult. Migrant populations tend to have higher rates of TB infection and because of this such groups spread the disease as they move.

1.7 Rationale for the study

Four factors prompted this study. Firstly, although TB is a curable disease, the incidence of TB in South Africa remains dangerously high; thus researchers should continue to improve their understanding of the disease. Secondly, there is a chance that the recently emerged strains of XDR-TB and MDR-TB could spread to healthy people, thereby threatening the health of the whole African continent. There is a need to contain the spread of XDR-TB and MDR-TB. Thirdly, TB and HIV/AIDS are increasingly perceived as twin diseases and a dual stigma of the two diseases has developed. The current dual stigma of TB and HIV/AIDS has caused more TB patients to become non compliant to treatment increasing the possibility of an outbreak of MDR-TB and XDR-TB. This perception of a dual stigma exists despite the differences between the two diseases: namely, most strains of TB are curable if detected early, whilst HIV/AIDS is incurable, although manageable. Fourthly, TB research has been neglected in favour of HIV/AIDS studies and researchers are therefore challenged to restore the balance.

Despite the generally improved living conditions in South Africa, the TB epidemic is undermining socio-economic development gains post-1994. Individuals representing different disciplines are challenged to make urgent attempts to contain TB in terms of our understanding and management of the symptoms. Knowing that social stigmatisation will

undermine attempts to contain the disease, through behaviours such as resistance to treatment efforts and non-compliance, the objective of this study is to understand the current nature of attitudes and perceptions towards TB with a specific focus on Grahamstown East in the Eastern Cape of South Africa.

This study is based on a survey research design and aims to ascertain the existing knowledge, attitudes and behaviours towards TB among the residents of Grahamstown East. Grahamstown East has had an annual increase of TB patients in the last five years which has ranged from 5,9% to 20% thus TB and HIV/AIDS infections are prevalent in the community (South African TB Vaccine Initiative, 2006). In addition there are fears that MDR-TB and XDR-TB could spread in the area. For the purposes of this study a questionnaire was constructed and, in 2007, a household survey of Grahamstown East residents older than 18 years was conducted. The survey aimed at ascertaining the following TB-related factors:

- Knowledge of the causes and nature of TB.
- Perceived personal susceptibility of contracting TB.
- Perceived severity of TB.
- Perceived benefits of avoiding and managing TB.
- Perceived barriers to obtaining TB treatment.
- Cues to action to prevent TB.
- Self-efficacy in managing TB.
- Attitudes towards assisting people with TB.
- Attitudes towards TB in relation to its association with HIV/AIDS.
- Attitudes towards the TB temporary disability grant in South Africa.
- Judgmental dimension towards people infected with TB: the AIDS Related Stigma Scale was adapted for TB.
- Judgmental dimension towards people infected with HIV/AIDS: the AIDS Related Stigma Scale was replicated.

1.8 An outline of the structure of the thesis

This thesis comprises five chapters. Chapter one is an introductory chapter which focuses on discussing TB as a disease, the effects of TB on the mental health of infected and affected persons, the history of TB in South Africa, the incidence of TB in South Africa, the relationship between TB and poverty, and finally the goals of the study. Chapter two situates the study within the context of a literature review of previous research conducted internationally and locally. Chapter two also presents conceptualisations of the attitudes, knowledge and perceptions towards TB using psychological theories and models such as the Health Belief Model (Rosenstock, Strecher & Becker, 1994) and the Social Cognitive Theory (Bandura, 1986).

Chapter three describes the research methodology pertaining to the goals and objectives of the study. The chapter covers sampling techniques, participants, data collection, data analysis, as well as validity and reliability of the study. The findings of the study are presented in chapter four and discussed in chapter five. Finally chapter six includes the limitations of the study and recommendations for future research. This chapter concludes the study.

1.9 Chapter summary

Chapter one provides a brief introduction to the research study. The nature and causes of TB are discussed as well as the effect that the disease has on the mental health and wellbeing of TB patients and other members of society. The history, incidence and prevalence of TB in South Africa are discussed. South African studies aimed at understanding the social nature of TB are briefly referred to in the chapter. The objectives and possible benefits of the study are discussed. The Health Belief Model and the Social Cognitive Theory, that underpin the theoretical framework of the study, will be discussed in the next chapter. An outline of the structure of the thesis, covered in chapters two to six, is presented.

CHAPTER 2

LITERATURE REVIEW

2.1 Chapter preview

This chapter includes a review of the relevant body of literature used to conceptualise and understand the attitudes and perceptions towards TB in this study. The concept of disease stigma is discussed as well as the social and cultural constructions of stigma using a social learning perspective. The Health Belief Model (Rosenstock et al., 1994) and the Social Cognitive Theory (Bandura, 1986), are presented and these are then described in terms of this study which aims to understand health related behaviour regarding TB.

2.2 Attitudes and perceptions towards TB in developing nations

International research conducted in sociology, social psychology and health psychology has shown that, worldwide, stigma attached to TB has contributed to the spread of the disease, causing it to be a global health emergency (Weiss, 2001). A health psychologist, Jaramillo (1999), conducted a survey in Columbia in which he explored the correlates of prejudice as an attitudinal component of TB-related stigma. The results from his study showed that scientifically unfounded beliefs about transmission of the disease were the main significant predictors of the function of this attitude.

According to Bennstam et al., (2004, p. 308), "the general attitude towards TB in Mexico City is stigmatisation, whereby infected individuals are thought to be dirty and are seen as outcasts or shunned by society". These prejudices make TB a disease of distance: contact with TB victims is avoided creating social and physical distance between persons in society. In the Kuria culture of Kenya, relatives discourage children from having contact with their infected parents. It was found however that TB patients desired the support of family members and their communities (Liefooghe Michiels, Habib, Moran & De Muynck, 1995). In the Mai Ndome District, Congo, it is common for people to

abandon their partners if they are infected with TB. In this society young people with TB have a very low chance of getting married, even after recovery. International studies in developing nations show that when TB affects someone, then family and friends no longer see the individual as a person because they only see the TB, the disease within the body (Bennstam, Strandmark & Diwan, 2004). Since TB is an infectious disease healthy people keep their distance; they avoid close contact with people with TB because they fear contracting the disease and death. The above studies illustrate the negative perceptions associated with TB, such as avoidance and being shunned by other people.

In the Venda culture within the Limpopo Province of South Africa there is a belief that a husband and a wife cannot have intercourse whilst one of them is infected with TB. This usually results in family and social disharmony amongst married couples. In such situations TB can result in breaking of family bonds and social relationships between people in society. The disease is regarded as a social disease which presents social challenges (Edginton et al., 2002).

In developing countries it is believed that TB is an incurable and dangerous disease that only affects the poor due to their unhygienic habits (Westaway, 1989). The beliefs and perceptions surrounding TB bring social blame and shame to TB patients thereby making TB a social as well as a medical challenge. People in developing countries perceive infection with TB as a disgrace; that it shows that someone is poor and from a low class. TB is often associated with dirt, poverty, poor nutrition, smoking, alcohol and low living standards (Edginton et al., 2002). According to Long, Johansson, Diwan and Winkvist (2001, p. 124), "different cultures perceive different causes of TB and the disease is discussed in the same group of diseases such as leprosy". There is a belief in some communities, mostly in developing countries, that TB patients remain contagious after completing the course of treatment. For instance in the Punjabi community, there is a widespread belief that pregnancy reactivates TB infection. The belief that TB is given by God as a form of punishment is accepted in many cultures and in Vietnam most families do not allow TB patients to share facilities with other family members (Long et al., 2001). In some communities members believe that TB is an inherited genetic disease and

genetic inheritance constitutes a mechanism of transmitting TB (Gibson, Cane, Doering & Harms, 2005). In rural Philippines it is commonly believed that TB can be contracted by passing a sufferer on the street, sharing food, telephones, beds or other facilities (Yamada , Cabellero, Matsunaga, Agustin & Magana, 1999). All of these studies show that knowledge regarding TB is not convincing in some of these poor communities. The attitudes and perceptions towards TB are generally seen to be negative.

2.3 Attitudes and perceptions towards TB by TB patients in developing nations

TB often has an impact on the physical, social and mental well-being of patients and this may be influenced by the negative perceptions held by communities regarding the disease (Rajeswari, 2005). It is believed that most TB patients, even after they have fully recovered from the disease, feel the disease can never be completely cured (Long et al., 2001). According to Lawn (2000, p. 84), "patient perception about TB is usually stained and patients permanently hold negative feelings towards the disease". It is believed that TB patients show a lot of reactions concerning their disclosure of their diagnosis. These include feelings of loneliness, depression, suicidal thoughts, fear, apathy, shock, concern, surprise and acceptation. The possible reasons for these emotions may be the stigma, discrimination and social isolation attached to the disease (Marra, Marra, Cox, Palepu & Fitzgerald, 2004).

Studies show that other people generally possess negative attitudes towards people infected with TB in some communities. For example, TB patients in the Punjab region of Pakistan perceived the attitudes of their neighbours and community members at large to be negative because they felt isolated and ignored and this neglect usually continues long after completion of full treatment. Possibly the reason why neglect continues long after treatment is completed could be the fears that people hold regarding the disease and how difficult it is to be completely cured (Marra et al., 2004). In a study carried out by Long et al. (2001) in Vietnam, TB patients felt that their relationships with their families and the community had suffered due to their infection. However, it is believed that the extent to which TB patients are isolated and stigmatised depends on the cultural values and beliefs

held within the community (Gibson et al., 2005). In a study in Mexico City half of the surveyed population believed that they would not be fully received back into their families if they where infected with TB (Chang, Hansel & Diette, 2004).

2.4 Differences in the attitudes and perceptions towards TB according to gender in developing nations

TB affects both males and females socially and economically although the perceptions held by males may generally vary from those held by females (Long et al., 2001). In poor developing nations data show that more men are diagnosed with and die from the disease than women (Gibson et al., 2005). This result may possibly be due to working conditions, perceptions and attitudes held by males regarding the disease. Males are believed to be less willing and slower at changing their health behaviours. The poor working and living conditions that males are generally exposed to in developing nations may also account for their higher infection rates of TB (Gibson et al., 2005). TB often affects women in their economically active and reproductive years. Therefore the disease has a strong impact on the care they give to their children and their ability to undertake household activities (Long et al., 2001).

Studies show that there are differences in attitudes, knowledge and perceptions towards TB held by males and females. In a study carried out in the Limpopo Province the majority of male TB patients continued to live a normal life with their families after diagnosis whilst the majority of the female patients continued to isolate themselves to protect the other family members from the disease even after full treatment (Edginton et al., 2002). The main difference between the male and female TB patients was that the male patients seemed to be more concerned with the economic implications of the disease, whilst the female patients were more concerned with the social implications of the disease. The economic concerns relating to the disease that affected the male patients in the study included absenteeism from work and the possibility of losing employment opportunities. The study suggested that female patients were more concerned with the social implications associated with the disease (i.e., social interaction). In addition it was also shown that females generally possessed a greater awareness and knowledge

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regarding the disease than males. From this study it was found that on average more females had a tendency to visit health care institutions than males. This tendency is possibly attributed to family planning health care issues and pregnancy related issues. It was therefore suggested that because of a higher frequency of visiting of health care institutions by females they had a higher chance of receiving additional health care information on diseases such as HIV/AIDS and TB (Bennstam et al., 2004).

There are studies that show that females experience more social problems as a result of the disease than males. In Vietnam unmarried women with TB are likely to have more difficulty finding a marriage partner than unmarried men with TB (Gibson et al., 2005). TB is perceived to be an excuse for divorce by couples already experiencing marital problems in Vietnam as men were perceived as being more independent and were more likely to accept divorce than the females. From the literature it can also be seen that women are generally more knowledgeable about TB compared to males. From the study by Gibson et al. (2005), it is also shown that women are believed to be more compliant to TB treatment and knowledgeable about the disease than men. Insufficient knowledge and individual cost during treatment were reported as the main barriers to compliance among men (poor patient compliance), while sensitivity to interaction with health staff and stigma in society (poor health staff and system compliance) were reported as the main barriers among women.

2.5 Attitudes and perceptions towards TB in South Africa

The findings of an investigation undertaken by Cramm (2006) to determine compliance towards TB treatment within the Eastern Cape of South Africa suggest that people's health beliefs are crucial components for compliance. It was found that perceived barriers for TB treatment had the greatest impact on non-compliance. In the study the compliant TB patients believed that compliance with their TB treatment would allow them to be healed from the disease. The study found that the directly observed treatment short-course (DOTS) volunteers were apparently an important compliance factor. Non-compliance with TB treatment, however, was caused by the social stigma, the burden of the disease and the rules and restrictions that come with the treatment. In addition,

boredom was an important factor for those hospitalised TB patients who escaped from the hospitals because they felt that they were completely idle for months (Cramm, 2006).

According to the findings of the study community health care workers and non-compliers recognised the importance of health beliefs and self-efficacy. Both groups appreciated the importance of an intrinsic motivation, namely self-efficacy. Compliers in the study however felt that intrinsic motivation was the most important determinant for their successful recovery and that non-compliers were simply people who did not want to deal with the challenges posed by the disease. They did not want to change their lifestyle, especially their drinking habits, and they cared less about their health. In the study the majority of the respondents blamed defaulters for being infected with TB, and for putting society at risk (Cramm, 2006). The study shows that TB patients could be assisted to adhere to treatment if they had an intrinsic self belief that they can be cured from the disease and if there were no social barriers present.

In a rural district in the Limpopo Province there is a strong belief that TB is a result of breaking cultural rules, such as abortion, or the lack of abstinence after the death of a family member (Edginton et al., 2002). Community members in this area attribute TB to spiritual causes such as punishment and sin. This study shows how cultural beliefs influence the existing attitudes and perceptions towards diseases. Kelly (1999) suggests that in South Africa many people believe that individuals who are infected with TB are usually co-infected with the deadly HIV/AIDS. Kelly (1999, p. 39), says that "HIV/AIDS is a stigmatised disease in South Africa and as a result of this TB patients are stigmatised". From the above literature it can be noted that cultural beliefs play a big role in influencing the attitudes and perceptions towards a disease. The studies above suggest that intrinsic motivators (e.g., self belief) are necessary components in influencing the success of treatment in TB patients. The literature also shows that generally negative attitudes are held towards TB in South Africa due to the association of the disease with the already stigmatised HIV/AIDS pandemic. Stigmatising attitudes are therefore held regarding TB. Disease stigma attached to TB is possibly a major barrier which prevents

people from seeking treatment and adopting positive health related behaviours against the disease.

2.6 Global strategies for TB health care services

The WHO developed a National TB programme (NTP) as a world standard for treating TB globally (WHO, 2007a). In 2000 the WHO launched the Stop TB Partnership to realise an international goal of eliminating TB. The Stop TB Partnership was part of the NTP spearheaded by the WHO and comprised a network of international governments, non governmental organisations and private organisations that all had a common goal of eliminating TB globally. Under the supervision of the WHO these stakeholders were committed to working together to realise this common goal. The main aims of the plan included:

- Expanding the operations of DOTS strategy.

- Addressing TB, HIV/AIDS and drug resistant strains of TB (MDR-TB/ XDR-TB) collaboratively and implementing these collaborative activities at all levels such public and private sector levels.

- Contributing positively to the general strengthening of the global health care system by adopting and implementing innovations from other fields.

- Engaging all health care providers to work collaboratively which includes engaging the private and public health care providers.

- Empowering TB patients and communities with high rates of TB through community participation and social mobilisation initiatives.

- Enabling and promoting research to develop new vaccines and diagnostic strategies for people infected with TB (WHO, 2007a).

NTPs are mostly offered by public health care services and the diagnostic procedures are standardised in accordance with well-defined objectives set by WHO. Medical services in public health care institutions are free because they are funded by the government. It costs three times more to cure a TB patient through hospitalisation than through a

community based DOTS programme. The cost of curing a TB patient through hospitalisation also includes social and economic expenses in the form of loss of income and alienation of the TB patient. Hospitals pose a huge risk for immune-compromised patients due to the presence of antibiotic resistant organisms that can possibly infect patients (WHO, 2007a).

2.6.1 DOTS programme

Within the Stop TB partnership launched by the WHO (2007a) the DOTS strategy was at the forefront of curbing the worldwide spread of TB. The DOTS programme is a patient-centred approach that provides support from persons who observe TB patients while they take their treatment and swallow their TB drugs to ensure that the patients adhere to their treatment regime by completing the treatment. A DOTS health care worker is expected to regularly examine the TB patient to see whether the treatment is working and also whether the patient has any other problems. The main components of the DOTS strategy as outlined by the Stop TB partnership include:

- Government's full commitment to the NTP.

- Early case detection of TB through a passive case finding.

- Conducting DOTS for all smear positive pulmonary TB cases.

- Ensuring a system of programme monitoring and evaluation through an uninterrupted supply of drugs (WHO, 2007a).

The challenge posed by the DOTS strategy is that it is a globally standardised strategy with minimal flexibility to suit the varying contextual and cultural differences (WHO, 2007a). The DOTS strategy is not adaptive in its application through the NTP. According to Erstad (2006), TB control needs to change from a global focus to a more local contextual focus within each region. TB control programmes need to also focus directly on addressing the relationship between global inequalities and the spread of TB. The DOTS strategy does not fully take into consideration the external role of social support in promoting patient adherence to treatment. Adopting a standardised DOTS strategy globally limits the ability to cope with possible syndemic interactions of diseases.

2.7 The South African health care system

The South African National Health Bill (2003) established a health care system with a decentralised management structure. The Health Bill includes setting up a District Health System based on the principles of a Primary Health Care approach (Stephen, Kurt, Rana, Steven, & Gilbert, 2004). The underlying foundation of the District Health System is organisation of the health care system according to the geographic sub-divisions of the country. These geographical sub-divisions are then managed through a decentralised management structure (Mc Coy & Engelbrecht, 2003). Decentralisation is the transfer of responsibilities, resources and authority from the Department of Health to other peripheral structures which are regions, provinces and districts (Collins, Green & Newell, 2002). The South African Primary Health Care System involves national hospitals and clinics that employ health care workers. Voluntary community health care workers are also part of the South African Health Care system although they are not fully recognised by this system (Stephen et al., 2004).

According to Nicholson (2002) the Primary Health System approach in South Africa is based on the following principles:

- Resources must be distributed equitably, which means that those areas that have the least resources should be given the most assistance.

- Communities should be involved in the planning, provision and monitoring of their health service. This allows for different needs to be met in different communities.

- A greater emphasis should be placed on services that help prevent disease and promote good quality health.

- Technology must be appropriate to the level of health care. This means that all clinics should have refrigerators that work efficiently for the storage of vaccines.

- In the Primary Health System, the provision of food, education and shelter should become central to health care delivery.

Primary health care is one of the main core policies of the WHO. The WHO offers support to nations adopting these values of primary health care (WHO, 2007a).

The South African Primary Health Care System is responsible for implementing the NTP to control TB within South Africa. The South African Primary Health Care System adopted DOTS as its NTP strategy (South African TB Vaccine Initiative, 2006). The main aim for implementing this strategy was to break the cycle of TB transmission by treating cases as early and efficiently as possible (Walker et al., 2004). The DOTS strategy is alleged to have failed to become fully successful in South Africa. This is because DOTS volunteers are not fully equipped and acknowledged by the Department of Health (Walker et al., 2004). For the DOTS strategy to be successful it also needs to be introduced in a context where the health system is functional and structured. This is difficult to attain in the South African public health sector because this sector is poorly equipped thereby making the DOTS strategy a challenge to implement and sustain.

There are challenges to access of TB health care services in South Africa that stem directly from the broad historical deficiencies in health care services in South Africa. These deficiencies are believed to stem from the pre-existing apartheid system that was present in South Africa (Stephen et al., 2004). It is noted that there are still huge inequalities that exist between public and private health care sectors in the South African Primary Health Care System. Health care facilities in the public sector are poor and inadequate whereas health care facilities in the private sector are fully equipped and efficient (Walker et al., 2004). Kumaranayake and Sinanoviv (2006) carried out a study in South Africa to compare the quality of TB care provided by the public and private health care sectors, respectively. It was found that patients supervised in public clinics had lower treatment completion rates than those patients supervised in private health clinics.

However, the national budget for health care in South Africa for 2006/7 was criticised for not being adequate. In a context with an increasing burden of HIV/AIDS that worsens the prevalence of opportunistic diseases such as TB, the national budget allocation was insufficient. On the other hand the Eastern Cape Department of Health constantly faces

problems of massive under-spending and shortages of staff (Public Service Accountability Monitor, 2007). This under-spending is assumed to be as a result of the lack of commitment and skills towards service delivery to the under-privileged communities of the region. Under-spending is caused by a lack of capacity to absorb funds at all levels within the province and to use them appropriately (Public Service Accountability Monitor, 2007). These cited works show that there are structural impediments that possibly cause the control and management of TB in the area to be difficult.

2.7.1 TB voluntary community health care workers in South Africa

According to the WHO (2007a), voluntary TB community health care workers are people who assist TB patients to take their medication and adhere to treatment. These health care workers monitor and regulate TB patients within their community. The criteria set by the WHO (2007a) for the selection of a competent community health care worker for TB include: literacy, permanent home address, residing nearby a TB patient, willingness to serve the community and an ability to respect confidentiality. In South Africa the South African National Tuberculosis Association (SANTA), as well as various non-governmental organisations throughout the country, aim at training voluntary community health care workers to work in the DOTS programme to assist TB patients (Kironde & Kahirimbayi, 2002). In South Africa voluntary TB community health care workers are given a basic stipend by SANTA. However, in the Eastern Cape, due to the lack of government funding, the SANTA offices were closed down in 2005 (Public Service Accountability Monitor, 2007). The closure of SANTA offices in the Eastern Cape has increased the burden of TB and workload of nurses in the clinics. It is acknowledged by all the stakeholders involved in health care within the region that more trained volunteers are needed (Erstad, 2006). The closure of SANTA offices within this region of South Africa thus poses a major health risk to this region.

Voluntary community health care workers are responsible for TB health care and implementing DOTS. They also perform other duties which include weighing babies and taking blood pressure. Voluntary community health care workers are also indirectly

responsible for offering patients with a firm support network. Their responsibilities vary between working within the clinic and visiting TB patients. In South Africa the majority of TB volunteers (78%) are females. This may be accounted for by women's customary maternal role within family life, their natural tendency to be care givers, since this is their traditional role in African culture (Kironde & Kahirimbanyi, 2002).

In South Africa more than half (52%) of the voluntary TB community health care workers were found to come from households where one or more members were sick from TB and had received assistance from voluntary community health care workers (South African TB Vaccine Initiative, 2006). In a study in Grahamstown East carried out by Erstad (2006) the majority of the voluntary community health care workers for TB patients were people who had experience in dealing with TB within their households. The results of the study established that generally people that have experienced TB in their households tend to be more empathetic and willing to support TB patients. It is believed that such people probably tend to be more aware of the perceived risks of leaving the disease uncured. People that have had a case of TB in their households are generally more aware and knowledgeable about the disease (Erstad, 2006).

2.7.2 Motivating factors for TB community health care volunteerism

According to Merrell and Williams (1999, p. 23), "altruism seems to be a crucial motivator for people who do voluntary community work". It is generally assumed that most volunteers have some time available. They feel that it is good for them to engage in activities that are constructive for themselves and their community. Research shows that there are benefits and incentives in becoming a voluntary TB community health care worker. In a study conducted in Grahamstown East by Erstad (2006) it was found that when TB patients were receiving soup and bread at the clinics some TB volunteers often joined them. Some of the volunteers would take some of the food home to give their family. The TB volunteers gained status and recognition within their community which would not have been afforded to them if they were regarded as unemployed or idle. The appreciation and encouragement which voluntary community health care workers can

receive from the community encourages the volunteers to continue their work (Erstad, 2006).

One of the motivating factors for voluntary community health care workers includes having hopes of future employment. In a region were there are high levels of unemployment more people would probably be willing to do community work. Such hopes can possibly be realised in South Africa if voluntary community health care workers were to be fully recognised and included in the National TB Control Programme of South Africa (Erstad, 2006). From the study conducted by Erstad (2006) in Grahamstown East the majority of TB volunteers (85%) considered possibilities of future careers in the health sector. This may possibly be because the majority of the TB volunteers were unemployed, thus they hoped to find employment opportunities in the area in which they had gained some experience.

According to Merrell and Williams (1999, p. 34), "remuneration is a great concern for voluntary community health care workers. Although altruism may be regarded as a crucial factor in influencing volunteerism, monetary rewards cannot be ignored in shaping people's choices"; this view was echoed by TB volunteers in Grahamstown East who felt that it was necessary to receive remuneration for the work they do (Erstad, 2006). The majority (90%) of the TB volunteers stated that although they were giving back to their community further recognition for their work was needed. Based on the cited literature, it appears that TB volunteerism is influenced by various incentives which include, for example, recognition and respect from other members in the community. Voluntary TB workers feel that by assisting patients they may one day be employed as health care workers and this is a huge motivator for unemployed people. A basic stipend is also seen as a possible motivator for people to engage in voluntary work.

2.7.3 Benefits of voluntary community health care workers to South Africa

Voluntary community health care workers can assist the South African health care sector to effectively achieve national TB treatment targets. These health care workers can also reduce the level of national spending (South African TB Vaccine Initiative, 2006). In

comparison to professional health care practitioners, such as medical doctors and nurses, voluntary community health care workers are a cheaper alternative for this level of provision of health care services. According to Kironde and Kahirimbayi (2002, p. 82), "voluntary community health care workers are readily available and less demanding in a context with high levels of unemployment and poverty". The South African health care sector is currently under pressure facing huge expensive challenges, such as the national control of drug resistant strains of TB and HIV/AIDS. Alternatives to alleviate the problems faced in the South African health care are needed (Public Service and Accountability Monitor, 2007). The literature therefore shows that voluntary community health care workers have valuable skills that are much needed in the South African health care sector.

A culture of volunteerism increases social solidarity and community participation (Taggart, Short & Barclay, 2000). The use of community volunteers allows the health care sector to be sustained in a context where there are limited and scarce resources. Voluntary community work can be seen as a way of empowering people by giving them skills and at the same time enhancing their employability. Voluntary community work can promote the sharing of skills between people within a community. The process of sharing skills can be regarded as a positive social experience; sharing of skills allows for breaking down of traditional divisions of labour whilst at the same time ensuring that technical knowledge and skills are acquired by all the people within the community (Merrell, 2000). The use of voluntary community health care workers also gives patients a sense of autonomy which is very difficult to achieve in a clinic-based healthcare system (Walker & Jan, 2005).

