Exploring perceptions and stigma of tuberculosis among the young adults in a rural area of KwaZulu-Natal

by

Siphesihle Khumalo

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Declaration

College of Humanities

I, Siphesihle Khumalo, declare that:

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2. This thesis has not been submitted for any degree or examination at any other university.

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Abstract

Tuberculosis continues to remain as one of the major health problems and it is the leading cause of death among youth in South Africa. Although several studies have explored community perceptions when it comes to tuberculosis, little is known about youth perceptions specifically. Therefore, this study aimed at exploring the perceptions and potential stigma of tuberculosis among young adults in a rural area of KwaZulu-Natal. This was the qualitative research study which adopted the individual in-depth interviews to collect data among the young adult males and among the young adult females aged between 18 to 35 years. The interviews were audio taped, translated and transcribed to verbatim English. The results revealed that while there was a high level of awareness of TB as a potential health condition, specific knowledge of transmission and treatment varied among the participants and it include the false beliefs regarding how TB could be prevented. The results also revealed that young adults had a positive interrelation with people who were infected with tuberculosis.The results further revealed the young adults possible stigma of tuberculosis by revealing some of the mitigating factors for tuberculosis stigma which were the lack of knowledge, fear of the disease, HIV/AIDS and tuberculosis interrelation as well as the reactions into fear and discrimination of tuberculosis. The results then showed young adults perceptions of TB infected people living in the community where it presented the attitudes of young adults towards tuberculosis infected individuals as well the community attitudes towards tuberculosis infected individuals. Therefore, the study findings revealed that the young adults did not uniformly hold, nor did they demonstrate stigma towards the individuals with tuberculosis. However, they were aware about the existing stigma in the community that is attached to tuberculosis within the rural area of KwaZulu-Natal.

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Abbreviations

TB: Tuberculosis

MDR-TB: Multidrug-Resistant Tuberculosis

Pre-XDR-TB: Pre–Extensively Drug Resistant Tuberculosis

XDR-TB: Extensively Drug Resistant Tuberculosis

DOTS: Directly Observed Treatment Service

AIDS: Acquired Immune Deficiency Syndrome

HIV: Human Immune-Deficiency Syndrome

WHO: World Health Organization

NDOH: National Department of Health

SANTA: South African National Tuberculosis Association

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Chapter 01: Introduction and Background

1.1. Background to the Study

"Tuberculosis (TB) continues to remain as one of the major global health problems, which is responsible for ill-health among millions of people each year" (WHO, 2015:18). Waako et al. (2013:01) reveal that "the World Health Organisation (WHO) declared tuberculosis (TB) as a global emergency, mainly affecting people in sub-Saharan Africa". Moreover, according to the WHO TB Report (2015:17), "in 2014, TB killed 1.5 million people (1.1 million HIV [Human Immune-Deficiency Syndrome]-negative and 0.4 million HIV-positive). The toll comprised 890 000 men, 480 000 women and 140 00 children. As a result, TB now ranks alongside HIV as a leading cause of death worldwide" (WHO: 2015). South Africa has the third largest TB epidemic in the world, with cases relating to TB doubling between 2000 and 2015, largely due to high HIV/TB co-infection rates (WHO TB Report, 2014). According to the Statistics South African report (2013:08) on morbidity and mortality among youth in South Africa, TB was the leading cause of death.

1.2. Problem Statement

As reflected on above, TB is one of the diseases that is regarded as a leading cause of mortality. Sikwese (2012:03) notes that there is limited data and information when it comes to the social aspects of tuberculosis, since most of the studies have focused more on the clinical aspects and operational research of tuberculosis. This view is supported by Fogel (2015) in his extensive review of the existing tuberculosis research. Fogel (2015) notes that many studies have contributed to knowledge of the epidemiology, pathogenesis, the immune response, treatment, and the control of tuberculosis. However, significantly less has been published on the existing perceptions of the disease, particularly those that are related to the stigma of tuberculosis.

Long et al. (2001:346) assert that tuberculosis has been and is still often considered as a "dirty disease", a "death penalty" or that which affects guilty people. Therefore, the process of assessing social stigma and perceptions which relate to tuberculosis is important in understanding the impact of the disease, as treatment seeking may be delayed in the context of the perceived stigma. When tuberculosis is not treated early enough, the treatment outcomes are poorer. In addition, those that begin

treatment may default in their treatment in the context of a lack of social support (Macq et al., 2006).