According to Walker and Jan (2005, p. 40), "when voluntary community health care workers are assisting TB patients they bring their own unique personal qualities". Therefore personal qualities and life experiences brought in by the community health care workers can enhance the quality of the health care service provided. These health care workers are probably more capable of understanding the possible barriers in treatment for TB patients within their respective community. Voluntary community health care

workers are able to understand the power and cultural dynamics that interplay within their community as they personally know the people within their community, their direct needs, and their history (Walker & Jan, 2005).

2.7.4 Attitudes and beliefs towards TB by South African health care professionals

According to Walker and Jan (2005, p. 77), "health care professionals are people who have the professional knowledge and skills to assist people facing health care problems". Professional health care practitioners, such as doctors and nurses, receive remuneration for assisting people. To be able to control TB and help the victims of TB, the local values and beliefs about TB must be understood and known by professional health care workers. It was suggested in a survey conducted in the Limpopo Province that some of the nurses did not share the same cultural beliefs about TB as those held by the rest of that society (Edginton et al., 2002). The health care professionals were reported as being too formal and their actions were based on their educational background regarding the biomedical nature of the disease. Health care professionals need to be able to understand the local beliefs held about TB for them to understand the behaviour and actions exhibited by TB patients (Kironde & Kahirimbanyi, 2002).

In South Africa it is reported that health care professionals usually create formal situations in which they treat the individual with TB as a case of infection; they focus on the disease per se rather than the patient as a person with feelings and emotions. TB patients are sometimes regarded by the health care professionals as bad people who are spreading the disease (Van der Walt & Swartz, 2002). Health care professionals need to use approaches that give a voice to the marginalised ill and assist them to have the energy and belief to adopt healthier behaviours. According to Moore and Charvat (2007, p. 65), "health care professionals in South Africa need to use approaches that draw on patients' strength and hope in having healthy lifestyles such as using the appreciative inquiry to promote healthier behavioural change".

2.8 Temporary disability grants in South Africa

At present in South Africa, people with TB have the right to access a temporary disability grant for the duration of treatment. A temporary disability grant is a form of a social grant given by the South African government. The grant is aimed at temporarily helping people with illnesses such as HIV/AIDS, TB and physical disability (Hardy & Richter, 2006). The grant aims at giving such people the ability to cope with the economic demands of daily life such as housing, buying food and transportation. Other forms of social grants in South Africa are child grants and old age pensions. The Department of Social Development is responsible for issuing grants (Hardy & Richter, 2006). With regard to TB patients, the temporary disability grant is aimed at ensuring that the patients can afford proper nutrition. People with pulmonary TB receive this grant for six months whereas re-treatment cases receive a grant for eight months. People with drug resistant TB qualify to receive a grant for a 12 month period (South African TB Vaccine Initiative, 2006)

Patients have to collect the grant forms from the Provisional Department of Social Development and present them to the doctors during consultation. The doctors are responsible for signing the form so that the TB patient can apply for the grant. An applicant for this grant has the legal right of getting a response within three months, but feedback is usually delayed with many of the sick dying before their cases have even been reviewed (Hardy & Richter, 2006).

People living with HIV/AIDS, just like people with TB, are eligible to receive a social grant. People infected with HIV/AIDS used to be given a permanent disability grant which was reviewed after every five years. Since the introduction of antiretrovirals (ARVs) HIV/AIDS patients receive the grant for 6–12 months only if their CD4 count is below 200 (South African TB Vaccine Initiative, 2006). The disability grant for people living with HIV/AIDS is only re-allocated if the patient has reached the World Health Organisation (2006a) stipulated clinical Stage 3. With the introduction of ARVs, HIV/AIDS is no longer seen as a permanently disabling disease by the South African government (Hardy & Richter, 2006).

A temporary disability grant, unlike the permanent disability grant, lapses once the patient is able to work again. The poor and the sick appear to hold different perspectives to those of the government with respect to disability grants. The poor regard disability grants as a means to alleviate poverty in marginalised poor communities with high rates of unemployment. The disability grants are perceived as compensation for being poor and sick but not for being unable to work (Nattrass, 2005). Disability grants are regarded as a form of indispensable income by people who are unemployed and live in abject poverty. In South Africa grants are sought after by millions of unemployed people who find it difficult to secure any form of employment. These people alter and modify their behaviour considerably so that they become eligible for such grants. These disability grants have created some perverse incentives that have impacted negatively on the treatment and management of illnesses, such as TB and HIV/AIDS (Nattrass, 2005).

2.8.1 Perverse incentives in contracting TB

Impoverished TB patients can be prevented from getting cured due to the perverse incentive to remain sputum positive and be able to sell the sputum whilst at the same time being able to receive a temporary disability grant (Nattrass, 2005). It is reported that some people in South Africa intentionally expose themselves to TB so that they are eligible for a temporary disability grant and this behaviour is mostly reported in young people (Kumaranayake & Sinanoviv, 2006). In the Eastern Cape there are reports that the trade of TB positive sputum is on the increase. This trade of TB positive sputum is seen as a way of becoming eligible for accessing the much needed temporary disability grant. People infected with TB sell their positive sputum whilst healthy people buy and take the TB positive sputum to the clinics for testing. Other healthy people are exposed and placed at risk by the circulation of TB infected sputum, whilst at the same time the sick TB patients remain sick in order for them to produce positive TB infected sputum (Siqoko, 2005).

According to Siqoko (2005) the trade of TB infected sputum is mostly driven by poverty and desperation. The TB patients who sell their sputum and the sputum buyers are regarded as people who make rational choices in a context with high levels of poverty

and unemployment. The extreme workload in South African clinics is also believed to be huge factor triggering the trade of TB sputum. In accordance to the practical guidelines of the South African TB programme, sputum samples are only supposed to be collected by the nurses in or outside of the clinics. Patients are not allowed to take the specimen containers home and to then bring back their sputum later. Due to the workload in most South African clinics the patients are allowed to bring in their collected sputum later (Siqoko, 2005). This occurs in Grahamstown because of the huge workload that prevents nurses in the clinics from adhering to the national guidelines of the South African TB programme (Erstad, 2006). A poorly monitored health care system can easily enable the trading of TB positive sputum within any impoverished community.

Improved health introduces the risk of loss of the disability grant by people living with TB which then would remove a main source of their household income. The disability grant acts as a perverse incentive in many TB households. In a study by Hardy and Richter (2006) it was found that most of the recipients of the disability grant spend their income supporting their households. Many impoverished South Africans who rely on a disability grant have a perverse incentive to remain sick in order to continue receiving the grant (Siqoko, 2005). The criteria stipulated to access disability grants influence the marginalised sick to choose between the right to social security and the right to good health. The marginalised sick make a rational choice to remain sick in a context where there are limited resources.

2.8.2 The disability grant as a household income

Disability grants have been found to act as a milestone for supporting economic growth, income distribution, social harmony and an increase in the level of education in impoverished communities (Hardy & Richter, 2006). It is estimated that by 2011, a population of 1,1 million South Africans will receive disability grants at a cost of R 9, 3 billion to the country thereby leading to a 75% increase in the disability grant budget (Nattrass, 2005). In South Africa, due to the estimated 40% rate of unemployment, it is suggested that temporary disability grants should be regarded as an important source of

income for many poor people as they depend exclusively on social grants as a source of household income (Erstad, 2006).

For the structurally marginalised, grants are seen as an important source of income constituting approximately 41–49% of their total income (Nattrass, 2005). People in marginalised communities organise and plan their lives based on social grants even though these grants are usually temporary. In a study conducted in Grahamstown East by Erstad (2006) it was found that approximately 60% of the TB patients interviewed had been entirely dependent on social grants at some stage in their lives. When people become healthy they are required to forfeit social grants. In impoverished communities obtaining a social grant and keeping it becomes an incentive concerning either life or death. Many people from marginalised communities regard poverty as a fair criterion for receiving a social grant. The social grants are regarded as a means by which the government should alleviate poverty in poor communities although this is not necessarily the case (Hardy & Richter, 2006).

Grants assist TB patients and their families to regain control of their own lives. This can increase their confidence in their ability to withstand social pressures, such as stigmatising and discriminating attitudes (Wilkinson, 2005). Less financial stress lessens patients' vulnerability to other diseases, and this generally increases their health status. However, the empowerment and confidence gained by grant recipients is temporary and can only be exercised within impoverished communities. Social grants are not a long lasting solution to alleviating poverty and controlling illnesses because the poor people who receive grants still remain disempowered, dependant and disadvantaged (Wilkinson, 2005).

2.8.3 Attitudes and perceptions towards disability grants by health care workers

Professional community health care workers in the Eastern Cape believe that disability grants make their jobs challenging because patients want to remain sick. Patients have a perverse incentive to remain sick and remain eligible for the disability grant (Erstad, 2006). The community health care workers feel disempowered by the disability grant

system because patients make rational choices of becoming non-adherent to treatment to retain the grant. It is assumed that patients who put their lives at risk to obtain and retain the disability grant base this choice on necessary and rational choices. Health care practitioners report that the sick constantly evaluate their health against accessing life saving financial resources (Wilkinson, 2005). The health care workers blame the Department of Social Development in South Africa for creating the problem of non-adherence to treatment. With the continual prevalence of TB in the Eastern Cape and the dangers of developing drug resistant strains of TB such as XDR-TB and MDR-TB, non-adherence is a critical community oriented issue. Some community health care workers believe that poor patients in the Eastern Cape are experiencing a dilemma with perverse incentives to remain sick and keep their families alive or to get well but be unable to sustain their families (Nattrass, 2005). The disability grant transforms patients into providers and this increases their confidence and respect. But at the same time the grant causes patients to become less committed to dealing with their illness (Nattrass, 2005).

2.9 The concept of a syndemic interaction between TB and HIV/AIDS

According to Singer and Claire (2003, p. 67), "a syndemic interaction of two or more diseases refers to the interaction between two or more co-existent diseases which increases the total burden of the diseases". Within a syndemic interaction, although the actual biological interaction between the two diseases is considered, focus is also given to the environmental and social factors that cause the relationship between the diseases. The social and environmental conditions that promote this relationship usually include poverty, health care disparities and structural violence (Singer & Claire, 2003). Having an understanding of the social conditions that surround a disease may be more useful in managing a disease than only having an understanding of the biomedical nature of the disease. Most diseases do not exist in isolation of other diseases. Attitudes and perceptions regarding most diseases are influenced by the external attitudes and perceptions of other diseases and health conditions. An example of a global syndemic interaction between two diseases is the relationship between TB and HIV/AIDS (Singer & Claire, 2003).

Globally more than 21 million people are co-infected with TB and HIV/AIDS, of whom 70% are concentrated in Africa. TB is the leading cause of death among people who are HIV-positive. Up to 50 % of people who are HIV-positive develop TB resulting in TB being the most prevalent opportunistic disease killing people with HIV/AIDS (WHO, 2007a). In Africa, HIV/AIDS is the single most important factor contributing to the increase in incidence of TB since 1990 (Kelly, 1999). South Africa is among the nations in the world that are most affected by HIV/AIDS and it is estimated that by the end of 2005 there were five and a half million people living with HIV/AIDS in South Africa, and almost one thousand HIV/AIDS related deaths occurring every day (WHO, 2007a). An estimated 66% of all current TB cases in South Africa are co-infected with HIV. It is estimated that over five million South Africans living with HIV/AIDS are likely to contract and die from TB in the course of their lifetime (South African Institute of Race Relations, 2008).

Collaboration between HIV/AIDS and TB programmes can increase the proportion of HIV infected persons who can benefit from programmes such as voluntary counselling and testing centres (VCT). HIV/AIDS and TB form a lethal combination, each speeding the other's progress (Bunnell, 2006). HIV/AIDS weakens the immune system. An individual who is HIV-positive and infected with TB bacilli is more likely to become sick with full blown HIV/AIDS. In South Africa it is believed that most people stigmatise HIV/AIDS and perceive people with HIV/AIDS to also have TB. People seem to have a good knowledge of HIV/AIDS but limited knowledge of TB. People who lose weight, have fever and cough continuously are defined as having HIV/AIDS rather than TB and this may result in TB patients delaying treatment because of fear of HIV/AIDS detection (Bond & Nyblade, 2006).

2.10 The concept of stigma

According to Deacon (2005, p.11) stigma refers to bodily signs designed to expose something unusual and bad about the moral status of the signifier. During past centuries signs were cut or burnt into the body thus advertising that the bearer was a slave, a

criminal, or a traitor; a blemished person, ritually polluted, and to be avoided, especially in public places. The definition of stigma by Deacon (2005) signifies that it is an attribute that is discrediting and dehumanises individuals to being tainted and discounted. Stigmatised individuals are therefore believed to possess some attributes or characteristics that convey a social identity that is devalued by society. According to Schulte (2002), stigma is a product of social interactions between people who possess a stigmatised attribute and other 'normal' people in society. Stigma is not static but is a phenomenon that exists within a specific socio-cultural context. Attributes that are stigmatised evolve as cultural changes take place within a society. For stigma to develop and evolve, social interactions are believed to be a prerequisite (Schulte, 2002). Attributes that are individually held reflect the broader socio cultural context to sustain stigma in society.

There are two main types of stigma, namely internal stigma and external stigma (Deacon, 2005). External stigma refers to the actual physical and emotional experience of discrimination. This includes experiences such as harassment, blame, ignorance, resentment, silence, anger, accusation and exclusion. Internal stigma, on the other hand, is an indirect outcome of the whole stigmatisation process. Internal stigma is the shame and guilt experienced by individuals who possess stigmatised attributes. Internal stigma is seen as a coping mechanism to protect an individual from external stigma and usually results in the denial and unwillingness of the individual to disclose and seek assistance. Individuals with stigmatised attributes may choose to hide their conditions because of their awareness of the possible negative socio-cultural connotations surrounding the stigmatised attribute they possess (Deacon, 2005).

According to Schulte (2002) disease-related stigma occurs when individuals with an illness are deemed undeserving of assistance and support from other individuals in the society. Over time certain illnesses, such as TB, have been associated with reduced social status and these negative reactions may impede coping and recovery (Rosenfield, 1997). According to Fife and Wright (2000) the psychological adjustments to illness by a patient are negatively influenced primarily by the negative perceptions that other people within

the society might hold. Stigma is seen to play a huge role in the experience of illness by TB patients. Therefore a critical understanding of the stigma that exists towards the disease needs to be developed.

Deacon (2005, p. 21) defines disease stigma as "a complex social process linked to competition for power and tied into existing social mechanisms of exclusion and dominance." Weiss (2001) adds another facet to the definition by suggesting that illness-related stigma is characterised as medically unjustified avoidance, disgrace and ignominy resulting from a social response to illness. Stigmatising ideas have a very powerful hold on society because of the way in which they fit into existing prejudices and power alliances. Disease stigma can be viewed as an ideology claiming that people with a specific disease are different from the rest of society, more than simply through their infection with a disease agent. This ideology links the presence of a biological disease agent to negatively defined behaviours or groups in society (Deacon, 2005).

Disease stigma is characterised by four interrelated processes:

a) distinguishing and labelling differences,

b) linking labelled persons to undesirable characteristics (i.e., negative stereotypes),

c) placing labelled people in distinct categories to accomplish some degree of separation, and

d) experiencing of status loss and discrimination by labelled persons (Link & Phelan, 2001).

This conceptualisation of stigmatisation as a social process is useful for researchers because it provides a more sophisticated understanding of the relationship between stigma, discrimination, identity and power (Kelly, 1999). According to Joffe (1999) the stigmatisation of some individuals by other individuals allows them to deny their own risk by projecting risk onto other individuals that they perceive as outside groups. Optimistic bias makes the stigmatisers think that other individuals are more likely to experience negative events rather than themselves.

Disease stigma is created by psychological mechanisms of causing boundaries between the group of the morally uninfected individuals and the other immoral deviate group that is infected, as a strategy for protecting identity of groups (Joffe, 1999). Society allocates more blame to those individuals who contract stigmatised diseases that are perceived as controllable and stable, as compared to those individuals that contract diseases that are supposedly less controllable (Weiner, Perry, & Magnusson, 1998). Disease stigma needs to be understood as a social process involving differentiation. The attribution of stigmatised diseases to a lack of personal responsibility and perceived negative behaviours allows the moral majority to distance themselves from the infected. This relationship gives rise to what is known as the *"Blaming Model"* (Joffe, 1999). Categories of blame often reflect deep social class biases because illness is frequently associated with poverty and becomes a justification for social inequalities.

2.10.1 Dual stigma HIV/TB in South Africa

A new disease stigma has unfolded in sub-Saharan Africa known as the TB-HIV/AIDS stigma. Visible signs of TB have become a signal for HIV/AIDS and this has caused a stigma towards TB to develop (Bond & Nyblade, 2006). In the South African context TB stigma can no longer be addressed separately from the HIV/AIDS stigma and likewise TB and HIV/AIDS control programmes immediately need to be integrated (Eastwood & Hill, 2004). The current TB-HIV/AIDS stigma has made it more difficult to control HIV/AIDS through VCT and it has also made it difficult to control TB through the DOTS programmes. Individuals who are infected with HIV/AIDS in South Africa have a 50% lifetime risk of developing the full blown TB disease and they possess higher rates of TB mortality than people that that are not infected with TB (WHO, 2007a). The factors that drive the TB-HIV/AIDS stigma have been identified to be judgment, blame and shame. These factors have been concurrently related to drive the growing stigma towards TB (Joffe, 1999).

A number of factors have been identified for the increasing severity of the HIV/AIDS epidemic in South Africa, including a poor health delivery system to monitor the disease and the stigma that is attached to the disease. The South African government is blamed

for having delayed to take action towards HIV/AIDS and recognising that the disease is a national threat thereby worsening the burden of the disease (Kalichman & Simbayi, 2004). The stigma attached to HIV/AIDS is also blamed for worsening the spread of the HIV/AIDS pandemic in South Africa. Stigma towards the disease has been identified as a cause for the delay of treatment by HIV/AIDS infected people. In research conducted in Cape Town by Kalichman and Simbayi (2004) the social stigma attached to HIV/AIDS was found to be a more powerful deterrent to HIV/AIDS testing than the attitudes towards testing itself. While people are aware of the VCT programme provided by South African medical institutions they are still reluctant to use these facilities because of the stigmatised nature of the disease so they avoid being labelled as having the disease. The prevention and education programs seeking to improve HIV/AIDS testing and preventative patterns need to focus on reducing social stigma against people with HIV/AIDS. VCT services in South Africa also need to be promoted to be able to control the HIV/AIDS pandemic.

In South Africa the stigma attached to HIV/AIDS has grown due to the association of the disease with promiscuity and poverty which are socially stigmatised attributes in South Africa (Deacon, 2005). In developing countries TB is the first indication of HIV/AIDS and people with both diseases also suffer double discrimination. TB makes the poor even poorer as people become sick and income is lost in families that are already battling. The stigma surrounding HIV/AIDS causes problems for TB sufferers in communities that view HIV/AIDS as a burden and stigmatise the epidemic (Bond & Nyblade, 2006).

The infectious nature of TB has added to the complexity of the TB-HIV/AIDS stigma and there is an inherent tension between the appropriate precautions to prevent the transmission of TB and fair differential treatment (Crawfield, 1994). Diseases, such as TB, have been seen as markers for social differences and because of this they are stigmatised. In areas that have high rates of the HIV/AIDS pandemic, the increased awareness and stigmatisation of the co-infection between TB and HIV/AIDS and inadequate knowledge of TB causes TB patients to delay seeking TB care and to not adhere to treatment (Gandy & Zumla, 2002).

2.11 Theoretical foundations of the study

The theoretical foundation of the study is based on two models which are the Health Belief Model (Rosenstock et al., 1994) and the Social Cognitive Theory (Bandura, 1986). An integrated theoretical approach was adopted in the study to critically understand and explain the attitudes, perceptions and behaviour towards TB. Constructs from each of the two models were used in the research design and in the analysis of the results. The shortcomings of each the models was compensated by the other.

2.11.1 The Health Belief Model

According to Harvey (1997), the Health Belief Model is a value expectancy model which is used to describe and explain individuals' health behaviour based on their attitudes, perceptions and knowledge. The model suggests that individuals will adopt a positive health-related behaviour if they perceive that the behaviour is beneficial to them, perceive that they are at threat (perceived susceptibility) and perceive that there are no barriers in adopting positive health related behaviour (Ogden, 2004). The model investigates the behaviours that are believed to be under the control of an individual and it functions on the proposition that people are rational and act in rational ways that are beneficial to them (Rosenstock et al., 1994). The model assumes that when people are required to make health-related decisions, they rationally consider the healthy and unhealthy related consequences (social and economic) of their actions.

The Health Belief Model is built on the components of two social learning theories: the stimulus response theories and cognitive theories. These theories combined are known as value expectancy theories (Harvey, 1997). The components from the stimulus response theories adopted in the Health Belief Model include parts of learning theories. The stimulus response theories operate on the main premise that learning results from consequences of events (reinforcements) that determine and influence future behaviour (Harvey, 1997). According to Rosenstock et al. (1994), from the perspective of stimulus response theories, cognitive functions such as thinking and reasoning are influential in explaining and predicting behaviour. Reinforcements are also crucial for influencing

future behaviour. There are two types of reinforcements, namely positive reinforcements and negative reinforcements. The former are the positive rewards that promote a given action after it has occurred whilst the latter are the negative consequences that follow a given action (Rosenstock et al., 1994). According to Kelly and St. Lawrence (1988), for any given positive health related behaviour, the immediate consequences of that behaviour tend to have a greater immediate influence than any delayed beneficial (or detrimental) influence of that behaviour.

The second type of learning theories that make up the Health Belief Model are known as cognitive theories or value expectancy theories. These theories focus on the individual`s cognitive operations in predicting and explaining behaviour (Harvey, 1997). According to Rosenstock et al. (1994) cognitive theories explain behaviour as a product of the subjective expectation that a particular action will achieve a valued outcome. Cognitive theories differ from the stimulus response theories because they do not believe that reinforcements operate directly in influencing behaviour but instead operate by influencing expectations of a given action (Ogden, 2004). From the value expectancy theory in the Health Belief Model, value is regarded as the desire to maintain good health and avoid illness whereas expectancy refers to the beneficial behaviour and action that will prevent and avoid illness. Expectancy can further be determined by an individual's perceived susceptibility to and perceived severity of contracting an illness.

Health beliefs are seen as directly related to the attitudes and perceptions regarding a disease. If the health beliefs are generally negative people do not adopt positive health related behaviours relating to the disease. The Health Belief Model assumes that demographic and socio-economic factors indirectly influence health beliefs regarding diseases such as TB. The demographic factors include age, gender, marital status and family. These factors influence how individuals behave regarding a disease and their attitude towards preventing the spread of a disease. The socio-economic factors which influence health beliefs and the spread of TB include income, and the availability of health care services (Liefooghe et al., 1995).

The constructs of the Health Belief Model include perceived susceptibility, perceived severity of the disease (one's opinion of how serious a condition and its consequences are), perceived barriers, perceived benefits, self efficacy, and health motivation.

2.11.1.1 The constructs of the Health Belief Model

2.11.1.2 Knowledge

According to Ogden (2004) knowledge of the nature of the health risks and preventative actions to avoid contracting a disease are essential for promoting healthy behaviours towards a disease. Knowledge is crucial in performing a motivational role for promoting healthy behavioural changes. Knowledge alone cannot bring about sustained adoption of healthy behaviours but it is a crucial starting point in the behaviour change cycle (Harvey, 1997). The Health Belief Model suggests that if individuals possess a high level of knowledge about a disease and its health-related consequences then they would adopt a positive health-related action towards the disease, such as going early for TB testing or acting as DOTS volunteers. On the other hand, if individuals have a limited knowledge of the disease and its consequences they would adopt negative health related behaviours towards the disease, such as not going for TB testing and being non-compliant to TB treatment. The Health Belief Model shows that individuals act according to their knowledge and beliefs and if individuals are informed about the negative consequences of a certain behaviour they will then make rational and informed choices to modify this behaviour (Harvey, 1997).

2.11.1.3 Perceived personal susceptibility

Perceived personal susceptibility is the process by which individuals subjectively perceive themselves as susceptible to contracting a health condition and their chance of being infected (Rosenstock et al., 1994). The first crucial step taken by individuals to reduce the threat of contracting the disease is acceptance and recognition that their chance and vulnerability of contracting a disease is high. The model implies that if an individual's knowledge, attitude and perceptions are positively altered and reinforced, the

individual's perceived susceptibility towards a disease becomes high resulting in the individual adopting positive health-related actions towards that disease (Harvey, 1997).

If individuals perceive themselves as susceptible to TB they are more willing to adopt practices that will prevent infection of the disease such as, seeking early treatment and helping TB patients so that the disease is not spread to other people. Once people perceive themselves as susceptible to a disease they perceive themselves as vulnerable to infection. High levels of perceived personal susceptibility towards illnesses such as TB are crucial for the adoption of positive health related behaviours against the spread of TB (Liefooghe et al., 1995).

2.11.1.4 Perceived severity

Perceived severity of illness concerns the individual's feelings regarding the seriousness of contracting an illness and the personal costs and burden of being infected with the disease. This includes evaluating both the economic consequences, such as medical expenses or loss of job, and social (isolation) consequences of the disease (Ogden, 2004). If perceived severity of a disease is regarded as high by an individual then the individual perceives being personally at a high risk of contracting the illness. Individuals will try to adopt positive health-related behaviours to avoid and prevent a disease such as TB if their perceived severity of the disease is high. This can be in the form of becoming DOTS volunteers to help combat TB spreading in their community (Kelly, 1999). According to Ogden (2004), perceived susceptibility is very closely linked to perceived severity and usually individuals are unable to separate the two when they are considering potential threats. According to the Health Belief Model, acknowledging the potential threat of a disease is seen to be a vital cognitive process in adopting healthy related behaviours to avoid infection. If the perceived severity level of danger of TB infection is assumed to be high, and the perceived personal vulnerability to TB infection is assumed to be relatively high (i.e., the individual would be well informed), then perceived effectiveness of the preventive measure (i.e., taking treatment) is high (Ogden, 2004).

2.11.1.5 Perceived benefits

Perceived benefits refer to the positive consequences of adopting a certain health related behaviour and action. The perceived benefits represent the components of the value outcomes of the Health Belief Model (Ogden, 2004). Individuals adopt health promoting behaviours if they believe that their behaviour and action will reduce their chances of acquiring a disease because the focus would be on the positive outcomes of the action (Ogden, 2004). Individuals who perceive the benefits of avoiding TB infection are able to easily adopt positive health related behaviours to prevent being infected by TB. They actively engage in preventative practices against TB such as assisting TB patients and not stigmatising the condition. Individuals who perceive the benefits of not contracting TB are able to perceive the benefit of a society free from TB (Liefooghe et al., 1995).

2.11.1.6 Perceived barriers

Perceived barriers are the potential negative consequences or prohibitory factors that may result from adopting health promoting behaviours and these may include physical, psychological and financial consequences (Harvey, 1997). According to Johnson, Ostrow and Joseph (1990) the factors that are related to the adoption of a healthy behaviour which are perceived by the individual as negative, in the sense that they may be expensive, unpleasant or painful, could act as barriers to a desired action. Individuals cognitively evaluate the positive and negative aspects that accompany a behaviour type and this represents a value outcome of the Health Belief Model (Ogden, 2004). Perceived barriers for people to seek early treatment towards TB also include stigma and discrimination. The stigma that is attached to TB makes people avoid assisting people with TB and adopting positive supportive attitudes towards those infected with TB. The stigma and discrimination towards TB inhibits the growth of health promoting behaviour within individuals (Liefooghe et al., 1995). The perceived barriers for TB patients to complete treatment successfully include the intake of large amounts of medication and stopping some social habits, such as smoking and drinking (Kelly, 1999). The Health Belief Model assumes that if there were no social or economic barriers people would be

more willing to adopt positive health beliefs regarding TB such as seeking early treatment.

2.11.1.7 Cues to action

Cues to action are the events that motivate individuals to adopt positive health related actions and could include physical (visible bodily symptoms of a disease) or environmental (media) motivators (Ogden, 2004). According to Rosenstock et al. (1994) cues to action are very important factors that give a disease a human face and make people aware of the reality of the disease. Cues to action in the TB campaign can be conveyed to the general public by showing images of ordinary people infected with the disease and the harmful effects it has on their bodies and lives. This may be seen as a cue to action to motivate individuals to take up positive health related actions to avoid TB infection.

2.11.1.8 Self efficacy in the Health Belief Model

The concept of self-efficacy was adopted from Bandura's (1986) Social Cognitive Theory and incorporated into the Health Belief Model to take into account personal and social determinants of health related behaviour (Rosenstock et al., 1994). Bandura (1986) defines self-efficacy as the self belief and confidence that an individual possesses to successfully adopt behaviour necessary to achieve a desired outcome. The concept of self-efficacy is thus a crucial factor in creating and maintaining behavioural change and this is shown by its incorporation into the growing body of research in health related spheres such as dieting, drug addiction, and sporting. Progressive self confidence and a cognitive sense of self belief are needed for the adoption of positive health related behaviours towards TB (Liefooghe et al., 1995).

2.11.1.9 Criticism of the Health Belief Model

The Health Belief Model has been criticised for not accounting for the gap between intentions and actual behaviour, which in most cases is made up of a broad spectrum of social, emotional and physiological factors which influence health related behaviour

(Ogden, 2004). A limitation of the model is that it overlooks the influence of the social and economic environment in predicting and explaining behaviour but instead places a lot of emphasis on the cognitive processes of individuals (Rosenstock et al., 1994).

The Health Belief Model was adopted in this study because research that has been done in South Africa indicates that lower perceived susceptibility towards TB by individuals results in a greater spread of the disease (Cramm, 2006). The spread of TB is a major public health threat in South Africa due to its direct association with increased morbidity and costs of TB control programs. The said model will be used collaboratively with the Social Cognitive Theory in this study because it can be operationalised methodically. There is also sound and sufficient literature relating to its application which is available for the study.

2.12.1 The Social Cognitive Theory

In the present study the Social Cognitive Theory is used to predict and explain the respondents' behaviour, motivation and action towards health related issues. This theory is used to understand how individuals can adopt and sustain positive health related behaviours. Pajares (2002) propose a theory of social learning and imitation that states that humans are motivated to learn positive behaviours through observing and imitating other humans. The theory of social learning fails to take into account the processes of delayed and non-reinforced imitations. Bandura (1986) developed the Social Cognitive Theory which aimed at presenting an integrated model to explain and predict human behaviour, motivation and action. It was argued that the theory of social learning does not include a key aspect known as self-efficacy.

Bandura (1986) proposed a view of human functioning and learning that accords a central role to cognitive, vicarious, self-regulatory, and self-reflective processes in human adaptation and change. According to Pajares (2002, p. 56), "human beings are viewed as self-organising, proactive, self-reflecting and self-regulating rather than as reactive organisms completely shaped and influenced by environmental forces". The Social Cognitive Theory is an interactional model that views human functioning as the product

of a dynamic interplay of personal, behavioural, and environmental influences, known as the notion of triadic reciprocal causation (Bandura, 1986). This notion proposes that people interpret the results of their own behaviour which inform and alter their behaviour. The personal factors individuals possess inform and alter subsequent behaviour (Pajares, 2002). The concept of triadic reciprocality is derived from the view that (a) personal factors (in the form of cognition and biological events), (b) behaviour and (c) environmental influences, create interactions that result in a triadic reciprocality. Bandura (1986) altered the label of his theory from social learning to social 'cognitive' to emphasise that cognition plays a critical role in people's capability to construct reality, self-regulate, encode information, and perform behaviours.

According to Miller (2005), Bandura's (1986) Social Cognitive Theory stands in clear contrast to theories of human functioning that overemphasise the role that environmental factors play in the development of human behaviour and learning. Behaviourist theories assume that human functioning is caused by external stimuli whilst inner processes are viewed as transmitting rather than causing behaviour. From the perspective of behaviourist theories, inner processes are dismissed as redundant factors in the cause and effect processes of behaviour and unworthy of psychological inquiry (Pajares, 2002). Bandura (1986 p. 17) argues that "a theory that denies that thought can regulate actions does not lend itself readily to the explanation of complex human behaviour and motives".

Social cognitive theory is rooted in a view of human agency in which individuals are agents proactively engaged in their own development and who can make things happen by their independent actions. Among other personal factors that individuals possess are self-beliefs that enable them to exercise a measure of control over their thoughts, feelings, and actions. What people think, believe and feel, influences how they behave. Bandura (1986) provided a view of human behaviour in which the beliefs that people have about themselves are critical elements in the exercise of control and personal agency. Thus, individuals are viewed both as products and as producers of their own environments and social systems. Because human lives are not lived in isolation, Bandura (1986) expanded the concept of human agency to include collective agency. Referring to

the concept of collective agency it is assumed that people work together on shared beliefs about their capabilities and common aspirations to better their lives. This conceptual extension makes the theory applicable to human adaptation and change in collectively-oriented societies as well as individualistically-oriented societies (Pajares, 2002).

Environments and social systems influence human behaviour through psychological mechanisms of the self system. Based on the Social Cognitive Theory, Pajares (2002) deduced that factors such as economic condition, socioeconomic status, and educational structures affect human behaviour indirectly because these factors influence people's aspirations, self-efficacy beliefs, personal standards, emotional states, and other self-regulatory factors.

2.12.1.1 Bandura's five fundamental human capabilities

Bandura (1986) proposed that individuals possess certain capabilities that define what it is to be human. These human capabilities primarily include the ability to symbolise, plan alternative strategies (forethought), learn through vicarious experience, to self-regulate, and to self-reflect. These capabilities provide human beings with the cognitive capabilities that are influential in determining their own destiny and course of life (Miller, 2005).

Firstly humans possess an extraordinary capacity to symbolise, which refers to the ability to draw internal cognitive symbolic representations of the world to create meaning of the environment, construct guides for action, solve problems cognitively and gain knowledge by reflective thought. Symbols are the constructs of thought and by symbolising experiences humans provide their lives with structure, meaning, and continuity. Symbolising allows individuals to store information that can be used to guide future behaviours and actions (Bandura, 1986). Pajares (2002) adds that the ability to symbolise allows humans to communicate with each other at any distance in time and space.

The second human ability (Bandura, 1986) that allows individuals to solve cognitive problems through the use of symbols is known as the ability of forethought which relates

to the ability of humans to plan courses of action and anticipate the likely consequences of these actions. It is because of the capability to plan alternative strategies that humans are able to anticipate the consequences of an action without actually engaging in it.

Thirdly, Bandura (1986) states that individuals learn, not only from their own experience, but by observation of the behaviours of others, gaining a distanced experience which is known as vicarious learning. Vicarious learning enables individuals to acquire behaviour without undergoing the trial and error process of performing it. This ability to learn vicariously allows humans to avoid making fatal mistakes (Pajares, 2002). The observation of a behaviour and action are symbolically coded in the individual's mind and used as a guide for future action. Observational learning is influenced by the processes of attention, retention, production and motivation. Retention refers to the ability of individuals to selectively observe and assimilate the actions witnessed. Observed behaviours can be reproduced only if they are retained in memory; a process made possible by the human capability to symbolise. Individuals are ultimately motivated to adopt observed behaviours that produce valued results and expectations (Bandura, 1986).

Fourthly, Bandura (1986) states that individuals have the capacity to self-regulate which allows humans to possess the ability to change their behaviour by themselves. The ability for individuals to self-regulate their own behaviour appropriately and consistently involves their ability to self-observe and self-monitor themselves accurately (Miller, 2005). Humans consistently assess the outcome of their behaviour and action. This process of assessment and self regulation influences the future behaviour they adopt.

The fifth human ability that mediates all the main determinants of human functioning is the ability to self-reflect. According to Bandura (1986, p. 21), "if there is any characteristic that is a distinctively human, it is the capacity for reflective self consciousness." By self-reflection, people make sense of their experiences, explore their own thoughts and self-beliefs, engage in self-evaluation, and alter their thinking and behaviour accordingly. Bandura (1986) further elucidates that the five fundamental

human capabilities are necessary to allow the reciprocal interaction between the environmental determinants, personal and behavioural determinants that allow humans to learn and acquire new behaviours.

2.12.2.2 Self-efficacy in Social Cognitive Theory

According to Bandura (1986, p. 391), "self-efficacy refers to people's judgments of their own capabilities to organise and execute courses of action required to attain designated types of performances". Self-efficacy is the self belief of an individual that makes it possible to successfully and consistently adopt a new behaviour (Pajares, 2002). Self-efficacy beliefs provide the foundation for human motivation, well-being, and personal accomplishment (Bandura, 1986). The concept of self-efficacy highlights the essential distinction between possessing self regulative skills and being able to successfully use and apply them under practical circumstances. Bandura (1986, p. 393) affirms that, "self-efficacy in dealing with the environment does not simply involve having the knowledge of what actions to perform". Instead self-efficacy involves a generative capability in which cognitive, social, and behavioural sub-skills are organised into integrated courses of action to serve innumerable purposes.

Bandura (1986, p. 394) states that the role of self-efficacy beliefs in human behaviour is that "people's level of motivation, affective states, and actions are based more on what they believe than on what is objectively true". It can be noted that how people behave can often be better predicted by the beliefs they hold about their capabilities than by what they are actually capable of accomplishing. Identifying the perceptions of self-efficacy can assist in predicting what individuals do with the knowledge and skills they possess (Bandura, 1986). The concept of self-efficacy helps us understand why human behaviour sometimes deviates from the actual knowledge and skills possessed that are applied successfully. People's accomplishments are generally better predicted by their self-efficacy beliefs than by their previous attainments, knowledge or skill. Although no amount of self-belief alone can produce success when the requisite skills and knowledge are absent (Pajares, 2002).

Self-efficacy beliefs can enhance human accomplishment and well-being in many ways by influencing the choices people make and the courses of action they pursue. Unless people believe that their actions will have the desired consequences and outcomes, they have little incentive to engage in those actions (Bandura, 1994). As Miller (2005) also points out, individuals tend to select tasks and activities in which they feel competent and confident and avoid those tasks in which they do not feel competent.

According to Pajares (2002), self-efficacy beliefs help determine how much effort individuals put in given tasks, how long they will persevere when confronting obstacles, and how resilient they will be in the face of adverse situations. Individuals, who have a high sense of self-efficacy to accomplish a task, put great amount of effort, persistence, and resilience into achieving their goals (Bandura, 1994). People with a strong sense of personal belief approach difficult tasks as challenges to be mastered rather than as threats to be avoided. They have greater intrinsic interest to overcome and master challenges; they set themselves challenging goals and maintain a strong commitment to them (Pajares, 2002). When these individuals fail they quickly recover their sense of efficacy and attribute their failure to insufficient effort, knowledge or skill which they believe can be improved.

Bandura (1986) states that at times individuals who possess high levels of self efficacy may behave in ways that are contrary to their beliefs and abilities mainly because they lack the necessary resources or simply because of social constraints. Therefore individuals may feel skilled, knowledgeable and capable of behaving in a certain way and may still not behave in that manner. Bandura (1994) argues that strong self-efficacy beliefs are generally the product of time and multiple experiences; they are highly resistant and predictable, therefore weak self-efficacy beliefs require constant reappraisal if they are to serve as predictors of positive behaviour.

Bandura (1986, p. 396) further argues that "measures of self-efficacy must be tailored to the domain of the psychological functioning being explored". This means that in order to explore the relationship between efficacy and behaviour we need to be certain that we are

measuring the self-efficacy beliefs relevant to the behaviour we are focusing on (Pajares, 2002). Therefore if the aims are unclear and performance ambiguity is perceived, the sense of self-efficacy does not aid in predicting behavioural outcomes. According to Bandura (1986) individuals develop self-efficacy by interpreting information from four sources which are mastery experience, vicarious experience, social/verbal persuasion and somatic/emotional states. These sources show the primary importance of reciprocal determinism and how self-efficacy influences human thoughts and behaviours.

Firstly, the most influential source is the interpreted result of one's previous performance, or mastery experience. Individuals assess and interpret the results of their actions and use these interpretations to guide future behaviour. Outcomes interpreted by individuals as successful raise their self-efficacy and those interpreted as failures lower it. Individuals who possess a low self-efficacy discount their successes and do not change their beliefs positively (Bandura, 1986).

Secondly, people form their self-efficacy beliefs through the vicarious experience of observing other individuals perform tasks. According to Bandura (1986), the vicarious experience, as a source of information, is weaker than mastery experience in helping to create self-efficacy beliefs because people are uncertain about their own abilities when they have limited prior direct experience. Individuals who possess attributes that are similar can provide the greatest comparative information for gauging their individual abilities. The process of modelling occurs when individuals acquire new skills or behaviours through observing other similar individuals. Vicarious experience is very powerful when observers see similarities in some attributes and then assume that the model's performance is diagnostic of their own capability. The effect of vicarious experience is minimised when individuals perceive the model's attributes as highly divergent from their own. A significant model in an individual's life can assist in creating self-beliefs that will influence the behaviours and actions of that individual (Bandura, 1986, 1994).

Thirdly, self-efficacy is developed through the process of social/verbal persuasion, whereby individuals develop self-efficacy through the social persuasion they receive verbally from other individuals. Individuals who positively persuade and motivate other individuals strengthen and enhance the self-efficacy thus developed by other individuals (Pajares, 2002). Effective persuasion must cultivate the individual's beliefs in their capabilities whilst at the same time ensuring that the envisioned outcome is realistically attainable. The concept of social persuasion allows us to note that it is much easier to weaken self-efficacy beliefs through negative appraisals than to strengthen such beliefs through positive encouragement (Bandura, 1986).

The fourth source of self-efficacy relates to the somatic and emotional states individuals go through such as anxiety, stress, arousal, and mood states. When individuals are contemplating an action they are able to assess their level of confidence by the emotional state they experience during the process (Pajares, 2002). Positive or negative emotional reactions to an anticipated behaviour provide cues about the anticipated success or failure of that action. When individuals experience negative thoughts and fears about their capabilities then those reactions can themselves lower self-efficacy perceptions and trigger additional stress and agitation that result in inadequate performance and failure (Bandura, 1986). An individual's level of self-efficacy can be raised by improving the individual's physical and emotional well-being and reducing negative emotional states. According to Bandura (1994), individuals can enhance their self-efficacy by altering their own thinking and feelings that directly have an influence on their psychological states.

The Social Cognitive Theory is useful in designing and implementing health education and health behaviour programs. This theory explains how people are able to acquire and maintain behavioural patterns. The theory can also be used in providing a basis for the development of intervention strategies (Glaze, France, Fassin, Grundlingh & Kartz, 2002). Within the present study, components of the Social Cognitive Theory are used to aid in explaining how the respondents in the study acquire and maintain behaviour towards health related choices.

2.12.2.3 Adoption of the Social Cognitive Theory to health related behaviours

The psychosocial determinants of health and the personal determinants of health can be addressed broadly by the Social Cognitive Theory which recognises that social systems have an impact on the adoption of health behavioural changes. The attitudes and beliefs that people hold in their collective efficacy directly affects their adoption of positive health related behaviours. The Social Cognitive Theory, when adapted to health related matters, aims at assisting people to adopt and maintain healthy habits by implementing effective self-regulatory habits. If people are able to exercise some control over health related issues that affect them they are able to experience a healthy lifestyle. Self-regulatory skills that enhance health are very useful and can improve an individual's lifestyle. Research that is guided by the theory can help us understand how social factors and cognitive factors can contribute in improving human health.

The Social Cognitive Theory is adopted within the study to explain and understand how the attitudes and behaviours people hold impact on their health related behaviours. The decision was made to use the theory in this study because it seeks to explain and understand the internal and external factors that influence people in the adoption of health related issues. Self-efficacy plays a pivotal role in the adoption of positive health-related behaviour. The greater the level of self efficacy within individuals then the greater the chances are that they will adopt and maintain a positive health related behaviour. According to the Social Cognitive Theory,, normative influences regulate people's behaviours because humans desire to undertake behaviours that are normatively accepted by society. Individuals regulate their behaviour in light of the accepted and enacted norms within their society. Therefore if there is a culture of volunteering to assist TB patients within a given community then TB volunteering is more accepted and becomes more prevalent within that community.

Perceived barriers in individuals make the adoption of positive health related behaviours challenging (Bandura, 1994). The theory identifies two different barriers to the adoption of positive health related behavioural change. The first is comprised of personal impediments which represent lack of people's self efficacy to adopt positive health

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related behaviours. The other type of barrier is made up of situational impediments. Situational impediments are those impediments that are caused by structures of health services and impede the adoption of health related behaviours by individuals (Bandura, 1986). For example, in South Africa, the challenges posed by the DOTS strategy act as an impediment for people to seek TB treatment (Erstad, 2006). Referring to the Social Cognitive Theory, the personal and situational impediments to TB treatment include, stigma, discrimination, travelling, loss of daily wages, health worker's pessimism about the patient's abilities to change their health habits, inadequately informed patients, and prejudiced helpers. The social stigma associated with TB results in patients not disclosing their condition and avoiding treatment at clinics. When considering the Social Cognitive Theory it can be noted that the negative attitudes and behaviours displayed by health care workers may act as impediments for TB patients to successfully complete treatment. TB voluntary workers that are ill informed can also act as situational impediments to TB treatment compliance (Bandura, 1986, 1994).

2.13 Theoretical summary

Theoretical models are aimed at understanding and explaining a phenomenon (Harvey, 1997). However, there is no single theory or model that is able to explain broadly the scope of all health related behaviours and attitudes (Liefooghe et al., 1995). A combination of theories is needed to explain and describe variations in health related behaviour. For example, when people perceive the threat of TB their target behaviour is the adoption of positive health related behaviour. Perceived threat of TB is a construct of the Health Belief Model, but behavioural capability to adopt a positive health related behaviour is a construct of the Social Cognitive Theory. For health-related behaviours to be addressed components of both theories need to be integrated.

Behavioural capabilities to adopt positive heath related behaviour are influenced by the level of knowledge and skills that an individual possesses which are constructs of the Health Belief Model. Social Cognitive Theory provides an in-depth description of health-related behaviours. By referring to the Social Cognitive Theory and the Health Belief

Model, a rich description towards health-related behaviours is provided within the study. The Social Cognitive Theory explains some determinants of human functioning which the Health Belief Model fails to account for adequately. The Social Cognitive Theory fully incorporates an emotional component to human functioning and also includes the prominent influence of an individual's social environment in shaping behaviour.

The Social Cognitive Theory shows the crucial reciprocal nature of the relationship between individuals, their environment and health related behaviour. The contribution of the Social Cognitive Theory together with the Health Belief Model provides a broad theoretical framework that guides the study and will assist in analysing and explaining the findings of the study. Both these models are used in the study to describe and explain attitudes towards TB because they complement each other. The Health Belief Model is a comprehensive model that attempts to understand and explain health-related behaviours. The Social Cognitive Theory is used in the present study to understand and explain the results of the study with a focus on the cognitive and environmental factors that influence people's health related behaviour towards TB.

It is proposed that a broad understanding and explanation of the factors which possibly result in the continual spread of TB can be provided by integrating these two theories. Research on the current attitudes and perception towards TB within a holistic theoretical framework that explains health related behaviour is more capable of providing a broader base for which future interventions can be developed (Harvey, 1997).

2.14 Chapter summary

The chapter gives an account of relevant literature that is used to understand the attitudes and perceptions towards TB. The chapter discusses the stigma that is attached towards TB in South Africa and other developing nations. The spread of HIV/AIDS in South Africa has caused a resurgence of the stigma attached to TB and this is discussed in this chapter. The chapter reveals that there is a dual stigma towards TB and HIV/AIDS, making the control of these two intertwined pandemics challenging. The theoretical foundation of the study based on the components of the Social Cognitive Theory and the

Health Belief Model is discussed. It is argued in this chapter that the models adopted within the study provide a broad theoretical integration to thoroughly explain and describe the attitudes and perceptions towards TB.

CHAPTER 3

METHODOLOGY

3.1 Chapter Preview

This chapter covers the methodological considerations critical to the study. The aims and objectives of the study are discussed. Methods of data collection, the research population, sampling method, research procedure, data analysis, as well as the validity and reliability of the study, are presented. The chapter ends by highlighting the ethical considerations pertaining to the study.

3.2 Aims and objectives of the research

This research is a component of a project carried out by the Institute of Social and Economic Research (ISER) which investigates the quality of life in the Eastern Cape. The ISER research project as a whole aimed to investigate the levels of satisfaction with quality of life among residents of the Eastern Cape. Within the larger ISER research project the attitudes, beliefs and perceptions towards TB were also investigated with a focus on destigmatisation of TB within this area where a high incidence of HIV/AIDS prevails.

This study contributed to the overall research project by assuming part of the data collection and data analysis. The results of this research analysis were subsequently included in the final report of the ISER research project. The researcher specifically selected all the questions from the large project that focused on attitudes and perceptions towards TB within the Grahamstown East region.

There are two broad aims and several objectives that motivated the need for this study. Firstly, the research aimed at understanding the nature of present attitudes, perceptions and knowledge of Grahamstown East residents regarding TB since there are no answers available as to why there is such a high incidence of the disease in this area. In other

words, research is needed to provide a thorough understanding of the behavioural and socio-economic factors that influence and promote the spread of TB within the area.

The second aim of the research was to understand the present attitudes and perceptions towards TB in relation to HIV/AIDS as well as understanding what, if any, impact HIV/AIDS has made on these current attitudes and perceptions towards TB. The study focused on ascertaining whether these two diseases are seen as twin diseases and to what extent people in Grahamstown East perceive there to be a relationship between the two diseases. Hence the research aimed at exploring the possibility that there is a dual stigma associated with TB and HIV/AIDS.

The literature shows that in developing nations, including South Africa, TB and HIV/AIDS have been regarded as inseparable diseases and that there is a syndemic interaction between the two diseases in South Africa. The syndemic interaction between the two diseases has worsened the burden posed by TB in South Africa. Despite the existent syndemic interaction between the two, and the common supposition that they are twin diseases, most strains of TB are curable whereas all strains of HIV/AIDS are incurable (Singer & Claire, 2003). Further research is therefore needed to understand how the syndemic interaction between the two diseases can be managed.

Sub-goals of the research were concerned with establishing whether gender, education, and the experience of assisting TB patients influence the attitudes, perceptions and knowledge regarding TB within Grahamstown East.

3.3 Research framework

To effect these goals, the study will be situated in a positivistic paradigm. According to Guba and Lincoln (1998) a paradigm is a basic set of beliefs or a set of assumptions, which serve as touchstones in guiding research activities. A research paradigm guides the methodology, analysis and interpretation process of a study to ensure that the overall study is cohesive and valid. A study conducted within the positivist paradigm is a formal, objective and systematic process in which quantitative data is utilised to obtain

information about the world (Whitelaw, 2001). A positivist paradigm makes use of quantitative methodology. In a quantitative methodology the relationship between variables is shown through statistical means (Bless & Higson-Smith, 1995). The positivist paradigm is based on a set of principles and assumptions, which include empiricism, determinism, generality and parsimony. Empiricism is defined as the collection of evidence which is verifiable to support a hypothesis. Determinism means that there are causative factors for all events, and by understanding these causal factors, all events can be predicted and explained. Generality regards the generalisation of observed phenomena to other similar contexts. The process of explaining observed phenomena in the simplest possible manner is known as parsimony (Bless and Higson-Smith, 1995). The positivistic paradigm was adopted because this study aimed at first understanding the causal factors that perpetuated the prevalence of TB within Grahamstown East and then considering the findings in terms of other similar contexts in order to complement the existing body of knowledge.

3.4 Research design

A household survey was used to collect the data. According to Presser (2003) a survey questionnaire design is any data collection operation that gathers information from human respondents by means of a standardised questionnaire. The survey administered in this study was in the form of a household face-to-face interview questionnaire.