Research by Sikwese (2012:04) has suggested that one of the factors that have led to TB mortality is the “lack of proper knowledge about tuberculosis as well as existing stigma and perceptions among the societies about tuberculosis and people infected with tuberculosis”.

Tolosa et al. (2014), based on data collected in Shinile Town during the year of 2014, reported that there was a lack of knowledge related to TB among the community, particularly among the young adults. Within the South African context, a study by the Soul City Institute (2015) reveals that tuberculosis is understood by most respondents in communities to be a disease of the lungs.

Sikwese (2012:03) argues that “understanding community perception, beliefs and knowledge about TB can therefore provide a pathway to understanding people’s health seeking behaviour and factors affecting early diagnosis seeking”. Therefore, it is critical to assess and to explore the existing perceptions and stigma of tuberculosis among the community, particularly among young adults, in order to address the tuberculosis epidemic.

1.3. Aim of the Study

The main aim of the study is to explore the perceptions and stigma of tuberculosis among the young adults in a rural area of KwaZulu-Natal.

The aim and objectives are:

- To explore the awareness of young adults with regard to tuberculosis.
- To assess the perceptions of young adults with regard to tuberculosis.
- To understand the experiences of young adults in relation to people who are diagnosed of tuberculosis.
- To explore the possibility of stigma among young adults with regard to tuberculosis.

1.4. Research Questions

The Research Questions are as follows:

- What awareness do young adults have with regard to tuberculosis infection and treatment?
- What are the perceptions of young adults with regard to tuberculosis?
- What are the attitudes of young adults towards people who are diagnosed with tuberculosis?
- What is the possible stigma of tuberculosis that exists within the context of young adults and further to the community that they belong to?

1.5. Theoretical Framework of the Study

The research study is guided by the Social cognitive Theory. Bandura (2001:57) indicates that the "social cognitive theory explains human behaviour in terms of three-way dynamic reciprocal models which are personal factors, environmental influences and behaviour, continually". Therefore, the framework is the premise of the study, as it aims to explore the perceptions and stigma of tuberculosis that may exist among the young adults. The integration of this framework informs the study in understanding the cognitive constructs and perceptions which the young adults have acquired through observation, behavioural factors and interaction with the environment.

Bandura (2001:58) articulates that "the basic premise of this theory is that people learn, not only through their own experiences, but also by observing the actions of others and the results of those actions". Furthermore, Bandura (2001:58) argues that in the "social cognitive view, people are neither driven by inner forces nor automatically shaped and controlled by external stimuli". Therefore, reflecting on the above premise, the theory seeks to explain the cognitive views of people by looking at the inner forces and external forces which may influence behaviour, particularly the young adults towards tuberculosis. Bandura (2001:59) articulates that "a person, their behaviour and the environment [are] all inseparably intertwined to create learning in an individual". Therefore, integrating this framework within the study supports the study in understanding the actions and perceptions of the young adult participants regarding tuberculosis, and towards people diagnosed with TB in a rural area.

1.6. Structure of the Dissertation

1.6.1 Introduction

The chapter uncovers and introduce the fundamental aim of the study as well as background of the study, the problem statement, the objectives of the study as well as the theoretical framework that guided the research study.

1.6.2. Literature Review

The chapter uncovers the literature surrounding possible factors that endorse the stigma of TB among young adults and the community. Additionally, this chapter investigates research related to TB stigma and perceptions, the prevalence of TB in rural areas, the awareness of TB among young adults and the existing TB treatment.

1.6.3. Methodology

The chapter focuses on the methodological framework for this review. This includes how data was collected through the in-depth interviews. The chapter also describes the thematic analysis of the data.

1.6.4. Findings

This chapter details the findings of the research in this study, in line with the theoretical framework and key questions guided by this research.

1.6.5. Discussion

The chapter contains a discussion of the findings, the recommendations as well as the conclusion of the research study.

Chapter 02: Literature Review

2.1. Introduction

The chapter begins with the definition of concepts related to the study, viz. tuberculosis, multi drug resistant tuberculosis (MDR-TB), pre–extensively drug resistant tuberculosis (Pre-XDR TB), extensively drug resistant tuberculosis (XDR TB), perceptions, stigma, self-stigma, public stigma, stigma by association, structural stigma, and young adults as well as the community. The chapter will also discuss the prevalence of tuberculosis in rural areas and among young adults. It further discusses some of the studies which were conducted on exploring the perceptions and stigma of tuberculosis. The chapter will then provide a brief summary of the literature as well as a justification for the current study.

2.2. Concepts Defined

2.2.1. Tuberculosis

The South African National Tuberculosis Association (2016:03) defines tuberculosis as a disease caused by an organism called *Mycobacterium tuberculosis*. These bacteria can attack any part of the body, but they commonly attack lungs because it is easier for them to flourish there. The National Department of Health (NDoH) Tuberculosis Report (2013:14) further reveals that tuberculosis is spread through the air when a person with active TB coughs, sneezes, spits or speaks. Moreover, if left untreated, a person with active tuberculosis can infect 10 to 15 people each year (NDoH, 2013:14). The common symptoms of active tuberculosis include a cough for longer than two weeks, blood in the sputum, fevers and night sweats, as well as weight loss (NDoH, 2013:22). Active TB of the lungs is usually diagnosed with a sputum test, a tuberculin skin test and a chest X-Ray (NDoH, 2013:23). The NDoH (2013:23) noted that a definitive TB diagnosis may be challenging and, as a result, the disease is often missed by health care professionals.

2.2.2. Multi-Drug Resistant Tuberculosis (MDR-TB)

Multidrug-resistant tuberculosis is defined as TB that is resistant to both isoniazid and rifampicin, two of the first-line drugs used in treating pulmonary tuberculosis. Furthermore, MDR–TB requires an extended duration of treatment for individuals who are infected (National Institute for Communicable Diseases, 2014).

2.2.3. Pre–Extensively Drug Resistant Tuberculosis (Pre-XDR TB)

Pre-XDR TB is defined as TB that is resistant to both isoniazid and rifampicin and either a fluoroquinolone or second-line injectable agent, but not both (National Institute for Communicable Diseases, 2014).

2.2.4. Extensively Drug Resistant Tuberculosis

Extensively drug-resistant tuberculosis (XDR-TB) is defined as MDR-TB with additional resistance to any fluoroquinolone (FQ) and to at least one of three injectable second-line anti-tuberculosis drugs used in treatment such as capreomycin, kanamycin or amikacin (National Institute for Communicable Diseases, 2014).

2.2.5. Perceptions

Perceptions are regarded as "a process by which organisms interpret and organise to produce a meaningful interpretation of the world" (Lindsay and Norman, 2013:20). Therefore, perceptions pertain to the way in which something is regarded, understood and interpreted. In this case, perceptions could be the way in which tuberculosis is regarded, understood and interpreted by young adults and the community.

2.2.6. Stigma

According to Moya and Lusk (2013:549), stigma is a social process that exists when elements of labelling, stereotyping, separation, loss of status and discrimination occur in a power situation which allows them to. Furthermore, the concept of stigma originates from the classical Greek concept where it was used to brand outcast groups with a physical and permanent mark of their moral status (Moya and Lusk, 2013:549). Brown et al. (2001:346) further define social stigma as an undesirable or discrediting attribute that an individual possesses, thus reducing that individual's status in the eyes of society. However, in the context of the current study, it should be noted that there are diverse forms of stigma which exist among the communities such as self-stigma, public stigma, structural stigma and stigma by association.

2.2.6.1. Self-Stigma

Stutterheim et al. (2009) found that stigma has detrimental effects on the psychological well-being of the stigmatised individuals. Therefore, Bos et al. (2013) note that stigma may be internalised to the extent that perceptions of self-worth are affected, with consequent psychological distress. Self-stigma impacts the cognitive,

affective and behavioural components, and it operates both explicitly and implicitly (Bos et al., 2013).

2.2.6.2. Public Stigma

Apart from the self-stigma, there is also a public stigma. Bos et al. (2013) articulate that public stigma relates to the collective perceptions of a group of people (perceivers) regarding those who possess the stigmatised conditions (targets). It may be noted that public stigma relies on individuals who convey stigmatising attitudes and reactions to those who hold stigmatised conditions. Therefore, as a result of this stigmatising behaviour, the cognitive features of a stigmatised condition can trigger negative emotional and behavioural reactions (Bos et al., 2013).