A household face-to-face interview survey was selected because it allows for a description of the characteristics of large samples and the analysis of multiple variables within the selected sample. As a research instrument, this method of data collection via questionnaire was selected as it is easy to administer and large sample populations can be covered (Annexure A). A face-to-face interview survey questionnaire also provides direct contact between a respondent and a researcher allowing rapport to be established. The shortcoming of a face-to-face interview survey questionnaire is that it may lack flexibility posed by its use of structured questions. This often inhibits useful unstructured responses from respondents as they cannot state their own responses and opinions (Babbie, 2004).

The questionnaire administered in the study was developed by the researcher in collaboration with an academic member of ISER at Rhodes University. In designing the questionnaire various literature such as the Health Belief Model, the Social Cognitive Theory and related scales, such as the AIDS Related Stigma Scale (Kalichman & Simbayi, 2004), were referred to. The selection of questions was based on a pilot study conducted within the area and the results from a focus group study conducted earlier (see section 3.10 below). Some medical practitioners who work in clinics within the area of Grahamstown were consulted for advice when the questionnaire was drafted. The structured questionnaire comprised 21 close-ended questions and three open-ended questions. The questionnaire was designed to investigate the attitudes and perceptions towards TB.

The questionnaire was divided into four sections:

- Background information on household.

- Background information on respondent.

- Quality of life.

- Attitudes and beliefs about TB.

Questions were presented in both isiXhosa and English. Translation of the isiXhosa questions was done by a local professional linguist fluent in both languages. The reason for having both isiXhosa and English questions was because isiXhosa is the dominant local language in the area; however some of the terminology used for health-related issues is commonly expressed in English. The questionnaire was designed in such a way that it could be completed between 45 and 60 minutes.

3.4.1 Background information on household

The aim of this section of the questionnaire was to obtain an understanding of the background and composition of each household selected. The questions in this section covered the following variables:

a) the source of income of the household,

b) the size of the household,

c) age and occupation of the household dwellers.

3.7.2 Background information on respondent

Questions in this section of the questionnaire elicited data on the selected respondent's personal and socio-economic background. The questions focused on the following variables regarding the respondent:

a) age,
b) gender,
c) occupation,
d) education,
e) marital status.

3.4.3 Quality of life

This section was only used in the aforementioned larger ISER project and was not included in the present study. This section aimed at understanding how satisfied the respondents felt about the quality of their lives. This section was characterised by an inventory known as the Anamnestic Comparative Self Assessment (Kalichman & Simbayi, 2004). This inventory allowed the respondents to show their level of satisfaction with the quality of their life. The results from this section of the questionnaire were not analysed or discussed in the present study.

3.4.4 Attitudes and beliefs about TB

Firstly, this section aimed at understanding the attitudes and perceptions each respondent held towards TB health-related matters. A second goal was to ascertain how each respondent viewed other people's attitudes and perceptions towards TB health-related matters, as well as to find out what attitudes and perceptions the respondents held towards TB in relation to HIV/AIDS. In this section the questions covered compliance to

TB treatment in an attempt to identify the reasons why some patients are non-compliant. This section also aimed at understanding the attitudes that people in Grahamstown East have towards assisting people with TB who receive temporary disability grants.

The questions in this section also focused on understanding the following variables regarding the attitudes and perceptions towards TB:

a) the level of education and knowledge that people within the community have about TB as a disease,

b) the level of stigma towards TB,

c) the level of stigma towards HIV/AIDS,

d) risk factors that cause TB,

e) attitudes people have within the community towards assisting people with TB and the temporary TB disability grant,

f) perceived susceptibility of the respondent towards contracting TB,

g) perceived benefits of the respondent towards TB treatment,

h) the perceived threat of TB by the respondent,

i) the perceived severity of TB.

Information based on answers to questions based on all the above selected variables would facilitate an in-depth understanding of the attitudes and perceptions regarding TB in the area. The questions used to ascertain the level of stigma the respondents have towards TB and HIV/AIDS were adapted from the questions in the AIDS Related Stigma Scale (Kalichman & Simbayi, 2004). This scale is the only stigma scale that has been validated for the South African population in terms of content and concurrent validity. When the scale was adapted for the South African context it proved to be reliable and valid in three different languages which are English, Xhosa and Afrikaans. Supporting the construct validity of the scale, higher scores were recorded for individuals who avoided having contact with people infected with HIV/AIDS.

3.5 Population

A population is defined as a group of individuals, events and objects sharing some common characteristic (Babbie, 2004). The population in the present study consisted of

all Grahamstown East residents. From this population respondents, who met the desired inclusion criteria, were selected to participate in the study. In order for respondents to be selected for the study they had to have resided in Grahamstown East for a minimum of six of the previous twelve months and to be 18 years or older. In addition the respondents could not suffer from any legal disability such as insanity which would have prevented them from effectively completing the questionnaire. Gender, religion and marital status, did not affect the eligibility of respondents. The residents of Grahamstown East were generally low-income earners who live in a fairly crowded and impoverished township area. Grahamstown East is sub divided into various densely populated neighbourhoods which include the following neighbourhoods, Fingo, Tantyi, Xolani, Hlalani, Makanaskop/Joza, Extension 1 (Thatha), Extension 2 (Pumlani Extension 2), Extension 3 (Pumlani Extension 3), Extension 4, Extension 5, Extension 6, Lingelihle formal, Extension 7, Extension 8, Extension 9, Vukani I, Vukani II, Transit camp, Phaphamani, Eluxolweni, Zolani, Ethembeni, Hlalani informal, and Mnandi.

3.6 Sampling

Sampling is the probabilistic selection of respondents from a larger population, with the aim of approximating a representative outcome of the whole population (Tredoux, 1999). Multistage stratified random sampling was used in this study as it allows for large sample sizes with different subgroups within the same population. The multistage stratified sampling adopted in the study ensured that all the people within Grahamstown East stood an equal chance of being selected to participate in the study. The sampling process adopted in the study consisted of the three stages.

In the first stage of the multistage sampling process, stratification was carried out. Stratification is defined as the process of identifying different sub groups which are homogenous within a population (Tredoux, 1999). The stratification process within the study was carried out by identifying all the various sub groups (neighbourhoods) within Grahamstown East. Each neighbourhood that was identified became a stratum. The various strata identified within the study included all the various 24 neighbourhoods within Grahamstown East. Stratification was carried out so that all of the 24

neighbourhoods within Grahamstown East would be included within the study to provide a representative study of the whole area. In other words stratification was carried out so that all the citizens from various parts of Grahamstown East would stand a chance of being included in the study.

The second stage of sampling was systematic sampling. Systematic sampling is a form of random sampling that includes a process whereby within each sampling frame a starting point is chosen at random and thereafter regular proportional intervals are selected (Tredoux, 1999). In the present study a random starting point was selected within each of the 24 strata and thereafter every tenth household was selected systematically for inclusion in the sample. A random starting point ensures that all the households within each stratum stood an equal chance of being included in the survey. Systematic sampling was applied to select proportional sample sizes from each of the identified stratum. The sample size of each stratum was determined randomly through systematic sampling and was proportional to the total number of households within each stratum. The strata were of different sizes depending on geographic placement and the varying sizes of the neighbourhoods.

The third and final stage of sampling within the multistage sampling framework was simple random sampling. Simple random sampling included carrying out a random sampling process within each systematically selected household. All the eligible respondents at a systematically selected household stood an equal chance of being selected. In each systematically selected household a list was drawn up of all the persons who were eligible to act as respondents. One respondent was selected from each household using a random table known as the Kish grid (Kish, 1949). This grid was used to ensure that all eligible persons in each household stood an equal chance of being selected. If the selected respondent was present and gave informed consent the research assistants administered the questionnaire. If the selected respondent was not present at the time of the visit, an appointment was made to administer the questionnaire at a later time. Up to four visits were made to the household to try to find the selected respondent to administer the questionnaire. If, however, the research assistants failed to find the

selected respondent for a household after four visits then another systematically sampled household was selected.

3.7 Data collection

Data collection is the planned, systematic process of gathering information, such as figures, words or responses, that describe some situation from which conclusions can be drawn (Babbie, 2004). Permission was obtained from the Makana Municipality of Grahamstown for the researcher and the ISER to conduct the research and approach Grahamstown East residents. Over a period of four weeks, the fieldwork was conducted by the researcher and a team of trained research assistants outsourced from Development Research Africa (DRA). The researcher worked with the team of trained DRA research assistants by supervising their fieldwork and implementing quality assurance procedures. The researcher allocated each research assistant with a number of questionnaires and assigned him/her to a particular area in which to administer the questionnaires. The research assistants consulted the researcher if they had any problems during the fieldwork.

On approaching a selected household, the research assistants firstly introduced themselves and explained the purpose of the survey. After obtaining informed consent, the research assistants prepared a list of all the eligible household dwellers and then used a Kish grid to randomly select an eligible respondent. After obtaining informed consent from this selected eligible respondent the research assistants administered the survey questionnaire. The research assistants asked the questions in the language the respondent preferred (isiXhosa/English) and repeated those questions the respondents did not clearly understand. The research assistants recorded the responses and double checked all the responses with the respondent at the end of the face-to-face interview. After completing ten questionnaires the research assistants returned all the completed questionnaires to the researcher. The researcher then performed a quality check of all the questionnaires and followed up any omissions made by the research assistants or contradictions in the responses. Some of the omissions the researcher looked for included identifying questionnaires of selected respondents who were not eligible to participate in the study. If

the researcher felt that a questionnaire was not correctly completed the researcher would send it back to the assistant researchers in the field so that it could be re-administered.

3.9 Data analysis

The aims of the study and the relevant theoretical framework adopted in the research were used to guide the data analysis. The researcher selected specific questions from the whole questionnaire which contained the specific items which the researcher aimed at understanding to fulfil the aims and goals of the research. According to Babbie (2004) the responses from questions in a questionnaire should not be aggregated collectively into broad components such as attitudes, knowledge and perceptions, but instead they should be analysed individually. The analysis of data in the study was guided by the assumption that aggregate scores would be of minimal use because a researcher may not be able to make conclusions only from overall aggregate scores (Rosenstock et al., 1994).

The constructs of the Health Belief Model and the Social Cognitive Theory were all used to interpret and analyse the results obtained. The constructs that were directly applied to interpret and explain the results included knowledge, perceived personal susceptibility, perceived severity, perceived benefits, perceived barriers, and cues to action. The researcher categorised all the questions within the questionnaire and analysed them using these constructs. The theories adopted in the study were used by the researcher to propose each respondent's behaviour and motivation in coping with health-related TB issues based on the responses to the structured questions. The selected responses from the questionnaire were firstly coded by the researcher to allow statistical analysis to be conducted through the SPSS statistical programme. The researcher, with the assistance of a statistician, carried out statistical analysis of the data obtained from the study. The first type of data analysis carried out by the researcher was univariate analysis which was used to generate frequencies, descriptions and to identify patterns in the data (Babbie, 2004). All the variables that were statistically analysed by the researcher in the study were:

a)   the level of stigma for both TB and HIV/AIDS,

b)   perceived TB susceptibility,

c) perceived threat of TB,

d) perceived benefits of TB treatment,

e) perceived severity of TB,

f) experience of and exposure to TB,

g) gender,

h) age,

i) education level, and

j) TB knowledge.

The level of stigma towards TB was analysed within the study. The relationship between TB and HIV/AIDS was also analysed. Since most of the response formats to the questions in the questionnaire were measured at the nominal level, frequency tables were adopted as the mode of descriptive statistics to display the data. Within the frequency tables generated, percentages were used to display the data and to identify any patterns in the data.

After the application of univariate analysis to generate descriptive statistics, bivariate analysis was carried out by the researcher to identify any relationships between variables. Analysis was carried out to identify the relationships between the following variables: age, gender, education level, the experience of assisting TB patients and the relationship between TB and HIV/AIDS. Using bivariate analysis the cross tabulations for the relevant items were calculated and displayed in the form of contingency tables. The contingency tables generated in the study were used to record and analyse the relationship between the selected variables. Pearson's chi-square test was applied to identify significant differences between the selected variables. This statistical application was used to compare the relationship between the nominal and ordinal variables such as gender and the level of TB stigma. This statistical application was used to identify if there was a relationship between the educational level or experience of assisting TB patients and stigmatising attitudes towards TB. The relationship between TB and HIV/AIDS was analysed through this statistical application to identify if there was a significant relationship between the two diseases which varied according to gender, educational level and the experience of dealing with TB.

3.10 Reliability and validity

According to Bless and Higson-Smith (1995) reliability is the extent to which a measuring instrument consistently measures the researched phenomenon. When a research instrument is able to give an accurate and consistent measurement of an unchanging value it is regarded as having a high level of reliability. Validity is the extent to which a research instrument or inventory is able to measure what it claims to be measuring (Whitelaw, 2001). There are different types of validity. In the given study the focus was on measurement validity. This is the degree to which a measure is able to accurately measure the phenomenon it claims to measure (Whitelaw, 2001). The present study met the criteria of two general forms of measurement validity, namely, face validity which is the extent to which an instrument seems to capture the characteristic of interest, and content validity which refers to the extent to which an instrument appears to measure the phenomenon it claims to measure.

As mentioned in section 3.7, a pilot study was conducted using the questionnaire in Grahamstown East to ascertain the attitudes and perceptions towards TB and the non-compliance of TB patients. The pilot study, which preceded the actual research study, was carried out on a group of 50 randomly selected Grahamstown East residents. The pilot study was a self administered questionnaire. Within the selected sample all the respondents were older than 18 years old and both males and females were selected. The randomly selected sample included respondents from all the different neighbourhoods of Grahamstown East. A focus group discussion took place afterwards. Focus groups are able to provide valuable information from under-researched groups by facilitating effective communication (Babbie, 2004). The pilot study was used to avoid and remove ambiguous and difficult questions from the study. Most of the questions used in the pilot study were adopted into the final questionnaire. From the pilot study it was learnt that an informed and experienced assistant researcher was needed for administering the questionnaire. It was learnt that the assistant researcher should be able to explain to the respondents any ambiguous and difficult language terminology should this arise. After the pilot study was concluded valuable and constructive changes were made to the final questionnaire.

3.10 Ethics

Prior to administering the questionnaire the research assistants explained to the respondents the purpose of the research. The research assistants informed and encouraged the respondents to be honest and promised strict confidentiality. Although the respondents' names were known by the research assistants and the researcher, their names did not appear on any data and analysis reports to ensure that confidentiality was maintained. Finally the respondents were informed that their participation was voluntary and they were free to withdraw whenever they felt uncomfortable with the questions.

There was no potential risk of physical or psychological harm to the respondents, assistant researchers or the researcher in undertaking the research. Psychologically harmful questions and probing were avoided by the researcher and research assistants. The questions in the questionnaire were carefully constructed in such a manner to not promote misconceptions, myths about TB and HIV/AIDS that could add to further stigmatisation of people with these diseases. The research findings will later on be published in a local newspaper accessible to the respondents.

3.11 Chapter summary

This chapter outlines the methodology used to identify the attitudes and perceptions towards TB in the Eastern Cape. Data was collected by the researcher and a team of trained DRA research assistants using face-to-face survey questionnaires. A sample was obtained from the Grahamstown East population using a multistage stratified random sampling approach: in the first stage the population of Grahamstown East was sub-divided into 24 strata (neighbourhoods). Next, households within these different strata were selected by systematic sampling. The final stage was simple random sampling which was used to select eligible respondents for the study. The face-to-face survey questionnaire administered in the study had face validity and content validity. The results of the study are discussed in the next chapter.

CHAPTER 4

RESULTS

4.1 Chapter preview

The aim of this chapter is to outline the results obtained in the study. The results are presented according to the constructs of the Health Belief Model (Rosenstock et al., 1994) and Bandura's (1986) Social Cognitive Theory.

4.2 General results

The goal of the research was to understand the existing attitudes, knowledge, and behaviours towards TB among the relatively high risk group of Grahamstown East residents. The overall response rate in the study to the questionnaires was high. The targeted sample size was (n=1040). From the targeted sample size, 97,9% (n=1020) successfully completed the questionnaire. Reasons for not fully achieving the targeted sample size included non-availability of some selected respondents after four visits to their households. Certain selected respondents were unable to complete the questionnaire for age or health reasons. In the fieldwork other selected respondents were unwilling to complete the questionnaire, possibly because they felt that there were no immediate personal benefits to be gained from participating in the study.

The majority of the respondents who were selected and participated were women (73%, n=745) and a smaller percentage of the respondents (27%, n= 275) were men. A third of the respondents were married (33%, n=343) and just above half of respondents were single (52%). The median age of the respondents was 38 years. Although 40% of respondents (n= 408) had completed some secondary education, only 18% (n= 183) had matriculated. A very small percentage of the respondents (7%, n=72) had received further post matriculation education and training. A small percentage of the respondents (35%, n=357) had received no or some primary level of education.

4.3 Knowledge

The results from the questions seeking the knowledge the respondents have of TB are shown below. These results have been divided into three sections which are:

- General knowledge about TB
- Knowledge about the transmission of TB
- Knowledge about TB and its relationship to HIV/AIDS

4.3.1 General knowledge of TB

Table 1 presents the answers to questions regarding the respondents' general knowledge of TB as a social disease. From Table 1 it can be noted that a large percentage of the respondents (70%) responded that they had been informed about TB and knew the symptoms.

Table 1

General knowledge of TB

Question **("correct" responses are in bold type.)**	**Responses**		
	Yes	**No**	**n**
TB is only an African disease.	53,7%	**46,3%**	999
If you have multi-drug-resistant TB it takes many months to be cured.	**81,6%**	18,4%	969
There is no cure at present for extremely drug-resistant TB.	**62,5%**	37,5%	952
I have been informed about TB.	**70%**	30%	1014

4.3.2 Knowledge about the transmission of TB

Table 2 presents responses to questions aimed at determining the level of knowledge of the transmission of TB. The majority of the respondents (89,3%) knew that TB does not only affect people who live in poverty.

Table 2

Knowledge about the transmission of TB

Question ("correct" responses are in bold type.)	Response		
	Yes	**No**	**n**
Only people who live in poverty get infected with TB.	10,7%	**89,3%**	1016
Only people who are HIV-positive get infected with TB.	11,4%	**88,6%**	1014

4.3.3 Knowledge about the relationship between TB and HIV/AIDS

Table 3 presents the responses to questions that explored the respondents' level of knowledge regarding the relationship between TB and HIV/AIDS. A large proportion of the respondents (64,7%) knew that HIV/AIDS positive people could be cured of TB.

Table 3

Knowledge about the relationship between TB and HIV/AIDS

Question ("correct" responses are in bold type.)	Response		
	Yes	**No**	**n**
HIV/AIDS positive people can be cured of TB	**64,7%**	35,3%	1006
Almost all people with TB develop HIV/AIDS	60,3%	39,7%	1013

4.4 Attitudes

The results of the questions regarding the attitudes and perceptions towards TB by the respondents are presented in this section. The questions were sub-divided into the following sections:

- Perceived personal susceptibility of contracting TB

- Perceived severity of TB

- Perceived benefits of avoiding and managing TB

- Perceived barriers to obtaining treatment (including environmental barriers)

- Cues to action to prevent TB

- Self-efficacy in managing TB

- Attitudes towards assisting people with TB

- Attitudes towards TB in relation to its association to HIV/AIDS

- Attitudes towards the TB temporary disability grant in South Africa

- Judgmental dimension towards people infected with TB (the AIDS Related Stigma Scale adopted for TB)

- Judgmental dimension towards people infected with HIV/AIDS (the AIDS Related Stigma Scale)

4.4.1 Perceived personal susceptibility to contracting TB

Table 4 shows the responses to the questions relating to the respondents' personal susceptibility to TB. Table 4 shows that the majority of the respondents (92,3%) felt that anyone could get infected with TB because the TB germs were in the air.

Table 4

Perceived personal susceptibility to contracting TB

Question	Response		
	Yes	**No**	**n**
Anyone can get infected with TB because the germs are in the air.	92,3%	7,7%	1017
Do you do enough to avoid infection from TB.	52,8%	47,2%	1011

4.4.2 Perceived severity of TB

The responses to questions regarding the respondents' perceived severity of TB are presented in Table 5 which shows that the majority of the respondents (87,3%) felt that if a person who is infected with TB drinks and smokes he/she may never be cured of TB.

Table 5

Perceived severity of TB

Question	Response		
	Yes	**No**	**n**
There is no cure at present for extreme drug-resistant TB.	62,5%	37,5%	952
You will never be cured of TB if you drink and smoke.	87,3%	12,7%	1017
Being infected with TB is the greatest danger.	14,2%	85,8%	985

4.4.3 Perceived benefits of avoiding and managing TB

Table 6 presents the respondents' attitudes regarding their perceived benefits of receiving TB treatment and avoiding the spread of TB in the community. An overwhelming 96,7% of the respondents felt that if a TB patient completes treatment he/she should be regarded as a positive role model in society.

Table 6

Perceived benefits of avoiding and managing TB

Question	Response		
	Yes	No	n
Assigning TB patients with DOTS volunteers will help them complete treatment.	60%	40%	980
If a person completes treatment they should be seen as a hero and positive role model.	96,7%	3,3%	1018

4.4.4 Perceived barriers to obtaining TB treatment

The responses to the questions regarding perceived barriers for TB treatment are presented in Table 7 which shows that an overwhelming 94,7% of the respondents felt that people hide when they have TB because they are afraid of what other people would say about them.

Table 7

Question	Response		
	Yes	**No**	**n**
TB patients are afraid to collect their TB treatment at hospitals in case they are infected with other diseases.	31,2%	68,8%	1014
If you have TB people do not respect you.	51,3%	48,7%	1014
TB patients would stay on treatment if they were put in the same queues as people with chronic illnesses such as high blood pressure.	69,9%	30,1%	1017
If TB patients were allowed to drink and smoke in moderation they would complete treatment.	10,3%	89,7%	1016
People hide when they have TB because they are afraid of what people say about them.	94,7%	5,3%	1015

4.4.5 Cues to action to prevent TB

Table 8 presents the respondents' attitudes regarding cues to action. From the total sample of respondents, a third of the respondents (32,3%) knew of someone within their household who had previously contracted TB.

Table 8

Cues to action to prevent TB

Question	Response		
	Yes	**No**	**n**
There has been a case of TB in this household.	32,3%	67,7%	1020
I know/have known someone with TB.	61,4%	38,6%	1020
I have visited a TB patient in hospital.	45,6%	54,4%	1020

4.4.6 Self-efficacy in managing TB

Table 9 presents the responses to the questions that were asked to ascertain the perceived self-efficacy towards avoiding TB. From the total sample just above half of the respondents (52,8%) felt that they would be able to cope with TB.

Table 9

Self-efficacy in managing TB

Question	Response		
	Yes	**No**	**n**
I think I would be able to cope with TB	52,8%	47,2%	1020

4.4.7 Attitudes towards assisting people with TB

The respondents' attitudes towards assisting people with TB are shown in Table 10. As evident in Table 10 the majority of the respondents (63,1%) are willing to act as DOTS volunteers to assist people with TB.

Table 10

Attitudes towards assisting people with TB

Question	Response		
	Yes	**No**	**n**
Have you ever assisted a person with TB to take their treatment.	44,9%	55,1%	1018
Are you willing to act as a DOTS volunteer to assist people with TB.	63,1%	36,4%	1015
I have visited a TB patient in hospital.	45,6%	54,4%	1019

4.4.8 Attitude towards TB in relation to HIV/AIDS

Table 11 presents the responses to the questions that were asked to ascertain the attitudes towards TB in relation to HIV/AIDS. From the total sample of respondents, the majority of the respondents (88,9%) felt that all TB patients should be offered a confidential HIV/AIDS test.

Table 11

Attitude towards TB in relation to HIV/AIDS

Question	Response		
	Yes	**No**	**n**
There is more TB because of HIV/AIDS.	51,1%	48,9%	1015
If people knew their HIV/AIDS status, their TB could be treated.	96,6	3,4%	1014
All TB patients should be offered a confidential HIV/AIDS test.	88,9%	11,1%	1018

4.4.9 Attitudes towards the TB temporary disability grant in South Africa

The respondents' attitudes regarding the TB temporary disability grant aimed at assisting TB patients are presented in Table 12. As shown in Table 12 the majority of the respondents (61%) reported that only TB patients who are on both ARV and TB treatment can access a temporary disability grant.

Table 12

Attitudes towards the TB temporary disability grant

Question	Response		
	Yes	No	n
It is wrong for people to get infected with TB to get a temporary disability grant.	84,1%	15,9%	1016
People on a temporary disability grant should offer to do community work.	55,6%	44,4%	1014
All TB patients can get a temporary disability grant.	5,0%	95%	961
Only TB patients who are on both ARV and TB treatment can access a temporary disability grant.	61,0%	39,0%	1001
TB patients on the temporary disability grant spend it on liquor and cigarettes.	37%	63%	1009

4.4.10 Judgmental dimensions of attitudes towards people infected with TB

Table 13 presents the responses of respondents regarding questions assessing their moral and judgmental attitudes towards people infected with TB in the community. From the total sample of respondents, an overwhelming 90,4% of the respondents felt that it was mostly irresponsible people who are to blame for the spread of TB.

Table 13

Judgmental dimensions of attitudes towards people infected with TB

Question	Response		
	Yes	**No**	**n**
People who get TB through smoking and drinking get what they deserve.	71,2%	28,8%	1016
It is mostly irresponsible people who do not take their treatment who are to blame for spreading TB.	90,4%	9,6%	1015
People who get drug-resistant TB because they do not take their medicine get what they deserve.	77,9%	22,1%	1011
People with TB should only tell family members.	69,8%	30,2%	1018

4.5 AIDS related stigma scale adopted for TB

Table 14 presents the results of the questions that sought to determine the respondents' level of stigma towards TB. In the total sample of respondents, the majority of the respondents (78,3%) felt that people with TB must not be restricted in their freedom.

Table 14

AIDS related stigma scale adopted for TB

Question	Response		
	Yes	**No**	**n**
People who have TB are dirty.	1,3%	98,7%	1018
People who have TB are cursed.	1,0%	99,0%	1017
People who have TB should be ashamed.	1,6%	98,4%	1017
People with TB must expect some restrictions on their freedom.	21,7%	78,3%	1012
People with TB should be isolated.	6,0%	94,0%	1017
People with TB should not be allowed to work.	13,6%	86,4%	1015
I do not want to be friends with someone who has TB.	5,1%	94,9%	1018

4.6 AIDS related stigma scale

The results presented in Table 15 show the responses from the respondents that sought to ascertain the level of stigma the respondents have towards HIV/AIDS. As shown in Table 15 the majority of the respondents (86,9%) felt that people with HIV/AIDS should not be perceived as cursed.