2.2.6.3. Stigma by Association

As a result of the public stigma, Bos et al. (2013) further argues that the stigmatisation does not only affect those who possess the stigmatised condition; it also affects others. Bos et al. (2013) indicate that these are people who are associated with stigmatised individuals. Therefore, in the context of the study, it could be people who are associated with individuals who are infected by tuberculosis such as family, friends and caregivers. Bos et al. (2013) reveal that stigma by association further impacts those individuals and they are routinely devalued purely as a result of their connection to someone who holds a stigmatised condition.

2.2.6.4. Structural Stigma

Bos et al. (2013) articulate structural stigma as the ways in which societal ideologies and institutions exacerbate a stigmatised condition and stigma. It can be argued that this stigma reproduces existing social inequalities and it is perpetuated by hegemony and the exercise of social, economic and political power (Bos et al., 2013).

2.2.7. Young Adults

According to the National Youth Development Policy Framework of South Africa (2015), young people are described as those falling within the age group of 18 to 35 years.

2.2.8. Community

Manderson et al. (1992, cited in Brieger et al., 2006:05), described the concept of community as “a population which is geographically focused, but which also exists as a discrete social entity, with a local collective identity and common purpose’’. Therefore, the individuals who are young adults reside within the geographical area

called the Ezitendeni Community, which is characterised by the set of values, norms and principles that they tend to practice.

2.3. Tuberculosis

2.3.1 Tuberculosis Prevalence in South Africa

The high prevalence of tuberculosis in rural and urban areas within South Africa has also contributed to the spread of tuberculosis. According to Hossain et al., (2015:17), “In developing countries where large portions of populations are rurally located, TB incidence in rural areas is greater than or equal to that in large urban locales”.

According to the WHO TB Report (2014:23), the latest data from the South African NDoH submitted for inclusion in the WHO Global TB Report 2014, revealed that there were 349 582 cases of TB in 2012 (WHO, 2014:23). The WHO TB Report (2014:20) noted that South Africa has the third highest burden of disease in the world, after India and China, with an estimated incidence of 450,000 cases of active TB in 2013. Moreover, TB remains the leading cause of death in South Africa, contributing to 12% of deaths in 2009 (Statistics South Africa, 2013:13).

2.3.2 MDR Tuberculosis

According to the National Department of Health (2014:73), “TB can normally be treated with a course of four standard, or first line, anti-TB drugs’’. “However, if TB patients interrupt their treatment, multi-drug-resistant TB (MDR-TB) can develop” (NDoH, 2014:73). Therefore, in terms of the treatment, ”MDR-TB can take up to two-years to treat with second-line drugs, which are more expensive and have more side effects than first line drugs”. The National Department of Health (2014:20) further revealed that incidences of multi-drug resistant and extensive drug resistant TB are increasing, and South Africa has the second highest number of reported multi-drug resistant TB (MDR-TB) cases globally.

2.3.3 South African Provincial TB Incidences

The table below depicts the TB incidence in the provinces of South Africa in 2013. KwaZulu–Natal, the Eastern Cape and the Western Cape have the highest incidences of TB per 100 000 population; and Mpumalanga, Gauteng and Limpopo are the three lowest ranking provinces in terms of TB incidence per 100 000 population (Soul City Institute, 2015:20).

2.1. TB Incidences per Province

Province	Incidences/100 000 Population
KwaZulu-Natal	922
Eastern Cape	782
Western Cape	730
Northern Cape	728
Free State	724
North West	562
Mpumalanga	467
Gauteng Province	388
Limpopo	354

2.4. Extent of Tuberculosis among Young Adults

According to Statistics South Africa (2013:28), TB was reported as "the first leading underlying cause of death, followed by human immunodeficiency virus (HIV)". Furthermore, the leading cause of death, tuberculosis, was ranked first for the black African and Indian/Asian population groups, while it was ranked second for the coloured population group and seventh for the white population group (Statistics South Africa, 2013:28). Statistics South Africa (2013:30) further indicated that "tuberculosis was the leading cause of death among the youth in the seven provinces, except for the Western Cape and Northern Cape, where the human immunodeficiency virus was the leading cause".

2.5. Factors that Influence the Spread of Tuberculosis

Since tuberculosis may impact heavily on individuals residing within the rural areas, it is vital to assess and explore some of the contributing factors that perpetuate tuberculosis and the stigma which relates to it. Courtwright and Turner (2010:36) indicate that "understanding the origins of tuberculosis stigma is integral to reducing its impact on health". Therefore, one of the studies (Courtwright and Turner, 2010) on tuberculosis has attempted to explore and to identify some of the factors which are the sources that contribute to the spread of tuberculosis and stigma.

2.5.1 Lack of Knowledge

Lack of knowledge is one of the critical factors which have contributed to the issue of tuberculosis and stigma. According to Courtwright and Turner (2010:36), the "lack of knowledge regarding routes of TB transmission may also contribute to TB stigma". Courtwright and Turner (2010:36) further argue that even among people with relatively good knowledge of TB transmission and transmissibility, the perceived risk of transmission can lead to stigmatisation and isolation of individuals with TB.

Several studies such as those by Sikwese (2012) and Courtwright and Turner (2010) have indicated that there is a lack of knowledge among the community, particularly among rural communities. One of the studies reviewed indicated that some community members (including young adults) "professed to have no knowledge of the disease at all, beyond their awareness that such a disease exists" (Soul City Institute, 2015:06).

2.5.2 Poverty and its Impact on the Tuberculosis Pandemic and Stigma

Poverty has also been found to be one of the contributing factors to the tuberculosis pandemic. Millet et al. (2012:544) indicate that there is a concordance between the geographical TB distribution and poverty on the five continents. This association between poverty and tuberculosis has been attributed to malnutrition.

Courtwright and Turner (2010:36) further argue that other stigmatising beliefs regarding the causes of TB include the perceived associations of TB with malnutrition and poverty, in addition to being associated with the foreign-born and low social class. As a result, in low income areas where poverty is rife, the tuberculosis pandemic and stigma are more likely to grow. Therefore, Courtwright and Turner (2010:36) argue that TB-infected individuals perceive themselves to be at risk for a number of stigma-related social and economic consequences. For instance, "the stigmatisation of TB in Ghana has led to the prohibition of TB individuals from selling goods in public markets and in attending events" (Courtwright and Turner, 2010:36).

2.5.3 Alcohol Use and the Influence of Drug Use

Millet et al. (2012:544) reveal that in last few years there have been a number of publications which highlighted the key relationship between TB (active and latent) and tobacco use. According to Millet et al. (2012:544), socio-economic factors such

as poor living conditions, homelessness, incarceration, poverty, tobacco use and alcohol abuse, place people who use drugs at higher risk of developing TB.

Alcohol use has also been associated with tuberculosis and its development in the individual. According to the Soul City Institute (2015:17), “alcohol has a direct toxic effect on the immune system and the physical effects of alcohol abuse may impair the immune system”. Furthermore, excessive alcohol use has also been associated with poor TB treatment adherence, which can also lead to a higher relapse rate (Soul City Institute, 2015:17).

2.5.4 MDR–TB and its Impact on the TB Pandemic

Millet et al. (2012:544) revealed that there were 650,000 cases of MDR-TB amongst the 12 million cases in the world in the year of 2010. Furthermore, only one in every ten MDR-TB patients had access to adequate treatment (Millet et al., 2012:545). Therefore, the multi-drug resistant (MDR) tuberculosis has had a severe impact on the available tuberculosis programmes among communities. In the context of South Africa, the National Institute for Communicable Diseases (2014) conducted a South African tuberculosis drug resistance survey. The survey looked at the rate of MDR-TB prevalence in the provinces of South Africa. The survey revealed that the highest rate was observed in Mpumalanga Province, with an overall rate of 5.1% which included both new and previously treated cases, which was higher than the national rate. It can be argued that the potential reason for the high prevalence in this province was cross border migration (Swaziland is the immediate neighbouring country, and it has a high prevalence of MDR-TB). However, in the context of the study sampling area (KwaZulu-Natal), the survey indicated a lower MDR-TB prevalence rate compared to other provinces due to an effective treatment and cure programme (National Institute for Communicable Diseases, 2014:05).