Table 15

AIDS related stigma scale

Question	Response		
	Yes	No	n
People who have HIV/AIDS are dirty.	19,5%	80,5%	1013
People who have HIV/AIDS are cursed.	13,1%	86,9%	1013
People who have HIV/AIDS should be ashamed.	3,1%	96,6%	1014
People with HIV/AIDS must expect some restrictions on their freedom.	38,7%	61,3%	1013
People with HIV/AIDS should be isolated.	2,7%	97,3%	1018

4.7 Inferential statistics

The aim of this section of the analysis is to investigate if any relationships exist between the knowledge and attitudes towards TB according to the following variables, gender, level of education, and having an experience in assisting a TB patient. In this section cross tabulations were carried out to investigate the relationships.

4.7.1 Differences according to gender in the knowledge, attitudes and perceptions regarding TB

Table 16 presents the responses to questions in which statistically significant differences ($p < 0,05$) were found between the male and female respondents in their attitudes and perceptions regarding TB. Generally more female respondents than male respondents felt that successful TB patients stay on treatment because they do not listen to gossip.

Table 16

Gender differences in the knowledge, attitudes and perceptions regarding TB

Question	Response direction		
	Male	**Female**	**Significant value**
Do successful TB patients stay on treatment because they don't listen to gossip.	No	Yes	p<0,007
Do you consider TB to be your greatest danger.	No	Yes	p<0,018
Should people with TB disclose to the community.	No	Yes	p<0,042
TB is an African disease.	Yes	No	p<0,017
Almost all people with TB develop HIV/AIDS.	Yes	No	p<0,011

4.7.2 Differences according to the level of education in the attitudes and perceptions

Statistically significant differences in the responses given by respondents (p<0,05) who have a higher level of education in comparison to those with a lower level of education, are presented in Table 17. Compared to the non matriculants, more of the matriculated respondents felt that there was more TB because people do not comply with their treatment.

Table 17

Differences in attitude and perception according to the level of education

Question	Response direction		Significant
	Not matriculated	**Matriculated**	**value**
People infected with TB delay going to clinics for fear of being HIV positive.	Yes	No	p=0,007
There is more TB because people do not comply with their treatment.	No	Yes	p<0,031
Consider TB to be your greatest danger.	Yes	No	p=0,000

4.7.3 Differences according to experience in assisting a TB patient

Table 18 presents the statistically significant differences (p<0,05) between the responses of respondents who have reported that they have assisted someone (A) with TB and those who reported that they have never assisted (NA) anyone with TB. More respondents who stated that they had previously assisted someone with TB reported that they were willing to act as a DOTS volunteer.

Table 18

Differences according to experience in assisting a TB patient

Question	Yes/No	Response Direction		Significant value
		A	NA	
People who stay on treatment don't listen to gossip.	Yes	No		p<0.000
Only people who are HIV positive get TB.	Yes	No		p< 0,011
All TB patients should be offered a confidential test for HIV/AIDS.	Yes	No		p=0,030
Antiretrovirals help people with HIV/AIDS live longer.	No	Yes		p<0,006
HIV positive people who get infected with TB are likely to die.	Yes	No		p< 0,020
Are you willing to be a DOTS volunteer.	Yes	No		p=0,006
There has been a case of TB in the household.	Yes	No		p=0,000

4.8 Chapter summary

This chapter presents the results obtained in the study and the composition of the respondents' profile. The data is displayed using descriptive statistics in the form of frequency tables and cross tabulations of the significant differences between variables using Pearson's chi square test. Statistically significant differences between the variables of gender, level of education, and experience in dealing with TB, are presented in this chapter. The results suggest that the general level of knowledge regarding the nature of TB is high. The results show that the majority of respondents (92,3%) felt that anyone

was susceptible to TB. The results show that a large percentage of the respondents (60%) perceive the benefits of treating and managing TB by assigning DOTS volunteers to assist TB patients. The vast majority of the respondents (95,0%) reported that not all TB patients should be eligible for a temporary disability grant.

CHAPTER 5

DISCUSSION OF RESULTS

5.1 Chapter Preview

This chapter presents a discussion of the research findings within the context of the reviewed literature pertaining to TB. The theoretical foundation of the study is used to discuss and understand the results of the study.

5.1.1 Knowledge

5.1.1.1 General knowledge of TB

Knowledge of the nature of the risks and preventative actions to avoid contracting a disease are essential for promoting healthy behaviours towards a disease (Ogden, 2004). Although it alone cannot bring about sustained adoption of healthy behaviours, knowledge plays a crucial motivational role in promoting healthy behavioural change and is an important starting point in the behavioural change cycle (Harvey, 1997).

The results suggest that the majority of the respondents are generally knowledgeable about the nature of TB (see *Sections 4.3.1 and 4.3.2)*. The results show that respondents in the present study are generally knowledgeable about the various ways in which TB can be transmitted (see *Section 4.3.2*). When all the questions in the questionnaire regarding knowledge relating to TB were analysed, almost three quarters of the responses were correct and this shows that the general level of knowledge regarding TB in the respondents is high in the study. In South Africa there have been many World Health Organisation sponsored TB awareness campaigns aimed at the global prevention of TB. These campaigns have been targeted at all the clinics in both rural and urban areas (WHO, 2006b).

Despite the good results of the general level of knowledge regarding TB there was nevertheless evidence indicating that a significant proportion of the respondents still lack general knowledge about certain aspects of the disease. This result of the study is similar to the findings of a study carried out in South Africa by Edginton et al. (2002) who found that some of their respondents were poorly informed about TB. In that study there were strong beliefs that TB was as a result of not abstaining after the death of a family member. The results of the study by Edginton et al. (2002) showed that generally the level of knowledge regarding the nature of TB was not convincingly high.

Cross tabulations in the present study show that respondents who had assisted someone with TB (p<0,011) were generally more knowledgeable about TB (see *Section 4.7.3*). People who have experience in assisting someone with TB possibly gain more knowledge about the nature of the disease during the process of taking care of the TB patient. These people gain knowledge about the causes of TB and how it can be prevented and treated successfully. In the present study the cross tabulations carried out also show that respondents who had a higher level of academic education (p<0,031) are more knowledgeable about TB than less educated respondents (see *Section 4.7.2*).

5.1.1.2 Knowledge about the relationship between TB and HIV/AIDS

TB and HIV/AIDS are separate diseases although TB is the most common opportunistic disease that infects people with HIV/AIDS in South Africa. Because of the relationship that exists between TB and HIV/AIDS some people are unable to differentiate between the two diseases (Kelly, 1999). The results of the analysis show that the respondents were generally knowledgeable about the relationship between TB and HIV/AIDS although a reasonably large percentage of the respondents (60,3%) were still ill-informed and believed that almost all TB patients develop HIV/AIDS (see *Section 4.3.3*). According to Bond and Nyblade (2006), TB is perceived as an indication of HIV/AIDS and the visible signs of TB have become a signal for HIV/AIDS. This is believed to have resulted in the stigma attached towards HIV/AIDS being projected towards TB. The literature shows that HIV/AIDS is currently a stigmatised disease which is associated with poverty and

prostitution. From this association of TB with the already stigmatised HIV/AIDS pandemic a dual stigma between TB and HIV/AIDS has developed in South Africa.

From the cross tabulations in this study females were more knowledgeable (p<0,011) about the nature of TB and its relationship to HIV/AIDS than male respondents (see *Section 4.7.1*). Females were more aware of the threat and causes of TB and how the disease differs from HIV/AIDS. This could possibly be attributed to an exposure to health care and medical facilities. Females on average are more likely to visit clinics compared to males. Females are likely to visit clinics to receive contraception and in the process are likely to receive information about HIV/AIDS and TB (Harvey, 1997). A similar result was obtained by Gibson (2005) in a study conducted in Vietnam which found that females were more knowledgeable about the nature and causes of TB than males.

Despite having high levels of knowledge, some people in South Africa still strongly associate TB with HIV/AIDS, viewing them as the same disease, and a dual stigma of the two diseases has been perpetuated (Kelly, 1999). The dual stigma that exists between TB and HIV/AIDS in South Africa can possibly be due to the syndemic interaction that exists between the two diseases (Singer & Claire, 2003). The syndemic interaction between TB and HIV/AIDS is a result of the socio and biomedical relationship between TB and HIV/AIDS. More than 50% of HIV/AIDS patients in South Africa contract TB thus it is the most prevalent cause of death of people infected with the stigmatised HIV/AIDS pandemic (World Health Organisation, 2006a).

Despite the high level of knowledge regarding TB that some of the respondents in the present study possessed, the prevalence of TB defaulters and non compliance to TB treatment is still generally high within the area. However, this finding of a high level of knowledge towards TB contradicts a construct of the Health Belief Model, which states that individuals are more likely to engage in preventative behaviour if they have adequate knowledge and perceive themselves to be susceptible to the disease. According to Pajares (2002) accurate knowledge is a key component in designing interventions although knowledge alone is not enough for creating positively sustained healthier behaviour. The results from the present study show that good knowledge does not always fully translate

into positive health related behaviour as there are other variables that influence health related behaviour and actions. In the present study from the respondents (39,7%), it is noted that the dual stigma towards TB and HIV/AIDS, which is possibly also caused by the syndemic interaction of the diseases, prevents the knowledge that individuals possess from translating into positive health behaviour. Therefore attitudes also need to be considered to provide the crucial link between knowledge and the negative enacted behaviour in the form of non-compliance, stigma and discrimination.

5.1.2 Attitudes

A discussion of the attitudes that were assessed in the study is presented in accordance with the theoretical framework of the Health Belief Model (Rosenstock et al., 1994) and the Social Cognitive Theory (Bandura, 1986). In accordance with the Health Belief Model, a human being's attitudes and perceptions will influence their adoption of a positive or negative health-related action or behaviour.

5.1.2.1 Perceived personal susceptibility

The proponents of the Health Belief Model, state that positive behavioural changes are adopted by individuals who perceive that they are susceptible to a health condition (Harvey, 1997). Perceived personal susceptibility to a disease can influence an individual's enacted behaviour and actions against a disease. The results of the current study show that the vast majority of respondents (92,3%) felt that anyone could get TB and it was a condition anyone within their community could contract because the TB germs are in the air (see *Section 4.4.1*). Just above half of the respondents (52,3%) felt that they were personally susceptible to TB and felt that they took the appropriate preventive measures to avoid infection. This result shows that a considerable percentage of the respondents (48,2%) have lower levels of perceived personal susceptibility towards TB. It is noted, however, that there is a gap between the perceived personal susceptibility that the respondents have towards TB and the aggregate perceived susceptibility of TB amongst all the members of the community. The vast majority of the respondents (92,3%) were aware that there is TB in their community but just above half (52,3%)

perceived themselves to be personally susceptible to TB. This finding could possibly be attributed to the disease stigma attached to TB. According to Joffe (1999) the process of disease stigmatisation allows some individuals to project risk onto other labelled 'immoral' individuals and in the process deny their own risk. An optimistic bias by these individuals allows them to believe that the labelled 'immoral' individuals have a greater likelihood of experiencing negative events than themselves. As a result of perpetuating stigmatising attitudes towards other labelled 'immoral' individuals, some individuals perceive themselves as not being susceptible to contracting a disease. Such individuals perceive themselves to be better, with higher morals, than the other labelled individuals who they feel are more likely to contract diseases due to their immoral and devalued status.

A considerable number of the respondents do not perceive themselves to be susceptible to TB and this exposes them to the danger of contracting the disease: the majority of the respondents are less willing to adopt positive preventative steps to protect themselves against the disease. These results indicate some reasons why there is a high prevalence of the disease in the area, as a worrying percentage (47,2%) of the respondents showed that they are less willing to adopt healthier preventative behaviours towards TB.

5.1.2.2 Perceived severity

The most crucial step for the adoption of healthier behavioural options by individuals is to accept that a disease is fatal (Cassie, 2002). If perceived severity of a disease is regarded to be high then an individual will try to adopt better health-related behaviours to avoid and prevent the spread of the disease (Kelly, 1999). From the view of the Health Belief Model, the process of acknowledging the potential threat of a disease by an individual is a vital cognitive process in adopting healthy related behaviours to avoid infection (Ogden, 2004). For instance, if a person acknowledges that there is TB in the community and that it is fatal to all, then such a person will be more likely to adopt healthy positive related behaviours against the disease such as going for TB testing early to detect and cure the disease in its early stages.

The results of the present study show that a large percentage of the respondents (62,5%) felt that there is no cure at present for XDR-TB (see *Section 4.4.2*). The perception of the large percentage of respondents (62,5%) who felt that currently there was no cure for XDR-TB could possibly be due to the South African media coverage of the disease. National and local media extensively reported on the breakout of XDR-TB in some parts of South Africa such as in the KwaZulu-Natal Province. These media campaigns perpetuated a fear within South Africans of the severity of the disease if it was left untreated (South African TB Vaccine Initiative, 2006). The cross tabulations in the present study show that females have a higher level of perceived severity regarding TB ($p<0,018$) than the male respondents (see *Section 4.7.1*).

The lower levels of the perceived severity of TB in the male respondents of Grahamstown East may possibly be accounted for by the level of unawareness of these males to the seriousness of contracting TB and the personal costs of being infected with TB. These personal costs could possibly include social costs such as isolation and discrimination (Ogden, 2004). The results from the present study show that perceived severity/ level of danger of TB infection is fairly low amongst male respondents. Their perceived personal vulnerability to TB infection is therefore relatively low.

5.1.2.3 Perceived benefits

Individuals adopt health-promoting behaviours if they believe that these will reduce their chances of acquiring a disease (Ogden, 2004). The benefits perceived by the respondents in the study were assessed by identifying the respondent's perceptions of the effectiveness of beneficial preventative measures against TB (see *Section 4.4.3*). More than half of the respondents (60%) in the study felt that assigning DOTS volunteers to assist TB patients would help TB patients in completing their treatment. This result shows that a large percentage of the respondents (60%) believe that assigning DOTS volunteers to assist TB patients can cause more compliance to treatment and contain the spread TB in the community. This result also shows that most of the respondents have a high confidence in the methods of controlling and preventing TB such as the DOTS programme and perceive a benefit in the adoption of such preventative measures. Results

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from international studies show that the implementation of the DOTS programme in developing nations is more effective for treating TB patients at risk of non-adherence than the self administered therapy where the TB patient autonomously takes up treatment without being monitored (Cortioo et al., 2006).

A very large percentage of the local respondents (96,7%) felt that TB patients who completed their treatment should be regarded as positive role models in society and applauded for their accomplishment (see *Section 4.4.3*). This result is similar to a finding by Van der Walt and Swartz (2002) who felt that TB patients can be assisted to adhere to treatment if they are motivated with rewards for treatment completion.

5.1.2.4 Perceived barriers including psychological and environmental barriers

Factors related to the adoption of positive health-related behavioural options that are perceived by the individual as being negative, possibly because of their physical, psychological and financial consequences, can act as barriers for the adoption of healthier related behaviours (Johnson et al., 1990). If individuals perceive that the negative consequences of adopting a healthier related behaviour outweigh the positive benefits of adopting that behaviour, they may not adopt the healthier related behaviour. To understand why people avoid adopting positive healthier related behaviours it is very useful to first identify the negative connotations that are associated with the adoption of these healthier related behaviours (Harvey, 1997). The Social Cognitive Theory identifies forms of barriers that act as impediments for the adoption of positive health related behaviour. These impediments include personal and situational impediments. The personal impediments represent an individual's lack of self belief, whilst the situational impediments are as a result of structures of health care services that impede the adoption of positive health related behaviours (Bandura, 1986).

A fairly large percentage of the respondents (68,8%) believed that TB patients do not necessarily avoid going to clinics out of fear of getting infected with other diseases (see *Section 4.4.4*). The respondents indicated that the immediate fear of contracting other diseases at the clinic was not an immediate threat or barrier for seeking treatment. In the

study just above half of the respondents (51, 3%) felt that a person would not be respected in the community if he/she was sick from TB. The vast majority of the respondents (94, 7%) commented that people infected with TB hide because they are afraid of the negative comments that would be passed by the other healthier people in the community. The existence of social barriers such as discrimination, stigma and personal impediments for treatment for TB patients within the community are evident from the results (see *Section 4.4.4*).

These results confirm other studies such as that carried out by Liefooghe et al. (1997) who found that in the Kuria culture of Kenya the relatives of a TB patient would prevent the TB patient from having contact with other people including their spouse and children. From these results people within this culture might not seek TB treatment at a clinic or disclose their TB status for fear of isolation. The fear of isolation as a result of being infected with TB was a form of personal impediment for the adoption of preventative measures against the disease. A study by Bennstam et al. (2004) found that a young person with TB has a less chance of getting married even after recovery, indicating loss of social status. The reason why TB patients lose respect is because healthy people distance themselves from infected people out of fear of contagion. This fear is exacerbated by their awareness that TB is airborne and can easily spread.

According to Van der Walt and Swartz (2002) people are unable to differentiate between disease and the individual being in people infected with TB. The TB disease is associated inseparably with the person to become their marker and label in social interactions. As a result of this process the stigma towards the disease is developed and sustained. A large percentage of the respondents (69,9%) felt that TB patients would stay on treatment if they were placed in the same queues as people with chronic illnesses such as high blood pressure. The special queues that TB patients stood in were regarded as a marker for TB. This result is similar to the findings of the study by Moller and Erstad (2006) who found that the respondents felt that TB patients would visit the hospitals more regularly if they were placed in the same queues with people with ordinary chronic illnesses. The current hospital requirement which distinguishes TB patient with separate queues is seen as a

barrier for the patients to seek treatment at hospitals. It acts as a situational impediment for TB patients seeking treatment, a situational impediment which perpetuates and sustains the stigma attached to the disease.

A small percentage of the respondents (10,3%) in the study felt that if TB patients were allowed to drink and smoke they would stay on TB treatment. These respondents felt that the inability to smoke and drink by TB patients was in itself a barrier for the patients to disclose their illness and undergo treatment. These results seem to confirm the challenges of TB described in the literature. According to Ogden (2004) individuals cognitively evaluate the positive and negative aspects that accompany a health related behaviour type. The challenge of having to continuously take a large amount of medication for six months and having to stop the consumption of alcohol is seen as creating a personal impediment for TB patients (Kelly, 1999).

The vast majority of the respondents (94,7%) in the study reported that people do not disclose their TB status because they are afraid of what other people might say about them. This compares positively with the study carried out by Edginton et al. (2002) in the Venda culture in the Limpopo Province of South Africa where the results showed that people would hide and not disclose their TB status for fear of isolation. In this culture there was also a belief that a husband and wife could not have sexual intercourse if one of them was infected, consequently they would not disclose their TB status to one another.

In the present study a significant proportion of female respondents (p<0,007) felt that TB patients who do not listen to gossip stood a better chance of successfully completing their treatment (see *Section 4.7.1)*. This result is similar to the findings of Long et al. (2001) who reported that females were more concerned with the social connotations of the disease such as gossip whereas the males were more concerned with the counterproductive nature of the disease such as incurring expenses in medication and possible loss of employment. Perceived barriers need to be addressed so that people within such a society do not negatively perceive people with TB and perpetuate stigma

towards the disease. By addressing barriers to TB treatment the disease can be detected and treated in its early stages thereby preventing the disease from spreading.

5.1.2.5 Cues to Action

Individuals are motivated and influenced to adopt positive health-related behaviours by factors that include visible physical symptoms of the disease, and external environmental motivators such as the media and campaigns (Harvey, 1997). When individuals visibly observe the symptoms and the characteristics of a disease within an infected person they are motivated to adopt positive health related behaviours to avoid contracting the disease. The media and health related campaigns can raise awareness of the nature of the disease among people who are not in contact with the disease. The results show that almost two thirds of the respondents (67,7%) have not been in direct contact with TB and therefore may not perceive TB as an immediate threat in their area (see *Section 4.4.5*). This result could suggest that the majority of respondents do not acknowledge TB as a problem in their area since they do not perceive the disease as an immediate threat to themselves.

A small percentage of the respondents (32,3%) had direct experience of TB in their household; this possibly suggests that the larger percentage of respondents do not acknowledge that some people within their community are infected with TB. Just less than half of the respondents (45,6%) reported that they had visited someone with TB in hospital (see *Section 4.4.5*). The results suggest that there are not enough cues to action to promote the adoption of positive health related behaviours against TB within the area investigated. Stigma and discrimination towards the disease may possibly be the reason why some people infected with TB within the community tend not to disclose their status. The Health Belief Model suggests that if more people who are infected with a disease come out into the open, more people in the community would become aware of the disease and its negative consequences. Such awareness acts as a cue to action to encourage other members in the community to adopt positive healthier preventative behaviours against the disease.

5.1.2.6 Self-efficacy

Self-efficacy refers to the self belief by an individual that he/she is able to successfully acquire and sustain new health related behaviours (Rosenstock et al., 1994). In the present study just above half of the respondents (52,8%) reported that they felt that they would be able to successfully cope with TB if they were ever exposed to the disease (see *Section 4.4.6*). Nevertheless, the results also showed a worrying percentage of the respondents (47,2%) who projected low levels of self belief in coping with the disease. This result may possibly be due to lack of education, knowledge and cues to action. The results showed that the respondents who matriculated and had a higher level of education ($p=0,000$) had less fear of contracting TB and were more confident in adopting preventative health related behaviours against TB (see *Section 4.7.2*). These results suggest that individuals who had matriculated and had a higher level of education had a greater level of self-efficacy in adopting positive health related behaviours against the disease. Understanding the concept of self-efficacy is very important because it is a useful predictor of people's future accomplishments. Instead of having a greater focus on people's previous attainments, knowledge and skills as the predictors of their future behaviour, the concept of self-efficacy is believed to be a good predictor of success. According to Pajares (2002, p. 67), "there is no amount of self belief alone with no skills or knowledge that can ultimately produce success of the adoption of a given behaviour".

According to Bandura (1986) skills training is the most effective applied intervention when self-efficacy is very low. People need to receive an education and acquire skills in order for them to feel confident and competent to successfully engage in health related behaviours. In the area studied the level of literacy and education is generally low and this may account for a fairly large percentage of the respondents (52,8%) not being fully confident that they are able to protect themselves against TB (Public Service Accountability Monitor, 2007). For individuals with a strong sense of personal agency and self-efficacy challenging tasks are seen as opportunities to master challenges rather than threats to be avoided (Bandura, 1986).

5.1.2.7 Attitudes towards assisting people with TB.

The values and beliefs held about TB within a community must be clearly understood for there to be an effective and sustainable control of the disease (Khan, Walley, Newell & Imdad, 2000). The values and beliefs held within a group of people influence the types of behaviours those people adopt. In the present study just above half of the respondents (55,1%) reported that they had never assisted a person with TB (see *Section 4.4.7*). Just less than half of the respondents (45,6%) reported that they had visited a person who they knew had TB, whilst more than half of them (54,4%) reported that they had never before visited a person infected with TB. This finding is worrying considering that there is need for an urgent attention towards addressing the TB problem within most of the South African communities (Van der Walt & Swartz, 2002). The majority of the respondents have never assisted people with TB and this may also be contributed to by the disease stigma and discrimination attached to TB. The disease stigma attached to TB may possibly be as a result of the dual stigma that exists between TB and HIV/AIDS. Possibly as a further result of the disease stigma attached towards TB, labelled persons with TB are perceived as deviant and immoral by the other individuals. People infected with TB may possibly be blamed for contracting the disease and because of their negligence expose other people in society to risk of infection.

In the present study a fairly large percentage of the respondents (63,1%) reported that they were willing to act as DOTS volunteers to assist people infected with TB (see *Section 4.4.7*). This result also shows that within the investigated community there is a desire to assist TB patients but the people do lack the structural support and motivation to become DOTS volunteers. This finding might possibly be attributed to a lack of motivating factors that encourage and foster a culture of volunteerism towards assisting TB patients. According to Merrell and Williams (1999), having hopes of future employment, recognition and remuneration are all direct motivating factors to encourage participation in voluntary community health care work. The National TB Control Programme of South Africa on the contrary does not fully recognise voluntary community health care workers as part of the South African Primary Health Care System (Erstad, 2006). In the community investigated the SANTA offices that used to provide

voluntary community health care workers with stipends were closed down in 2005. The closure of SANTA offices within the area may have created a lack of support and persuasion for more people to act as TB volunteers within the area. People within the area possibly feel no incentive to become a TB volunteer.

Cross tabulations showed that respondents who had an experience in dealing with TB in their households were more willing to become DOTS volunteers (see *Section 4.7.3*). However, in South Africa it is believed that more than half (52%) of the voluntary community health care workers for TB are individuals that come from households that have had a TB patient (Erstad, 2006). The results of the present study tend to show that people who have had an experience and exposure of TB in their families are more empathetic and willing to act as TB volunteers. This may possibly be as a result of the direct exposure and experience such individuals would have regarding the disease. The exposure to the disease may, as a result, act as a cue to action for such individuals to adopt positive health related behaviours and assist in preventing the spread of the disease.

5.1.2.8 Attitudes towards the TB temporary disability grant

The study shows that the vast majority of the respondents (95,0%) reported that not all TB patients should receive a temporary disability grant. These respondents possibly felt that this would minimise cases of people who deliberately infect themselves with TB to receive the grant (see *Section 4.4.9*). According to Nattrass (2005), people deliberately get infected with TB to receive the temporary disability grant and this grant acts as a perverse incentive. According to Kumaranayake and Sinanoviv (2006) there are some TB patients in South Africa who are believed to be defaulting on their TB treatment because they fear that they would lose the grant if they get cured of TB. Some unemployed youths are believed to be exposing themselves to TB so that they can receive money through the temporary disability grant. In the present study the majority of the respondents (84,1%) reported that it was wrong for people to deliberately get infected with TB to be eligible for the TB temporary disability grant. This result from the study confirms the allegation that some people expose themselves to TB to receive the grant and such people perceive the grant as an indispensable source of income.

Just above half of the respondents (55,6%) felt that people on the TB temporary disability grant should do some work and not be idle and give society the burden of care. The respondents possibly felt that the grant gave some perverse incentives for TB patients to remain sick. As a result of the grant simply being given to all TB patients, the respondents might have felt that the grant would cause all marginalised communities to seek the grant to alleviate poverty.

A substantial percentage of the respondents (61%) reported that only TB patients co-infected with HIV/AIDS can access a temporary disability grant. This result may be attributed to the prevalence of HIV/AIDS and a high perceived severity of HIV/AIDS by the respondents in the study. According to the findings of the study, HIV/AIDS is perceived to be incurable and pose a major threat to society (see *Section 4.4.8*). In the study a small percentage of the respondents (37%) reported that they felt that the majority of TB patients spend their temporary disability grants on liquor and cigarettes. According to Kumaranayake and Sinanoviv (2006) some of the people who receive a TB temporary disability grant use these funds to support and sustain their families.

5.1.3 Judgmental dimensions of attitudes towards people infected with TB

According to Joffe (1999), stigma and discrimination have a major negative impact on the lives and experiences of most TB patients and the people around them. The stigma not only affects TB patients but also negatively affects the control and management of the disease. Individuals that perpetuate stigmatising behaviours towards people infected with TB are more likely to have a poor general knowledge of TB and lack the general experience of interacting with TB patients (Joffe, 1999). Stigmatising individuals allows the blame for the spread of the disease to be placed on others. These people perceive TB patients as out-groups and try to avoid any contact with infected people. This attitude of ignorance instead exposes these individuals to actual risk of contracting the disease.

In a study conducted in South Africa by Cassie (2002) it was found that the stigma and discrimination associated with TB in both urban and rural communities played an important role in the spread and control of the TB epidemic. In the present study the

majority of the respondents held strongly stigmatising attitudes towards people infected with TB (refer to *Sections 4.4.10*). The majority of the respondents (90,4%) blamed TB patients for contracting the disease due to negligent behaviour and reported that it was mostly the irresponsible people who were non-compliant in their treatment and who should be blamed for the spread of TB. This result also shows that the majority of the respondents are capable of shunning TB patients and seeing them as unworthy of respect because of their supposedly irresponsible behaviour. The results show that a large percentage of the respondents (71,2%) reported that people who get TB through smoking and drinking get what they deserve. This result confirms the results of the study conducted in Grahamstown by Moller and Erstad (2006) who found that most of the respondents felt that TB patients who are irresponsible and default treatment are to be blamed for the spread of the disease thus exposing society to risk. The concept of blame is a recurring result in the present study and this shows that blaming is a crucial determinant for stigma and discrimination to exist.

The majority of the respondents (77,9%) felt that people who get XDR-TB or MDR-TB as a result of non-compliancy need to be censured for this and get what they deserve (see *Section 4.4.10*). This result is worrying because it suggests a negative perception towards drug resistant TB patients held by the respondents thereby perpetuating stigma. This stigma towards drug resistant TB patients could possibly be perpetuated by the majority of the respondents (77,9%). This in turn could result in an unwillingness to seek treatment by TB patients thus enabling further spread of the disease in the area. The results show that most of the respondents (71,2%) attach stigma towards TB and hold irresponsible people accountable for the spread of the disease in their community. The reason why TB is possibly stigmatised is because the disease is associated with poverty, dirt, poor nutrition and bad health practices such as smoking (Barker & Palmer, 2006). Thus, these social factors are associated with promotion of stigma and discrimination of the disease.

5.1.4 Judgmental dimensions of attitudes towards people co- infected with TB and HIV/AIDS

In Africa HIV/AIDS is regarded as the single most determining factor contributing to the recent increases in incidence of TB (Kelly, 1999). Up to 50% of all reported deaths from HIV/AIDS are related to the TB-HIV/AIDS co-infection. Most HIV/AIDS patients contract and die from TB related illnesses (World Health Organisation, 2006a). The sysdemic interaction between the two diseases in South Africa has resulted in the prevalence of both diseases (Singer & Claire, 2003). Results from the present study show that the general level of the stigma attached to HIV/AIDS is high according to the AIDS Related Stigma Scale (see *Sections 4.5 and 4.6*). The stigma that exists towards HIV/AIDS is a result of the perceived modes of transmission of the disease which include promiscuity which is supposedly immoral conduct (Kelly, 1999). The results from the present study suggest that people who are infected with HIV/AIDS are afraid to come out because they are blamed for contracting the disease and labelled as being promiscuous. The results of the study suggest that there is a social stigma attached to HIV/AIDS.

A significant proportion of the respondents (p=0.003) who had assisted a person with TB before reported that only people with HIV/AIDS get TB (see *Section 4.7.3*). This result shows that the majority of the respondents who had a direct experience in assisting people with TB strongly felt that TB and HIV/AIDS are inseparable twin diseases. This result possibly suggests an existence of a dual stigma between TB and HIV/AIDS. According to Bond and Nyblade (2006) the current stigma surrounding HIV/AIDS is seen as a cause of problems for TB sufferers in communities that strongly view HIV/AIDS as a burden and stigmatise the epidemic. The stigma that is attached to HIV/AIDS is also being transferred and passed on to people infected with TB. This process of transferring stigma from one disease to another creates a dual stigma for both diseases. In the study the majority of the respondents (88,9%) felt that all TB patients should be offered a confidential HIV/AIDS test (see *Section 4.4.8 and 4.7.3*). This result strongly suggests that the majority of the respondents felt that people who have TB also have HIV/AIDS.

In the study just above half of the respondents (51,1%) felt that there were currently more cases of TB because of the HIV/AIDS pandemic. A very large percentage of the respondents (96,6%) felt that if people were aware of their HIV/AIDS status their TB could be treated more successfully (see *Sections 4.4.8*). The results from the study show that just above half (51,1%) of the respondents blame HIV/AIDS for the spread of TB and vice versa. The findings in the study show that some of the respondents attach a dual stigma towards TB and HIV/AIDS. Results show that there are negative judgemental attitudes towards people infected with TB and HIV/AIDS. The results of the study also indicate that the recent emergence of the stigmatised HIV/AIDS infection has caused the stigma associated with TB to re-emerge. This dual stigma attached to TB and HIV/AIDS has possibly become a barrier for TB patients and HIV/AIDS patients to seek treatment. Individuals who do not seek treatment are blamed for placing the rest of the society at risk and as a result of this they do not seek treatment or disclose their status to other people. The possible reason why such people do not disclose their status or seek treatment is because they have fears of possessing a reduced social status and receiving negative reactions. The negative judgemental attitudes towards TB need to be removed so that there can be better TB control to reduce death from TB and the spread of drug resistant TB.

5.2 Chapter summary

This chapter provides a discussion of the results found in the study using the components of the Health Belief Model (Rosenstock et al., 1994) and Bandura's (1986) Social Cognitive Theory. Within this chapter other studies carried out in similar areas to the study are referred to and compared with the results of the present study. The findings of the attitudes, perceptions and knowledge regarding TB are discussed. The findings suggest that there is a high general level of knowledge regarding the nature of the disease. Statistical cross tabulations ($p < 0,031$) revealed that the respondents who had received a higher level of education and had matriculated showed greater knowledge regarding the nature of the disease. This result possibly suggests that a higher level of education allows individuals to be more informed about the nature of TB. Cross tabulations ($p < 0,011$)

carried out showed that females were more knowledgeable about the nature of TB than male respondents. This result possibly could suggest that females were more informed about TB because of their greater exposure to and frequency of visiting medical institutions. Cross tabulations suggested that the respondents who matriculated and had a higher level of education (p=0,000) had a greater level of self efficacy and this may possibly be attributed to such individuals developing greater levels of confidence generated from their knowledge. Cross tabulations show that a significant proportion of the respondents (p=0.003) who had assisted a person with TB before reported that HIV/AIDS and TB were inseparable diseases. This result of the study possibly indicates that a dual stigma has developed between TB and HIV/AIDS

CHAPTER 6

CONCLUSION

6.1 Chapter preview

This chapter provides a summary of the research findings and the limitations of the study. Thereafter, the recommendations for future research and interventions are discussed and suggested. This chapter ends by highlighting the final conclusion of the study.

6.2 Summary of research findings

The primary objective of the study was to describe and explore the present attitudes, perceptions and knowledge regarding TB in Grahamstown East. The secondary aim of the study was to explore these attitudes and perceptions towards TB in relation to the existence of the HIV/AIDS pandemic. The results show that despite people having a fairly good level of knowledge of TB, the problem of TB is still pertinent. This is evident in the attitudes revealed in the study and the emergence of more dangerous drug-resistant strains of TB , namely MDR-TB and XDR-TB, in South Africa. Knowledge needs to be seen as a starting point for the adoption of healthy behaviours. The results show that knowledge alone is unable to sustain the adoption of positive health related behaviour. The attitudes and perceptions held by people are crucial elements that determine the adoption of positive health related behaviours. Having an understanding of the attitudes and perceptions held by society regarding TB can allow us to face the challenges that perpetuate the spread of TB in society.

The study shows that there is a stigma attached to TB and this stigma acts as a barrier for people infected with TB to seek treatment. The barrier is in the form of personal impediments and situational impediments. The personal impediments are in the form of low levels of self-efficacy (self belief) in coping with TB. The situational impediments in the adoption of preventative behaviour against TB are in the form of structural challenges

caused by some of the health care facilities in some areas of South Africa. The findings of the study show that the stigma attached to TB is a result of how the disease is negatively perceived. The syndemic interaction between TB and HIV/AIDS has also been found to cause the stigma that is attached to TB.

From the results it is suggested that TB has been re-stigmatised in these present times due to its association with the already stigmatised HIV/AIDS pandemic. The results of the study suggest that a dual stigma has developed between TB and HIV/AIDS. This dual stigma has mainly been caused by the high rate of co-infection between TB and the stigmatised HIV/AIDS pandemic. The study also shows how demographic factors influence the knowledge, attitudes and perceptions towards TB. In the study males have been seen to be greater stigmatisers and potential perpetrators of discrimination towards people infected with TB. The results suggest that more males generally have lower levels of experience and knowledge regarding TB. This may possibly be a reason why males stigmatise the disease more than females. Respondents who had matriculated were seen to be generally more knowledge about TB and its relationship to HIV/AIDS. The results of the study also show that the respondents who had an experience in assisting TB patients held less stigmatising attitudes towards people infected with TB. This result suggests that people who have experience in assisting TB patients possibly gain a general awareness and social tolerance of the disease. The results suggest that in the community investigated there is a weak support system that encourages the culture of volunteerism through becoming voluntary TB community health care workers or DOTS volunteers. The results also suggest however that there maybe a lack of incentives to motivate people to become DOTS volunteers. People may lack the motivation and will to become DOTS volunteers in the area without a sound recognition and appreciation system by National TB Control Programme of South Africa. From the results of the study it can be seen that there is generally a negative perception towards the TB temporary disability grant. This grant is believed to be fuelling perverse incentives for some people to remain ill from TB and to continue being eligible for the grant.

The study shows that perceived personal susceptibility towards TB was generally low amongst the respondents. This was felt as being accounted for by the stigma attached to TB. The stigma attached to TB possibly made individuals project risk onto the other 'immoral' individuals and in turn deny their own risk. Perceived benefits in the adoption of positive health related behaviour against TB were generally high in the study. However, the results show that the perceived severity of TB was generally low especially in the male respondents. This result was possibly due to their limited exposure and frequency of visiting health care facilities. It was perceived that women visit health care facilities more often to seek contraceptives and for general health matters. The results show that the level of self-efficacy in those respondents who had received a lower level of education was generally low and this may have possibly have been accounted for by a lack of awareness and knowledge of the disease.

6.3 Value of the study

The knowledge, attitudes and perceptions discussed in the study provide valuable insight regarding the role that these factors play in influencing health related behaviour towards TB in times of HIV/AIDS in an area such as Grahamstown East. The theory of the Health Belief Model (Rosenstock et al., 1994) and Bandura's (1986) Social Cognitive Theory were applied to explore and describe health-related behaviours. The research contributed to the psychological verification of these theories. The results of the study contributed to confirmation and validation of other earlier studies regarding TB conducted in similar areas. The study demonstrated the importance of understanding the knowledge, attitudes and perceptions regarding TB for the control and management of the disease in South Africa. The findings of the study added to the valuable body of knowledge regarding the social nature of TB and its relation to HIV/AIDS in South Africa and other similar developing nations.

6.4 Shortcomings of the study

The design of the study gave rise to some shortcomings. There were limitations in the sampling process owing to the design of the study. The household survey excluded

people who worked at night or who left their homes in the morning to go to work and returned in the evening. This shortcoming was further worsened by carrying out the household survey during week days when most working people were at work. Therefore some requisite respondents were lost from the study.

Restricting the study to respondents older than 18 years limited a range of findings. Younger respondents would have added valuable insights to the study enhancing the generalisability of the findings of the study to a larger population. Despite having ethical considerations as the main factor influencing the selection of respondents older than 18 years old, a consultative approach could have been adopted to include minors in the study. Consultation could possibly have been made in the presence of the parents or legal guardians of minor respondents.

Qualitative methods could have also been used in the current study to complement the quantitative approach adopted. The use of a qualitative approach in the form of a focus group in the main study would have possibly enriched the results of the study. A focus group would have enabled the respondents to be more open and honest about their feelings and perceptions regarding certain sensitive issues. The focus group would have also given the respondents time to be familiar with the researcher and be free to easily open up. On the other hand, the household survey was a once off process making it impossible to gather longitudinal findings that could reflect possible changes in the population over time. People's attitudes and perceptions are prone to alter over time as their contextual circumstances change. Conducting the study using a longitudinal design would have possibly provided a broader understanding of the perceptions investigated.

Another shortcoming of the study was that the face-to-face interview survey questionnaires that were adopted lacked flexibility. This was posed by the use of structured questions that possibly inhibited the obtaining of useful unstructured responses from the respondents. More open-ended questions could have been included in the questionnaire to allow the respondents to broadly express their opinions providing an opportunity for more valuable issues to be raised.

6.5 Recommendations

The recommendations presented are divided into recommendations for future studies and those regarding behavioural and educational interventions to contain the challenges posed by the TB epidemic in these times of HIV/AIDS.

6.5.1 Recommendations for future research

Further research is needed for the development of educational and behavioural change programmes aimed at changing people's behaviour towards TB within the society. The study shows that many people have re-stigmatised TB due to its association with HIV/AIDS. Further research needs to be carried out in psychology to have a greater understanding of the social factors that create and sustain disease stigma. Research is also needed to find out what could improve the treatment adherence of TB patients by removing the barriers that prevent them from seeking treatment. This research can possibly be in the form of investigating the causes of non adherence to TB treatment.

There is a need to manage the current dual stigma that exists between TB and HIV/AIDS. Further research needs to be carried out on ways of improving the DOTS programme in South Africa so that it does not end up as a barrier (situational impediment) for TB patients to complete their treatment. Psychology can play a crucial role in further understanding and assisting health care providers while local government and local non-governmental organizations (NGOs) can play a part through creating local environments conducive to controlling TB in these times of HIV/AIDS. Research needs to be carried out using the constructs of the Social Cognitive Theory and the Health Belief Model to understand the dynamics of these various constructs in the process of adjusting behaviour. Research in the future should explore other approaches of inquiry to promote healthy behaviour change such as the use of appreciative inquiry and cognitive behavioural approaches.

In future studies the quantitative methods adopted in this study could be complemented with qualitative methods so that a deeper level of understanding is obtained of the attitudes and perceptions towards TB. The qualitative methods can be in the form of a

focus group. A more in-depth study in the form of a doctoral thesis could be utilised to include additional theoretical approaches. The present research could be supplemented by additional analysis and theories to provide an in-depth understanding of the knowledge, attitudes and perceptions towards TB. The present research should be considered as a starting point for the psychological investigations of the psychosocial nature of TB in these times of HIV/AIDS.

6.5.2 Recommendations for interventions

After analysing and describing the findings of the study the researcher has been able to propose some recommendations that could be adopted to improve behavioural change approaches towards TB. These are presented below.

1. Accurate knowledge should be provided by ensuring that educational materials that are produced are appropriate for the various individuals' levels of literacy. Good knowledge is an initial stepping stone for the adoption healthier attitudes and behaviours. In the present study individuals who lacked a higher level of education had lower levels of self-efficacy in adopting healthier attitudes and behaviours towards TB.

2. Most people in underdeveloped societies would benefit from skill-based interventions such as those that enhance self-monitoring skills against diseases such as TB. Such skills empower people. Developing people's skills can enhance their level of self-efficacy in adopting positive healthier behavioural options against TB. In the present study the general level of reported self-efficacy skills was low.

3. There is a need to design an efficient system that appreciates and recognises more substantively the voluntary community health care workers (DOTS volunteers). In the present study most of the respondents were generally not willing to become DOTS volunteers because they lacked the incentive and motivation. DOTS volunteers are not fully recognised and appreciated as being part of the South African Primary Health Care System.

4. Local people affected with TB should come forward and be used to facilitate awareness of the immediacy of the threat that TB poses. This could possibly create cues to action for the adoption of positive health related behaviour against TB. This may increase the general level of awareness people have about the disease. Role models that have survived the disease, such as Nelson Mandela and Desmond Tutu, should be put forward in TB awareness campaigns. Giving a human face to the problem of TB in the community can influence other members in the community to acknowledge the perceived threat and severity of the disease. In the present study the perceived threat and severity of TB was generally low especially amongst the male respondents.

5. In TB prevention interventions the severity of MDR-TB and XDR-TB should be emphasised to increase the level of perceived personal susceptibility and threat of the disease. Healthy people should be made aware that these drug resistant strains of TB can easily be contracted. In the study the general level of perceived susceptibility to TB was low amongst the respondents.

6. TB prevention interventions should adopt different approaches for males and females owing to the differing approaches they take regarding health-related actions and behaviours. In the present study males were seen to possess more stigmatising attitudes than those of the female respondents.

7. There is a need to improve the administration of the TB temporary disability grant. This grant is believed to be an indispensable source of income by the marginalised poor. In the present study it was suggested that the grant creates perverse incentives for some TB patients to default treatment and remain sick.

6.6 Conclusion

The aims of this study have been achieved since the attitudes, perceptions and knowledge regarding TB in Grahamstown East have been fully investigated. The study has gone some way to provide an understanding of the nature of the attitudes and perceptions regarding TB in the current times of HIV/AIDS. The research shows how psychological

theories can be applied to explain and describe observed health related behaviour. The study is able to show the psychological function behind the adoption of health related behaviour within a society. It further provides recommendations for future research in this area. Recommendations for the development of health related interventions in South Africa have also been presented. The study has added to the overall development of quantitative research in TB and HIV/AIDS research in South Africa.

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APPENDIX A

Grahamstown East/Rhini, Makana, Household Survey 2007

SURVEY OF QUALITY OF LIFE AND HEALTH

In Grahamstown East/Rhini, Makana 2007

DRAID: *{Office Use}*			*Questionnaire No:* *{Office Use}*	
INTRODUCTION				
Hello, I'm …………………………………….. from DRA. We are conducting a study for Rhodes University to learn more about how people in Grahamstown East think about quality of life and health issues. We should like to put some questions to you. All households in Grahamstown East have an equal chance to be in the study. The answers you give will be treated confidentially. This is not a test. There are no right or wrong answers. We just would like to hear your views. The answers will be put together in groups, such as young women, older men, and people living in different neighbourhoods, etc., so that answers cannot be traced to individuals. Within a year results of the study will be reported back to residents through the local newspapers.				
A1. Sampling Area	1 = Fingo; 2 = Tantyi; 3 = Xolani; 4 = Hlalani; 5 = Makanaskop/Joza; 6 = Ext 1 (Thatha); 7 = Ext 2 (Pumlani Ext 2); 8 = Ext 3 (Pumlani Ext 3); 9 = Ext 4; 10 = Ext 5; 11 = Ext 6; 12 = Lingelihle formal 13 = Ext 7; 14 = Ext 8; 15 = Ext 9; 16 = Vukani I; 17 = Vukani II; 18 = Transit camp; Informal housing: 19 = Phaphamani; 20 = Eluxolweni; 21 = Zolani; 22 = Ethembeni (Ext 7 informal); 23 = Hlalani informal; 24 = Mnandi (between Ext 2& 3);			
A2. Stand Diary Number:				
Interviewer CODE				**Date Of Interview** *[dd/mm/yy]*
FOR SUPERVISOR / OFFICE USE ONLY:				
Name of supervisor			**Date checked** *[dd/mm/yy]*	
Name of quality controller			**Date checked** *[dd/mm/yy]*	

Name of 1st capturer		Date captured *[dd/mm/yy]*	
Name of 2nd capturer		Date captured *[dd/mm/yy]*	

ENUMERATOR DECLARATION

I declare that I have asked this entire Questionnaire as it is laid out and as I have been briefed.

I declare that all the responses and answers recorded by me in this Questionnaire were given to me by the correct respondent. This Questionnaire has been fully checked by me.

PLEASE PRINT:

First name	
Surname	
Signature	
Date	

A BACKGROUND INFORMATION ON HOUSEHOLD

May I first ask some questions about this household?

1.1	**How many people live in this household (e.g., share food and expenses and spend at least four nights a week in the household)? ____**	Write in Number:_____	
1.2	**How many members of this household are children 14 years or younger? ___**	Write in Number:_____	
1.3	**Is the household head a man or a woman?**	1 = Man/male 2 = Woman/female	
1.4	**Are any members of this household staying elsewhere because they are attending school or university away from home**	0 = 0 1 = 1 2 = 2 3 = 3 4 = 4 5 = more	
1.5	**Are any members of this household staying elsewhere because they are looking for work or working away from home?**	0 = 0 1 = 1 2 = 2 3 = 3 4 = 4 5 = more	
1.6	**Is anyone in this household employed in a full-time job?**	0 = 0 1 = 1 2 = 2 3 = 3	

1.7	Is anyone in this household employed in a part-time or casual job?	0 = 0 1 = 1 2 = 2 3 = 3	
1.8	Does this household receive any social grants or welfare benefits:		
1.8.1	Old-age pension	1 = Yes 2 = No	
1.8.2	Permanent disability grant	1 = Yes 2 = No	
1.8.3	Temporary disability grant	1 = Yes 2 = No	
1.8.4	Child support grant	1 = Yes 2 = No	
1.8.5	Foster care grant	1 = Yes 2 = No	
1.9	Does this household receive Welfare/ food parcels	1 = Yes 2 = No	

Migration

2.1	What do people living here call this area/neighbourhood?
	WRITE IN NAME _____

2.2	Do you know what Ward this is?
	WRITE IN WARD NUMBER OR COUNCILLOR _____

2.3	How long has this household been staying in this area?	1 = 1-2 years 2 = 3-5 years 3 = 6-10 years 4 = 11-20 years 5 = over 20 years	

2.4	Where was this household staying before?	1 = Never moved, always staying in this area 2 = Other formal housing area in Grahamstown East/Rhini 3 = Other informal housing area in Grahamstown East/Rhini 4= Transit camp in Grahamstown East/Rhini 5 = Other area of Grahamstown outside of Rhini 6 = Rural area/farm near Grahamstown 7= Other area of Eastern Cape 8 = Other South African province 9 = Outside South Africa	

2.5	If the household had a choice, where would it prefer to stay?	1 = Prefer to stay here; don't want to move 2 = Fingo	

		3 = Tantyi	
		4 = Xolani	
		5 = Hlalani	
		6 =Makanaskop/Joza	
		7 = Ext 1 (Thatha)	
		8 = Ext 2 (Pumlani Ext 2)	
		9 = Ext 3 (Pumlani Ext 3)	
		10 = Ext 4	
		11 = Ext 5	
		12 = Ext 6	
		13 = Lingelihle formal	
		14 = Ext 7	
		15 = Ext 8	
		16 = Ext 9	
		17 = Vukani I	
		18 = Vukani II	
		19 = Informal housing area	
		20 = Extension 10 to be built	
		21 = Grahamstown West	

Housing

3.1	Is this a formal (brick/cement block), informally built shack, or a traditional pole & mud house?	1 = Formal 2 = Informal (shack) 3 = Traditional mud dwelling	
3.2	Is this an RDP house?	1 = Yes 2 = No	
3.3	How many rooms does this household occupy (include kitchen but exclude toilet/bathroom):	1 = 1 2 = 2 3 = 3 4 = 4 5 = 5 6 = 6 and more	
3.4	Does this household own or rent this dwelling?	1 = Own 2 = Rent	
3.5	Has the roof leaked in the past year?	1 = Yes 2 = No	
3.6	Has this dwelling ever been flooded when it rained in the past year?	1 = Yes 2 = No	
3.7	Is the property fenced?	1 = Yes 2 = No	
3.8	Does this household grow vegetables for own use or to sell?	1 = Yes, only for own use 2 = Yes, own use and sells surplus	

| | | 3 = Yes, only to sell | |
| | | 4 = No | |

Assets

4.1	Does this household have any of the following in working condition?		
A	Electricity	1 = Yes 2 = No	
B	Radio	1 = Yes 2 = No	
C	Television	1 = Yes 2 = No	
D	Car in working order	1 = Yes 2 = No	
E	Refrigerator	1 = Yes 2 = No	
F	Hi-fi or music centre	1 = Yes 2 = No	
G	Telephone/ cellphone	1 = Yes 2 = No	
H	Computer	1 = Yes 2 = No	

4.2	Access to household services		
4.2.1	What type of toilet facility is available in this house?	1 = No toilet	

		2 = Bucket toilet	
		3 = Regular pit latrine	
		4 = A VIP (ventilated pit latrine) toilet	
		5 = Flush toilet	
4.2.2	**What is the main water source for this household?**	1 = No piped water 2 = Piped water more than 200 metres away 3 = Piped water on street within 200 metres 4 = Piped water in yard 5 = Piped water inside the house	

4.3	Does this household receive:		
4.3.1	Free basic water	1 = Yes 2 = No	
4.3.2	Free basic electricity	1 = Yes 2 = No	

4.4	Does this area have:		
4.4.1	Street lighting	1 = Yes 2 = No	
4.4.2	Tarred roads	1 = Yes 2 = No	
4.4.3	Graded gravel roads	1 = Yes 2 = No	
4.4.4	Refuse removal	1 = Yes 2 = No	

Neighbourhood

How satisfied is this household with how things are in this area of Grahamstown East/Rhini? Are you very satisfied, satisfied, dissatisfied or very dissatisfied that …….			
5.1	People in this area are friendly	1 = Very satisfied 2 = Satisfied 3 = Dissatisfied	

		4 = Very Dissatisfied	
5.2	**People in this area help each other without having to be asked**	1 = Very satisfied 2 = Satisfied 3 = Dissatisfied 4 = Very Dissatisfied	
5.3	**People trust their neighbours**	1 = Very satisfied 2 = Satisfied 3 = Dissatisfied 4 = Very Dissatisfied	
5.4	**Refuse is removed regularly**	1 = Very satisfied 2 = Satisfied 3 = Dissatisfied 4 = Very Dissatisfied	
5.5	**There have been no interruptions in water supplies in 2007**	1 = Very satisfied 2 = Satisfied 3 = Dissatisfied 4 = Very Dissatisfied	
5.6	**Ward councillors report back regularly**	1 = Very satisfied 2 = Satisfied 3 = Dissatisfied 4 = Very Dissatisfied	
5.7	**Residents get value for their rates**	1 = Very satisfied 2 = Satisfied 3 = Dissatisfied 4 = Very Dissatisfied	
5.8	**There are no stray animals**	1 = Very satisfied 2 = Satisfied 3 = Dissatisfied	

		4 = Very Dissatisfied	
5.9	**There is not a lot of crime in the area**	1 = Very satisfied 2 = Satisfied 3 = Dissatisfied 4 = Very Dissatisfied	

5.10	**Has this household experienced a housebreaking or burglary in the past year?**	1 = Yes 2 = No	
5.11	**Has any member of this household experienced a serious personal violent crime (e.g., murder, rape, assault) in the past year?**	1 = Yes 2 = No	

Income and savings

6.1	**What are the household's four most important sources of income?** **READ OUT OPTIONS** **(NAME UP TO 4)**	1 = Old-age pension 2 = Disability grant 3 = Child grant 4 = Income from a regular job 5 = Income from casual/odd jobs 6 = Income from own business, rent 7 = Remittances from working members 8 = Money from relatives living elsewhere 9 = Money from boy/girlfriends 10 = Begging 11 = Collecting and selling 12 = Money lenders Other (Specify)_____	
6.2	**Approximately what is this household's average monthly income?**	1 = R0-R100 2 = R101-200 3 = R201-500 4 = R501-R750 5 = R751-R1000 6 = R1001-R1500 7 = R1501-R2000 8 = R2001-R3000 9 = R3001-R4000 10 = R4001-R5000 11 = R5001-R6000 12 = R6001 –R7000 13 = R7001+	

6.3	What monthly income does this household need to get by?	1 = R0-R100	
		2 = R101-200	
		3 = R201-500	
		4 = R501-R750	
		5 = R751-R1000	
		6 = R1001-R1500	
		7 = R1501-R2000	
		8 = R2001-R3000	
		9 = R3001-R4000	
		10 = R4001-R5000	
		11 = R5001-R6000	
		12 = R6001 –R7000	
		13 = R7001+	
6.4	Does anyone in this household belong to a stokvel or savings club?	1 = Yes 2 = No	
6.5	Does anyone in this household belong to a burial club?	1 = Yes 2 = No	
6.6	To whom does this household turn if it has a money problem?	1 = Relatives	
		2 = Friends/neighbours	
		3 = Employer	
		4 = People at work	
		5 = Church people	
		6 = Stokvel/savings club	
		7 = Money lenders	
		8 = Welfare	
		9 = Not applicable (no money problems)	
		Other (Specify)_____	

6.7	Does anyone in this household work at Rhodes University as permanent staff or as a casual worker?	1 = Permanent staff 2 = Casual worker 3 = No	
6.8	Has anyone in this household had a temporary job or earned money during the National Arts Festival in the past five years?	1 = Yes 2 = No	
6.9	Compared to one year ago, how would you say things are for this household. Have things generally got better, stayed the same, or got worse for this household?	1 = Better 2 = Same 3 = Worse	

B BACKGROUND INFORMATION ON RESPONDENT		
Now, we'd like to ask you some questions about yourself:		
7.1	**Age: What is your age at your last birthday?**	Write in Years_____
7.2	**Sex:** **DO NOT ASK**	1 = Male 2 = Female
7.3	**Marital status:**	1 = Are you married/living together 2 = Single 3 = Separated or divorced 4 = Widowed
7.4	**What education have you completed?**	1 = None 2 = Some primary 3 = Some secondary 4 = Matric 5 = Matric plus further training 6 = University/Technical university
7.5	**Did you attend a pre-primary or early learning school?**	1 = Yes 2 = No
7.6	**What is your main occupation?**	1 = At school 2 = At technikon/university 3 = Full- or part-time job 4 = Casual jobs from time to time 5 = Own business such as hawking or spaza shop 6 = Houseminding/childminding/ looking for work, unemployed
7.7	**What is your position in the household?**	1 = Household head 2 = Income earner but not head of household

		3 = Housewife/homemaker	
		4 = Dependant (no regular income)	
7.8	**Do you earn any of the following social grants:** **READ OUT**	1 = Old-age pension 2 = Permanent disability grant 3 = Temporary disability grant 4 = Child support grant 5 = Foster care grant 0 = None of above	
7.9	**How would you describe your health these days?**	1 = Very good 2 = Good 3 = Average 4 = Poor 5 = Very poor	
7.10 ☞	**Do you belong to / go to a church or religious group?** **READ OUT**	1 = Catholic 2 = Mainline Christian churches (e.g., Methodist, Anglican, Congregational, Presbyterian, Seventh Day Adventist, Assembly of God) 3 = Newer Christian churches: Pentecostal and Charismatic Churches 4 = African Independent Churches (Zionist Churches) 5 = ZCC 6 = Traditional African Other, specify _____ 8 = None ➜ *SKIP TO Q7.13* 9 = Non-response. ➜ *SKIP TO Q7.13*	
7.11	**Are you born again?**	1 = Yes 2 = No	
7.12	**How often do you go to church or religious services?**	1 = Regularly 2 = Occasionally	

		3 = Seldom	
		4 = Never	
7.13	**How do you mainly keep yourself informed of news?**	1 = Television	
		2 = Radio	
		3 = Newspapers	
		4 = Listen to other people	

7.14	**Do you read Grocott's Mail?**	1 = Regularly	
		2 = Occasionally	
		3 = Seldom	
		4 = No/never	
7.15	**Are you proud to be a citizen of Grahamstown/Rhini?**	1 = Always	
		2 = Sometimes	
		3 = Seldom	
		4 = No/never	
7.16	**Do you think Grahamstown's name should be changed?**	1 = Yes, to Grahamstown/Rhini	
		2 = Yes to Rhini only	
		3 = Yes, to other name	
		4 = No, should remain Grahamstown	
		5 = Name change not an important issue / not as important as other issues	

C QUALITY OF LIFE

Now we'd like to talk to you about how you feel about your life.

8.1	**Taking all things together, how satisfied are you with your life as a whole these days? Generally speaking, would you say you are very satisfied, satisfied, dissatisfied or very dissatisfied?**	1 = Very satisfied	
		2 = Satisfied	
	Ukuhlanganisa izinto zonke, ungathi waneliseke kangakanani bubomi bakho buphela kulemihla? Ngokwentetho jikelele, ungatsho ukuba waneliseke kakhulu, wanelisekile, awanelisekanga okanye awanelisekanga kakhulu?	3 = Neither satisfied nor dissatisfied	
		4 = Dissatisfied	
		5 = Very dissatisfied	

Satisfaction with Life

Here are some statements with which you may agree or disagree . You should say if you strongly agree, agree, neither agree or disagree, disagree or strongly disagree.

Nantsi intetho onokuvumelana okanye ungavumelani nayo. Yitsho ukuba : uvumelana ngamandla, uyavumelana, akukho kuvumelana kungekho kungavumelani, awuvumelani okanye awuvumelani ngamandla.			
9.1	**In most ways my life is close to ideal** Ngokwendlela ezininzi ubomi bam bukufuphi ekufezekeni/ekugqibeleni.	1 = Strongly agree 2 = Agree 3 = Neither agree nor disagree 4 = Disagree 5 = Strongly disagree	
9.2	**The conditions of my life are excellent.** Limeko zobomi bam zibalasele/ziyagqwesa.	1 = Strongly agree 2 = Agree 3 = Neither agree nor disagree 4 = Disagree 5 = Strongly disagree	
9.3	**I am satisfied with my life** Ndanelisekile bubomi bam.	1 = Strongly agree 2 = Agree 3 = Neither agree nor disagree 4 = Disagree 5 = Strongly disagree	
9.4	**So far I have achieved/got the important things I want in life.** Okwakalokunje sendifikelele/ndizifumene izinto ezibalulekileyo endizifunayo ebomini.	1 = Strongly agree 2 = Agree 3 = Neither agree nor disagree 4 = Disagree 5 = Strongly disagree	
9.5	**If I could live my life over, I would change almost nothing.** Ukuba bendinokubuphila kwakhona ubomi bam, bendinokungatshintshi phantse nanye into.	1 = Strongly agree 2 = Agree 3 = Neither agree nor disagree 4 = Disagree 5 = Strongly disagree	
9.6	**Most of the time I feel in control of my life.** Ixesha elininzi ndiziva ndiselulawulweni lobomi bam.	1 = Strongly agree 2 = Agree	

		3 = Neither agree nor disagree	
		4 = Disagree	
		5 = Strongly disagree	

Quality-of-life ladder

All people have had good and bad times in their lives. We should like you to think of the best time of your life, when you felt BEST, that is very, very good about your life. Then we should like you to think of the worst time of your life when you felt WORST, that is very, very bad about your life. This should not be just a day or a week but a longer period of your life.

Bonke abantu bakhe banawo amaxesha alungileyo nangalunganga ebomini babo. Singathanda ukuba ucinge ngexesha elilelona limnandi ebomini bakho, apho wawuziva USEMAGQABINI, intwethi kwakumnandi ngeyona ndlela ebomini bakho. Kwakho singathanda ukuba ucinge ngexesha elilelona libi ebomini bakho, apho awuziva USEZANTSI, intwethi kwakukubi ngeyona ndlela ebomini bakho. Akumelanga ukuba ibe lususku nje okanye iveki kodwa ixesha elide lobomi bakho.

Now think of your life at present, the last two weeks:

On this ladder, 10 at the top means your life at present is as good as it was during the best time in your life (INTERVIEWER: POINT TO 10 ON THE LADDER ON THE SHOW CARD).

Kuleleli, u-10 ophezulu utheth'ukuthi ubomi bakho bulunge njengoko babulungile ngexa babugqwesile.

On this ladder 0 at the bottom means your life now at present is as bad as it was during the worst time in your life (INTERVIEWER: POINT TO 0 ON THE LADDER ON THE SHOW CARD).

Kuleleli, u - 0 ezantsi utheth'ukuthi ubomi bakho bubi njengoko babunjalo ngexa kwakukubi kakhulu ebomini bakho.

Please show the number on the ladder that corresponds to how you feel about your life now, in the present times (the last two weeks) – compared with the best and worst time periods in your life:

Nceda ubonise inani elihambelana nendlela oziva ngayo ebomini bakho ngoku, kumaxesha anamhla (kwiiveki ezimbini ezidlulileyo) – ngokuthelekiswa namaxa okugqwesa nokuba phantsi kobomi bakho:

10.1	
	WRITE IN NUMBER _____

10.2	What made it the best time of your life?

	RECORD ALL MENTION	
10.3	**What made it the worst time of your life?** *RECORD ALL MENTION*	
10.4	**How is your life now?** *RECORD ALL MENTION*	

D ATTITUDES AND BELIEFS ABOUT TUBERCULOSIS

	Now we'd like to talk to you about how you and people in your community think about health matters.		
11.1	**Which clinic do you and members of this household usually visit when they are sick?**	1 = Settler's Day hospital 2 = Town day clinic 3 = Raglan Road clinic 4 = Joza clinic 5 = V Shumane clinic (Extension 7) 6 = Middle Terrace clinic Other (Specify)_____	

Risk factors

	Anyone can get TB. But we've heard that some people are more likely than others to get TB in the Eastern Cape. Wonke ubani unakho ukusifumana isifo sephepha. Kodwa sivile ukuba abanye banako ukusifumana esi sifo ngokungaphezu kwabanye kwiMpuma Koloni.		
12.1	**I will read out a list. Please tell us which type of people on this list you think are most likely to get TB? Do not think too long; just tell us what comes to mind.** **(NAME UP TO FOUR)** Ndizakufunda oku kudwelisiweyo. Nceda usixelele loluphi udidi lwabantu koluluhlu ocinga ukuba ngabona banokufumana isifo sephepha(TB). Musa ukucinga ixesha elide; suka usixelele nje loonto ifikileyo engqondweni. **READ OUT OPTIONS** **People who:**		
1 = Are poor		1 = Abangamahlwempu	

2 = Are lazy	2 = Abonqenayo
3 = Are unemployed	3 = Abangaphangeliyo
4 = Are less educated	4 = Abangayangaphi ekufundeni
5 = Live in shacks	5 = Abahlala ematyotyombeni
6 = Live in RDP houses	6 = Abahlala kwizindlu zesibonelelo sikaRhulumente
7 = Live in overcrowded houses	7 = Abahlala kwizindlu ezinoxinaniso lwabantu
8 = Drink and smoke a lot	8 = Abasela baze batshaye kakhulu
9 = Visit shebeens	9 = Abaya ezi shibhini
10 = Are promiscuous/sleep around	10 = Abangenamkhethe/abahamba bethandana
11 = Work in places where there is a lot of dust	11 = Abasebenza kwiindawo ezinothuli kakhulu
12 = Whose immune systems/ body soldiers are weak	12 = Abanamajoni omzimba abuthakathaka
13 = Are HIV-positive	13 = Abanentsholongwane ka-Gawulayo
14 = Don't go to church regularly	14 = Abangayi rhoqo ecaweni
15 = Have spent time in prison	15 = Abakhe banexesha entolongweni
16 = Were not immunised when they were babies	16 = Abangazange bagonywe ngoko babengabantwana

Case finding

Most people know about the symptoms of TB (such as a persistent cough, night sweats, loss of appetite and weight loss) but not all people go to the clinic straight away to see if they need treatment.

Abantu abaninzi bayazi ngeempawu zesifo sephepha (ezifana nokhohlokhohlo olungayekiyo, ukubila kwasebusuku, ukungafuni kutya nokuhla komzimba) kodwa asingabo bonke abantu abaya eklinikhi ngoko nangoko ukuva ukuba badinga unyango na.

13.1	What are the most important reasons why some people delay going to the clinic? Sesiphi esona sizathu sibalulekileyo ngokwezimvo zakho esibangela abantu bangayi kwangethuba eklinikhi? (READ OUT OPTIONS; SELECT UP TO FOUR) Which in your opinion is the most important reason?	13.1.1 Important (Circle up to four)	13.1.2 Most important (Circle only ONE)
	There are long queues at the clinics / Kukho ukrozo olude ekliniki.	1	1
	They are afraid they will lose their job/income. / Banoloyiko lokulahlekelwa yimisebenzi/yimivuzo yabo.	2	2
	They are afraid that people will talk about their visit to the clinic. / Banoloyiko lokuba abantu bayakuthetha ngokuhambela/ngotyelelo lwabo ekliniki.	3	3
	They do not want to cough into the specimen bottle./ Abafuni kukhohlelelela ebhotileni yomboniso.	4	4
	They are afraid that TB treatment will be unpleasant and difficult. / Banoloyiko lokuba unyango lwesifo sephepha lungalubi yaye lube nzima.	5	5
	They are afraid the TB treatment will interfere with their social lives. / Banoloyiko lokuba unyango lwesifo sephepha lungaphazamisana nentlalo yabo.	6	6
	They are afraid they will be told they are HIV-positive. / Banoloyiko lokuba bangaxelelwa ukuba banentsholongwane ye AIDS.	7	7

	They first wish to consult a traditional healer. / Banqwenela ukuva kwi Nyangi yesintu/yesiXhosa kuqala.		8	8

| 13.2 | **Why do you think some people go to the clinic straight away to get treatment when they think they have TB symptoms?**

Ucinga ukuba kutheni abanye abantu besiya ngoko nangoko ekliniki ukuyokufumana unyango xa becinga ukuba baneempawu ze-TB? Zeziphi izizathu ezizezona zibalulekileyo?

What are the most important reasons?

(READ OUT OPTIONS;

SELECT UP TO TWO) | **1 = There is a clinic located near to where they** stay /

Kukho ikliniki ekufuphi apho bahlala khona.

2 = They want to get treated so they will be cured as soon as possible /

Bafuna ukuba selunyangweni ukuze baphile kwakamsinyane.

3 = They want to get treatment so that they will not infect others /

Bafuna ukufumana unyango ukuze bangasuleli abanye.

4 = They know they can count on their family to be supportive /

Bayazi ukuba bangathembela kwiifemeli/izizalwane zabo ukuba zibaxhase.

5 = They know they will get voluntary counselling and testing for HIV /

Bayazi ukuba bangafumana iingcebiso neemvavanyo ezinganyanzelekanga/ zokuzithandela kwi ntsholongwane ye AIDS. | |

Compliance

14.1	**TB patients usually have to take treatment for six months. What do you say are the important things among the following that help TB patients stay on treatment for six months?** Abantu abanesifo sephepha badla ngokufumana unyango lweenyanga ezintandathu. Ucinga ukuba zeziphi izinto ezibalulekileyo kwezi zilandelayo ezithi zincede abo banesifo sephepha bahlale elunyangweni iinyanga ezintandathu? **(READ OUT; SELECT UP TO FOUR)** **Which of these is the most important?** **(SELECT ONE)**	14.1.1 Important (Circle up to four)	14.1.2 Most important (Circle only ONE)
	They are strong willed. Banokungathandabuzi/bayakwenza abakufunayo.	1	1
	They don't listen when people gossip about them. Abamameli xa abantu behleba ngabo.	2	2
	They want to be cured so they can get on with their lives. Bafuna ukunyangwa ukuze babe nokuqhubekeka nobomi babo.	3	3
	They want to show others that TB is like any other curable disease. Bafuna ukubonisa abanye abantu ukuba i-TB injengaso nasiphina isifo esinyangekayo.	4	4
	They have support from family and friends. Bafumana inkxaso kwiifemeli/izizalwane nezihlobo zabo.	5	5
	They have a sympathetic DOTS volunteer who helps them stay on treatment. Bahanjelwa nguNompilo olivoluntiya(DOTS) elinovelwano nelibancedayo ekuqhubekekeni nonyango.	6	6

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They have enough food to eat. Banokutya okwaneleyo abakutyayo.		7	7
They stick to the rules of treatment. Bayanamathela kwimigaqo yonyango.		8	8
They don't drink or smoke while on treatment. Abaseli okanye batshaye ngexa beselunyangweni.		9	9

14.2	**There are different ways of getting treated for TB. How do you think most TB patients prefer to take their daily treatment? They prefer to take the daily treatment:** Kuneendlela ezahlukeneyo zokufumana unyango lwesifo sephepha(TB). Ucinga ukuba uninzi lwabane TB bakhetha luphi uhlobo lokuthatha unyango? Bakhetha ukuthatha unyango lwemihla ngemihla: **(READ OUT OPTIONS; SELECT ONLY ONE)**
	1 = In the TB hospital where the nurses care for them. KwisiBhedlele se TB apho bancedwa khona ngabongikazi. **2 = In the clinic – they visit the clinic every morning to take their medicine.** Ekliniki- baya khona qho kusasa ukuyokufumana amayeza abo. **3 = At home/work and a family member collects their medicine for them.** Ekhaya/emsebenzini kwakunye nomnye wekhaya oyakuba thathela amayeza abo. **4 = At home and a DOTS volunteer visits them every day to bring the medicine.** Ekhaya apho batyelelwa khona livoluntiya le DOTS mihla le ukubaphathela amayeza. Other (Specify) _____
14.3	**Why do you say so?**
	(FIT THE REASON DESCRIBED BY THE RESPONDENT TO <u>ONE</u> CATEGORY BELOW) **1 = Convenience** / Ngokulungelelana **2 = Professional/better health care** / Ngokobuchule obusemgangathweni / uncedo lwezempilo

olungcono

3 = Privacy/confidentiality, less gossip / Ngokungasese/ngokwemfihlo, kungabikho kuhletywa

4 = Not isolated from society, can be with family and friends / Ngokungahlukaniswa noluntu lwasekuhlaleni, unokuba nosapho okanye izihlobo

5 = Less disruption in one's life at home or at work / Ngokunciphiswa kophazamiso lobomi bakho ekhayeni okanye emsebenzini

6 = Can continue working and earning money / Unokuqhubekeka nokusebenza yaye usamkela imali

7 = Can look after own possessions/own home / Unokukwazi ukujonga izinto ezizezakho / kwelakho ikhaya

Other (Specify)_____

14.4	**We have heard that some TB patients have difficulties completing their treatment. What are the main reasons among the following why they stop taking their treatment before they are cured?** Sivile ukuba abanye abaguli abanesifo sephepha(TB) bafumana ubunzima ekugqibezeleni unyango lwabo. Zeziphi ezona zizathu ziphambili phakathi kwezi zilandelayo ezibangela ukuba bayeke ukuthatha unyango bengekaphili? **(READ OUT; SELECT UP TO TWO)**	
	1 = They feel better and think they are cured. / Baziva bengcono baze bacinge ukuba baphilile.	
	2 = They are afraid people will talk badly about them when they go to the clinic to collect their pills. Banoloyiko lokuba abantu bayakuthetha kakubi ngabo xa besiya ekliniki ukuyokulanda iipilisi zabo.	
	3 = They do not want to be seen standing in the same queue as people collecting ARVs (antiretrovirals) in the clinic. / Abafuni ukubonwa beme kukrozo/kuluhlu olunye nabantu abazokulanda ii-ARVs ekliniki.	
	4 = They forget to take their medicine because they drink and smoke. /	

	Bayalibala ukuthatha amayeza abo kuba besela yaye betshaya. **5 = They are irresponsible and cannot be bothered to take their medicine.** Abakhathali yaye bengafuni kukhathazwa ngokunikwa amayeza abo. **6 = Their families and friends are not supportive.** / lifemeli/izizalwane kunye nezihlobo zabo azibaniki nkxaso. Other (Specify) _____	

Attitudes and beliefs

Here are some things we've heard people say about TB. Do you tend to agree or disagree with the following statements? Do not think too long but just tell us what comes to mind first: Nazi izinto esikhe seva abantu bezithetha nge TB. Ingaba uyavumelana okanye akuvumelani nale ngxelo ilandelayo? Ungathathi xesha lide ukucinga, suka nje uthethe loonto ifika kuqala engqondweni:		
15.1	**TB is an African disease.** Isifo sephepha(TB) sisifo salapha eAfrika.	1 = Agree/True 2 = Disagree/False	
15.2	**Only people who live in poverty get infected with TB.** Ngabantu abahlwempuzekileyo kuphela abathi basuleleke yi TB.	1 = Agree/True 2 = Disagree/False	
15.3	**Only people who are HIV-positive get TB.** Ngabantu abane ntsholongwane ye AIDS kuphela abathi basuleleke yi TB.	1 = Agree/True 2 = Disagree/False	
15.4	**Anyone can get infected with TB because the germs are in the air.** Wonke ubani angathi asuleleke yi TB kuba iintsholongwane zisemoyeni.	1 = Agree/True 2 = Disagree/False	
15.5	**TB can easily be cured these days if you take your treatment.** I-TB inokunyangeka lula kulemihla ukuba uthatha unyango lwakho.	1 = Agree/True 2 = Disagree/False	
15.6	**If you have multi-drug resistant TB, it takes many months to be cured.** Ukuba une TB eselikwiqondo eliphikisa ngokuphindaphindeneyo kunyango (MDR), ithatha iinyanga ezininzi ukunyangeka.	1 = Agree/True 2 = Disagree/False	
15.7	**There is no cure at present for extremely drug resistant TB.** Okwakaloku nje akukabikho lunyango kwi TB ekwiqondo eliphikisana ngokugqithileyo (EDR).	1 = Agree/True 2 = Disagree/False	
15.8	**Almost all people with TB develop HIV/AIDS.** Phantse bonke abantu abane TB baba nentsholongwane ye AIDS / i-AIDS.	1 = Agree/True 2 = Disagree/False	
15.9	**People tend to hide when they have TB because they are afraid of what people say about them.** Abantu baba nokuzifihla xa bene TB kuba besoyika oko kuthethwa ngabantu ngabo.	1 = Agree/True 2 = Disagree/False	
15.10	**People are afraid to collect their TB treatment in case they are infected with other diseases at the clinic.** Abantu bayoyika ukuyokuthatha unyango lwabo ekliniki kuba hleze bosuleleke zezinye izifo khona.	1 = Agree/True 2 = Disagree/False	

15.11	**If you have TB, people do not respect you.** Ukuba une TB abantu abakuhloniphi.	1 = Agree/True 2 = Disagree/False	
15.12	**Children who get infected with TB deserve our sympathy.** Abantwana abathi bosuleleke yi TB balufanele uvelwano lwethu.	1 = Agree/True 2 = Disagree/False	
15.13	**People who get drug-resistant TB from other people should not be blamed but deserve sympathy and support.** Abantu abathi bafumane kwabanye abantu i-TB ekwiqondo eliphikisana ngokuphinda-phindeneyo nonyango abamelanga kubekwa tyala koko balufanele uvelwano kwakunye nenkxaso yethu.	1 = Agree/True 2 = Disagree/False	
15.14	**People who get TB through drinking or smoking get what they deserve.** Abantu abathi bafumane i-TB ngokusela okanye ukutshaya bazuze oko bakufaneleyo.	1 = Agree/True 2 = Disagree/False	
15.15	**It is wise to stay away from people with TB unless you are certain they are taking their medicine as directed.** Kububulumko ukuba uhlalele kude kubantu abane TB ngaphandle kokuba ube uqinisekile ukuba amayeza abo bayawathatha ngokomyalelo.	1 = Agree/True 2 = Disagree/False	
15.16	**It is mainly irresponsible people who do not take their treatment who are to blame for spreading TB.** Ngabo bantu kanye bangenankathalo abangaluthathiyo unyango lwabo abamele ukuba babekwe ityala lokusasaza i-TB.	1 = Agree/True 2 = Disagree/False	
15.17	**It is wrong for people to try to get infected with TB in order to get a temporary disability grant.** Akulungile ukuba abantu bazame ukusuleleka yi-TB ukuze bafumane isibonelelo sikaRhulumente sexeshana kwabakhubazekileyo.	1 = Agree/True 2 = Disagree/False	
15.18	**People on a temporary disability grant should offer to do community work.** Abantu abakwisibonelelo sikaRhulumente sexeshana bamele ukunikela ngokwenza umsebenzi wasekuhlaleni.	1 = Agree/True 2 = Disagree/False	

	Here are some things that people have said about being treated for TB. Do you tend to agree or disagree with the following statements? Do not think too long but just tell us what comes to mind first: Nazi ezinye zezinto abantu abathe bazithetha ngokunyangelwa i-TB. Ingaba unokuvumelana okanye ukungavumelani nale ntetho ilandelayo? Musa ukuthatha ithuba elide ucinga koko suka usichazele nje oko kufika kuqala engqondweni:		
16.1	**You will never be cured of TB if you drink and smoke.** Akunakuze unyangeke kwisifo sephepha (TB) ukuba uyasela uze utshaye.	1 = Agree/True 2 = Disagree/False	
16.2	**People who get drug-resistant TB because they do not take their medicine get what they deserve.** Abantu abafumana i-TB ekwiqondo lokuphikisana nonyango (DR-TB) ngenxa yokungawathathi amayeza abo, bafumana oko bakufaneleyo.	1 = Agree/True 2 = Disagree/False	
16.3	**TB patients would stay on treatment if they were put in the same queues as people with chronic illnesses like high blood pressure ('high blood') and diabetes.** Abantu abanesifo sephepha bebenokuhlala kunyango lwabo ukuba bebenokubekwa kukrozo/uluhlu olunye nabantu abanezigulo ezingapheliyo ezifana ne high blood kunye neswekile (high blood pressure and diabetes).	1 = Agree/True 2 = Disagree/False	
16.4	**If TB patients were allowed to drink and smoke in moderation they would probably complete the course of treatment.** Ukuba abantu abane TB bebenokuvunyelwa ukuba basele baze batshaye ngokobungcathu, bebenakho mhlawumbi ukuligqiba ixesha lonyango.	1 = Agree/True 2 = Disagree/False	
16.5	**Traditional medicine can help you to regain your appetite and your strength while on TB treatment.** Amayeza esintu/esiXhosa anokukunceda ukubuyisela umdla ekutyeni kwakunye namandla akho ngethuba uselunyangweni lwe-TB.	1 = Agree/True 2 = Disagree/False	
16.6	**If a person completes the six-month TB treatment, they should be seen as heroes and positive role models for others.** Ukuba umntu uyazigqiba iinyanga ezintandathu zonyango lwe TB, ufanelwe kukubonwa njengegorha kwakunye nomntu ongumzekelo	1 = Agree/True 2 = Disagree/False	

	omhle omawulandelwe ngabanye.		
16.7	**All TB patients should be offered a confidential test for HIV.** Bonke abantu abane TB bamelwe kukunikwa iimvavanyo zabucala zentsholongwane ye AIDS.	1 = Agree/True 2 = Disagree/False	

	Here are two different opinions that people have. Which one comes closest to yours? Nazi izimvo ezimbini ezahlukeneyo abantu abanazo. Yeyiphi kuzo esondele ngamandla kolwakho? READ OUT, SELECT ONE	
16.8	1 = Some people say: Fellow churchgoers encourage TB patients to stay on treatment. / Abanye abantu bathi: Abo bahamba icawa/bakhonzayo bayabakhuthaza abane TB ukuba bahlale elunyangweni. OR 2 = Others say: Even church members gossip if a person has TB. Abanye bathi: Kwanamalungu ecawa ayahleba ukuba ubani une-TB.	
16.9	1 = Some people say: There is more TB in the Eastern Cape today than ten years ago because people infected with TB do not take their TB treatment as directed. Abanye abantu bathi: Yongezelelekile i-TB kwiphondo leMpuma koloni namhlanje kunakwiminyaka elishumi edlulileyo kuba abantu abane TB abaluthathi ngokomyalelo unyango lwabo. OR 2 = Others say: There is more TB in the Eastern Cape today than ten years ago because of AIDS. Abanye bathi: Yongezelelekile i-TB kwiphondo leMpuma Koloni namhlanje kunakwiminyaka elishumi edlulileyo ngenxa ye AIDS.	
16.10	1 = Some people say: HIV-positive people can be cured of TB like other people. Abanye abantu bathi: Abantu abanentsholongwane ye AIDS banokunyangeka kwi TB njengabanye abantu kanye OR 2 = Others say: HIV-positive people who get infected with TB are likely to die. Abanye bathi: Abantu abanentsholongwane ye AIDS abathi basuleleke kwi TB banakho ukuba bafe.	

	Here are some things that people have said about being treated for HIV/AIDS. Do you tend to agree or disagree with the following statements? Do not think too long but just tell us what comes to mind first: Nazi ezinye izinto abathe abantu bazithetha ngokumayela nokunyangelwa i-HIV/AIDS. Ingaba uyavumelana okanye akuvumelani nalengxelo ilandelayo? Musa ukuthatha ixesha elide ucinga suka nje usixelele oko kufika kuqala engqondweni.		
17.1	**It is the right thing to do to know your HIV status.** Kukwenza into elungileyo ukwazi ngesimo sakho ngokumayela nentsholongwane kaGawulayo.	1 = Agree/True 2 = Disagree/False	
17.2	**AIDS is now like high blood pressure or diabetes because it can be treated like a chronic disease with antiretrovirals.** I-AIDS ngoku injenge high blood okanye iswekile kuba inokunyangeka njengesifo esingapheliyo kusetyenziswa ii-antiretrovirals.	1 = Agree/True 2 = Disagree/False	
17.3	**There is no cure for AIDS as yet but antiretrovirals help people to live longer and healthier lives.** Okwakalokunje alukabikho unyango lwe AIDS kodwa ii-antiretrovirals zinceda abantu baphile ubomi obudana nobusempilweni.	1 = Agree/True 2 = Disagree/False	
17.4	**If people knew their HIV status, their TB could be treated more effectively.** Ukuba abantu bebezazi izimo zabo ngokwentsholongwane ye AIDS, i-TB yabo ibinokunyangwa ngokuchanekileyo.	1 = Agree/True 2 = Disagree/False	
17.5	**People do not want to know their HIV status because there is no privacy during voluntary counselling and testing (VCT) at health clinics.** Abantu abafuni ukuzazi isimo sabo se ntsholongwane kaGawulayo kuba akukho mfihlo ngexa benikwa iingcebiso neemvavanyo zokuzithandela (VCT) kwii kliniki zempilo	1 = Agree/True 2 = Disagree/False	

	Please say whether you tend to agree or disagree with the following statements about AIDS: NCEDA UTSHO UKUBA UYAVUMELANA OKANYE AKUVUMELANI NA NALE NGXELO ILANDELAYO NGOKUBHEKISELELE KWI-AIDS:		
18.1	**People who have AIDS are dirty.** Abantu abaneAIDS bamdaka.	1 = Agree / Ndiyavumelana 2 = Disagree / Andivumelani	
18.2	**People who have AIDS are cursed.** Abantu abaneAIDS baqalekisiwe	1 = Agree / Ndiyavumelana 2 = Disagree / Andivumelani	
18.3	**People who have AIDS should be ashamed.** Abantu abaneAIDS bafanele ukuba neentloni	1 = Agree / Ndiyavumelana 2 = Disagree / Andivumelani	
18.4	**People with AIDS must expect some restrictions on their freedom.** Abantu abaneAIDS kufanele balindele imiqathango ethile kwinkululeko yabo	1 = Agree / Ndiyavumelana 2 = Disagree / Andivumelani	
18.5	**A person with AIDS must have done something wrong and deserves to be punished.** Umntu oneAIDS makube kukhona into engeyiyo awayenzayo yaye ufanele ukohlwaywa	1 = Agree / Ndiyavumelana 2 = Disagree / Andivumelani	
18.6	**People who have AIDS should be isolated.** Abantu abaneAIDS kufanele ukuba babekwe bodwa.	1 = Agree / Ndiyavumelana 2 = Disagree / Andivumelani	
18.7	**I do not want to be friends with someone who has AIDS.** Andifuni ukuba ngumhlobo womntu oneAIDS	1 = Agree / Ndiyavumelana 2 = Disagree / Andivumelani	

18.8	**People who have AIDS should not be allowed to work.** Abantu abane AIDS akufanelanga ukuba bavunyelwe basebenze	1 = Agree / Ndiyavumelana 2 = Disagree / Andivumelani	
18.9	**It is women prostitutes who spread HIV in our community.** Ngamabhinqa athengisa ngomzimba athi asasaze intsholongwane ye AIDS kwindawo esihlala kuyo.	1 = Agree / Ndiyavumelana 2 = Disagree / Andivumelani	
18.10	**Promiscuous men are the ones that spread HIV in our community.** Ngamadoda ahamba ethandana athi asasaze intsholongwane ye AIDS kwindawo esihlala kuyo.	1 = Agree / Ndiyavumelana 2 = Disagree / Andivumelani	

	And please say whether you tend to agree or disagree with the following statements about TB?		
19.1	**People who have TB are dirty.** Abantu abaneTB bamdaka	1 = Agree 2 = Disagree	
19.2	**People who have TB are cursed.** Abantu abaneTB baqalekisiwe	1 = Agree 2 = Disagree	
19.3	**People who have TB should be ashamed.** Abantu abaneTB bafanele ukuba neentloni	1 = Agree 2 = Disagree	
19.4	**People with TB must expect some restrictions on their freedom.** Abantu abaneTB kufanele balindele imiqathango ethile kwinkululeko yabo	1 = Agree 2 = Disagree	
19.5	**A person with TB must have done something wrong and deserves to be punished.** Umntu oneTB makube kukhona into engeyiyo awayenzayo yaye ufanele ukohlwaywa.	1 = Agree 2 = Disagree	
19.6	**People who have TB should be isolated.** Abantu abane TB kufanele ukuba babekwe bodwa.	1 = Agree 2 = Disagree	
19.7	**I do not want to be friends with someone who has TB.** Andifuni ukuba ngumhlobo womntu oneTB	1 = Agree 2 = Disagree	
19.8	**People who have TB should not be allowed to work.** Abantu abneTB akufanelanga ukuba bavunyelwe basebenze.	1 = Agree 2 = Disagree	

Assistance for TB patients

20.1	**People who are on anti-TB treatment are assisted in several ways.**	
	Which of the following types of assistance do you think are most helpful to TB patients and their families?	
	(READ OUT; AND SELECT UP TO TWO)	
	Abantu abakunyango oluphikisana ne TB bancedwa ngeendlela ezahlukeneyo. Zeziphi kwezintlobo zoncedo zilandelayo ocinga ukuba zezona zincedayo kwabane TB kwakunye nee femeli zabo**?**	
	1 = Assigning a volunteer to TB patients to support them while they are on treatment. Ukumisela ivoluntiya kwabo bane TB ukuba libaxhase ngexa bekunyango.	
	2 = Providing porridge so TB patients do not take their medicine on an empty stomach. Ukubonelela ngepapa ukuze abane TB bangatyi amayeza abo kwizisu ezingenanto**.**	
	3 = Assigning special queues or a special room at clinics so that TB patients do not wait long when collecting their medicine. Ukumisela uluhlu olulodwa okanye igumbi elilodwa ezikliniki ukuze abane TB bangalindi thuba lide xa bezokulanda amayeza.	
	4 = Giving TB patients a temporary disability grant so they can be financially independent while on treatment. Ukunikezela ngesibonelelo sethutyana sabakhubazekileyo ukuze abane TB babe nemali eyeyabo ngexa beselunyangweni.	
	5 = Contacting people at work or school to inform them that the patient is not infectious because he or she is on treatment. Ukunxibelelana nabantu emsebenzini okanye esikolweni ngokubazisa ukuba umguli akasuleli kuba eselunyangweni.	

20.2	**Do any of the following types of assistance hurt rather than help TB patients and their families?**	
	Ingaba ikho kwezi ntlobo zilandelayo zoncedo ethi yonzakalise endaweni yokunceda abane TB neentsapho zabo?	
	(READ OUT AGAIN, CIRCLE APPLICABLE)	
	1 = Assigning a volunteer to TB patients to support them while they are on treatment. Ukumisela ivoluntiya kwabo bane TB ukuba libaxhase ngexa bekunyango.	
	2 = Providing porridge so TB patients do not take their medicine on an empty stomach. Ukubonelela ngepapa ukuze abane TB bangatyi amayeza abo kwizisu ezingenanto.	
	3 = Assigning special queues or a special room at clinics so that TB patients do not wait long when collecting their medicine. Ukumisela uluhlu olulodwa okanye igumbi elilodwa ezikliniki ukuze abane TB bangalindi thuba lide xa bezokulanda amayeza.	
	4 = Giving TB patients a temporary disability grant so they can be financially independent while on treatment. Ukunikezela ngesibonelelo sethutyana sabakhubazekileyo ukuze abane TB babe nemali eyeyabo ngexa beselunyangweni.	
	5 = Contacting people at work or school to inform them that the patient is not infectious because he or she is on treatment. Ukunxibelelana nabantu emsebenzini okanye esikolweni ngokubazisa ukuba umguli akasuleli kuba eselunyangweni.	
	6 = None of the above hurt; all are helpful. Akukho nanye kwezi zingentla eyonzakalisayo, zonke ziluncedo.	

Temporary TB Disability grant

21.1	**Some people get a temporary disability grant while they are being treated for TB.** **Who is eligible for the temporary disability grant?** Abanye abantu bafumana isibonelelo sexeshana sabakhubazekileyo ngexa beselunyangweni le TB. Ngabatheni abafanele ukunikwa esisibonelelo sexeshana sabakhubazekileyo? **(READ OUT; SELECT ONE ONLY)**	
	1 = All TB patients get a temporary disability grant. / Bonke abane TB bafumana isibonelelo sexeshana sabakhubazekileyo. **2 = Only TB patients who take their medicine as prescribed get a temporary disability grant.** Ngabo kuphela bathatha amayeza ngokommiselo bafumana isibonelelo sexeshana sabakhubazekileyo. **3 = Only people who are on <u>both</u> anti-retroviral and anti-TB treatment get a temporary disability grant.** Ngabakwi ARVs nabakunyango oluphikisana ne TB amabafumana isibonelelo sexeshana sabakhubazekileyo. **4 = Don't know** / Andiyazi.	
21.2	**Here are some things we've heard people say about the temporary disability grant:** **Which statement comes closest to your own point of view?** Nazi ezinye izinto esikhe saziva zithethwa ngabantu malunga nesibonelelo sexeshana sabakhubazekileyo: Yeyiphi kulentetho eyeyona isondeleyo kolulolwakho uluvo? **(READ OUT; SELECT ONLY ONE)**	
	1 = Most people who get a temporary disability grant share the money with other members of the household. / Uninzi lwabantu abafumana isibonelelo sexeshana bohlulelana nabo bahlala kunye nabo ngale mali.	

	2 = Most people who get a temporary disability grant use the money to buy nutritious food so the TB medicine works better.	
	Uninzi lwabantu abafumana esisibonelelo sexeshana luyisebenzisa lemali ekuthengeni ukutya okusempilweni ukuze unyango lwe TB lusebenze ngcono.	
	3= Most people who get a temporary disability grant spend it on liquor and cigarettes.	
	Uninzi lwabantu abafumana esisibonelelo sexeshana bayichitha etywaleni nasecubeni lemali.	
21.3	**We've heard rumours that some young people try to get infected with TB so that they can get a temporary disability grant.** **Is there any truth in the rumour?**	1 = Yes 2 = No
21.4	**Why would a young person want to get infected with TB to get a temporary disability grant? Which of the following comes closest to your point of view?** Yintoni enokubangela ukuba umntu omtsha afune ukusuleleka yi TB ukuze afumane isibonelelo sexeshana? Yeyiphi kwezi zilandelayo eyeyona isondeleyo kuluvo lwakho? **(READ OUT; SELECT UP TO TWO)**	
	1 = They want to prove to their friends that TB is curable. Bafuna ukubonisa izihlobo zabo ukuba i-TB iyanyangeka.	
	2 = They know they will be cured while they are earning money. Bayazi ukuba bayakunyangeka ngexa bezuza imali.	
	3 = They want to earn money so they will be respected by others. Bafuna ukuzuza imali ukuze babe nokuhlonitshwa ngabanye.	
	4 = They want to earn money so they can spend it on themselves. Bafuna ukuzuza imali ukuze babe nokuyichithela kwiziqu zabo.	

5 = They want to help their families to live a better life with the money. Bafuna ukunceda iintsapho zabo ziphile ubomi obungcono ngalemali.	

Risk assessment

People are exposed to many dangers these days. What do you consider to be the two greatest dangers that could happen to you among the following? **This danger could happen to me:**	1st Greatest danger	2nd Greatest danger
22.1 A serious road accident	1	1
22.2 An unwanted pregnancy	2	2
22.3 Assault/rape	3	3
22.4 Infected with TB	4	4
22.5 Infected with HIV	5	5
22.6 A prison sentence	6	6

Disclosure

23.1	**How do people in this community usually get to know that a person has TB?** Abantu apha ekuhlaleni bazi kanjani ukuba umntu une TB? **READ OUT; SELECT ONLY ONE ANSWER**	**1 = From the person who has TB** Bava ngomntu onayo i-TB. **2 = From gossip about the person** Bava xa umntu ehletywa. **3 = From the person's family** Bava ngefemeli yomntu onayo. **4 = From the person's friends/neighbours** Bava ngezihlobo/abamelwane bomntu onayo. **5 = From seeing the person taking medicine at the clinic** Ngokubona umntu ethatha amayeza ekliniki. **6 = From seeing that the person looks ill or has lost weight** Ngokubona ukuba umntu ukhangeleka engaphilanga okanye umzimba wakhe uhlile. Other (Specify)_____	
23.2	**What would you recommend to a person with TB?** Ungacebisa uthini kumntu one TB? **READ OUT; SELECT ONLY ONE**	**1 = To keep it secret** Makayingcine iyimfihlo. **2 = To tell only family members** Makaxelele izizalwane zakhe kuphela. **3 = To share this information with the community** Makabelane nabahlali ngolulwazi.	
23.3	**What would you recommend to a person living with HIV but not showing any symptoms?** **READ OUT; SELECT ONLY ONE**	**1 = To keep it secret** Makayingcine iyimfihlo. **2 = To tell only family members** Makaxelele izizalwane zakhe kuphela. **3 = To share this information with the community** Makabelane nabahlali ngolulwazi.	

Experience of TB

	Lastly, we'd like to know more about your knowledge and experience of TB:		
24.1	I have been informed about TB and know the symptoms.	1 = Yes 2 = No	
24.2	There has been a case of TB in this household.	1 = Yes 2 = No	
24.3	I know/have known someone with TB.	1 = Yes 2 = No	
24.4	I have visited a TB patient in hospital.	1 = Yes 2 = No	
24.5	I have assisted a person with TB to take their treatment.	1 = Yes 2 = No	
24.6	I think I do enough to avoid infection from TB.	1 = Yes 2 = No	

24.7	If you have had personal experience of TB, was this experience mainly positive or negative?	1 = Positive 2 = Negative 3 = Not applicable, no experience	
24.8	If you were asked, would you be willing to act as a DOTS volunteer to assist family, neighbours, or friends to take their TB treatment?	1 = Yes 2 = No	

THANK RESPONDENT AND CLOSE INTERVIEW

QUALITY CONTROL RECORD SHEET

| QUALITY CONTROL | | Q number | Description of problem | CORRECTION | | CORRECTION CHECKED | |
Date	Initial			Date	Initial	Date	Initial

KISH GRID

1.0	Area	1 = Fingo; 2 = Tantyi; 3 = Xolani; 4 = Hlalani; 5 = Makanaskop/Joza; 6 = Ext 1 (Thatha); 7 = Ext 2 (Pumlani Ext 2); 8 = Ext 3 (Pumlani Ext 3); 9 = Ext 4; 10 = Ext 5; 11 = Ext 6; 12 = Lingelihle formal 13 = Ext 7; 14 = Ext 8; 15 = Ext 9; 16 = Vukani I; 17 = Vukani II; 18 = Transit camp; Informal housing: 19 = Phaphamani; 20 = Eluxolweni; 21 = Zolani; 22 = Ethembeni (Ext 7 informal); 23 = Hlalani informal; 24 = Mnandi (between Ext 2& 3);			
1.1	Day of the week	1=Monday, 2=Tuesday, 3=Wednesday, 4=Thursday, 5=Friday, 6=Saturday, 7= Sunday		1.2	Date [dd/mm/yy]
1.2a	Erven Number				

1.3 House number		1.4 Street name	
1.5 Description			
1.6 Contact number			

1.7 Person code	1.8 Name of household members who SLEEP IN THIS HOUSEHOLD FOR FOUR OR MORE NIGHTS EVERY WEEK? *START WITH RESPONDENT THEN ENTER FROM OLDEST TO YOUNGEST*	1.9 Sex 1= Male 2 = Female	1.10 PRESENT age today *Record 0 if less than 1 year old*	1.11 Lived in this community for 6 months or more in the last year? 1= Yes 2 = No	1.12 Eligible for selection 1= Yes 2 = No

1	**DIARY RESPONDENT**				
2					
3					
4					
5					
6					
7					
8					
9					
10					
11					
12					
13					
14					
15					
16					
17					
18					
19					
20					

KISH GRID TO SELECT A RESPONDENT

List the names and person code of household members ELIGIBLE FOR SELECTION from oldest to youngest - in the table below. Using the last digit of the household roster number, find that number along the top row of the table. Follow that number down to the last line where the youngest person is listed. The number that you come to is the number of the person who should be interviewed. If they are available, interview them. If they are not available, try to make an appointment to interview that person.

ALL household members 18 or older Listed from Oldest to Youngest			Last digit of household roster number									
			1	2	3	4	5	6	7	8	9	0
Line #	Name	Person code										
1			1	1	1	1	1	1	1	1	1	1
2			2	1	2	1	2	1	2	1	2	1
3			3	1	2	3	1	2	3	1	2	3
4			4	1	2	3	4	1	2	3	4	1
5			5	1	2	3	4	5	1	2	3	4
6			6	1	2	3	4	5	6	1	2	3
7			7	1	2	3	4	5	6	7	1	2
8			8	1	2	3	4	5	6	7	8	1
9			9	1	2	3	4	5	6	7	8	9
10			10	1	2	3	4	5	6	7	8	9

1.19	Name of person selected		1.20	Person code	

DETAILS OF EACH VISIT			
1.21	**Fieldworker name & surname**	**1.22 Time**	**1.23 Outcome**
1			
2			
3			
4			
5			
6			
7			
8			
9			
10			
11			
12			
13			
14			
15			
16			
17			
18			
19			
20			

1.24 Final outcome		**1.25 Questionnaire number**	
1.26 selected respondent refused, reason for refusal			
1.27 Reason interview not after completed after the day			

HOUSEHOLD DIARY CODELISTS

Q1.23 Outcome codes

1 = Household roster and KISH grid complete, made an appointment

2 = No one home

3 = First respondent refused roster

4 = Responsible adult 18 or over not home

5 = Selected respondent not at home

7 = Selected respondent refused interview

9 = Interview partially completed

10 =Interview complete

> *IF NO ONE HOME, SELECTED RESPONDENT NOT HOME,* SELECTED RESPONDENT'S GUARDIAN NOT AT HOME, *MAKE AN APPOINTMENT/ TIME FOR NEXT VISIT FOR THAT DAY*
> *IF THE SELECTED RESPONDENT OR HIS OR HER GUARDIAN REFUSED, FILL IN REFUSAL ON FINAL OUTCOME (Q1.24) AND THEN FILL IN THE REFUSAL BLOCK (Q1.26)*
> *IF THE INTERVIEW IS PARTIALLY COMPLETE, MAKE AN APPOINTMENT TO COMPLETE*
> *IF THE INTERVIEW IS COMPLETE, FILL IN THE FINAL OUTCOME BLOCK (Q1.24) AND RECORD THE QUESTIONNAIRE NUMBER (Q1.25).*

Q1.24 Final outcome codes

2 = No one home

3 = First respondent refused roster

4 = Responsible adult 18 or over not home

5 = Selected respondent not at home

6 = Selected respondent's guardian not at home (if 16 or 17)

7 = Selected respondent refused interview

8 = Selected respondent's guardian refused interview (if 16 or 17)

9 = Interview partially completed

10 = Interview complete

-98 = Selected respondent interview not complete after final visit

Q1.26 Reasons for Refusals

1 = Uncomfortable with discussing personal issues/ crime issues

2 = Not interested/ just didn't want to

3 = Does not want family details recorded on household roster

4 = Selected respondent is very sick, deaf, mentally disabled or mentally ill

X = specify if other

As good as the **BEST** time in my life

10

9

8

7

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3

2

1
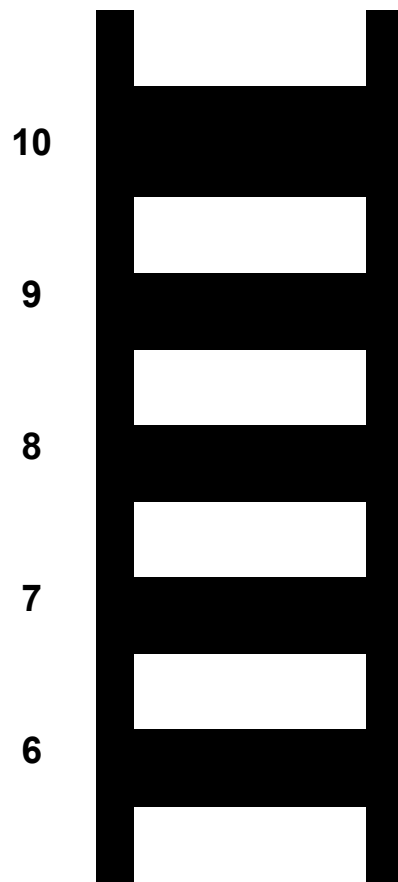
As bad as the **WORST** time
in my life

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