However, the MDR-TB was also associated with extensively drug-resistant tuberculosis (XDR-TB). According to the National Institute for Communicable Diseases (2014:08), “the occurrence of laboratory confirmed XDR-TB, a more resistant form of MDR, has long been recognised in South Africa and was managed as difficult–to–treat MDR TB cases”. A major outbreak of XDR-TB was reported in rural KwaZulu-Natal (Tugela Ferry) which affected 52 patients within the area and garnered worldwide attention (National Institute for Communicable Diseases, 2014:08).

2.6. Literature Relating to Tuberculosis Perceptions and Stigma

This section of the study will present and outline some of the literature and key findings which were identified in other studies in relation to tuberculosis stigma and perception among the community and young adults. This section will include the studies that were conducted over the last ten years or so that specifically focused on the perceptions and stigma of tuberculosis. In presenting this literature, the study has adopted the NDoH (2009:45) framework in addressing tuberculosis perception and stigma among young adults in the rural areas. The framework will be guided by the comprehensive approach which includes socially-related and client-related factors.

2.6.1 Client-Related Factors

The study will first outline and focus on discussing the literature that will solely focus on client- and individually-related factors which emanated from the issue of the perceptions and stigma of tuberculosis among the individuals in South Africa and other countries which has also led to the development of stigma-related perceptions of tuberculosis among young adults.

2.6.1.1 Tuberculosis-related stigma and delay in seeking care

Stigma in tuberculosis has been identified as one of the factors which has also contributed to the issue of delay in seeking care for TB at the onset of symptoms associated with the disease. According to Kurspahic-Mujicic et al.'s (2013) study conducted in Brazil, tuberculosis was considered to be a socially stigmatising disease, and, as a result, individuals delayed seeking care for tuberculosis. One may argue and infer that this was due to the stigma attached to TB-HIV association, as the symptoms of TB and that of HIV are interlinked.

A study that was conducted by Rundi (2010) in the Sabah area of East Malaysia in 2006 to assess the knowledge and perceptions of TB patients, as well as those of the community, about TB indicated that patients and relatives perceived the care provided by the government and the private sector to be fair. Despite this, the stigma associated with tuberculosis led individuals with TB to feel embarrassed about their illness so they delayed seeking treatment and did not readily inform others about their TB status.

Rundi (2010) found that TB patients often travelled to other clinics rather than attend the one in their village to obtain assistance, as the stigma of tuberculosis arguably comprised of fear and judgement from other individuals. The stigma therefore impacted health seeking behaviour, and resulted in delays seeking care and treatment for TB.

Pungrassami et al.'s (2010) quantitative study aimed at estimating the association of TB and AIDS stigma in patients with a delay in seeking care for TB symptoms; reported that men with a higher degree of TB stigma had a small increase in delay times, while women had a small decrease in delay times. These researchers found that patients presenting with haemoptysis also experienced a high degree of TB stigma, but this was associated with a small increase in delay times; while patients presenting with fever or extra pulmonary symptoms only, although experiencing a high degree of TB and AIDS stigma delayed seeking treatment to a lesser degree (Pungrassami et al., 2010:01).

Shasha (2013:18) conducted a study in the Eastern Cape which revealed that people with tuberculosis did not attend clinics regularly due to the fact that they did not want people to know that they suffered from TB. The stigma felt by them arose from the fact that the community associated TB with HIV. This was further confirmed by Skinner and Classens (2016) in their study that was also conducted in South Africa, which reported that the delay in seeking assistance for TB was also related to the association of TB and HIV. Therefore, it can be argued that the delay in seeking care and treatment for TB stems from the stigma of the disease being associated with HIV/AIDS. HIV/AIDS and TB are associated with each other as they share some common symptoms, such as severe chest pains. There is a lot of fear associated with TB disease, delays health seeking behaviour.

2.6.1.2 Fear of TB disease

One may also argue that the fear of contracting TB has led to the perpetuation of the stigma. According to the study conducted by Atre et al. (2015), which focused on exploring gender and community views of stigma and tuberculosis in India, the majority of the respondents in the study anticipated that persons with TB would hide

their condition and experience diminished self-esteem due to the disease. The respondents reported that the community could isolate persons with TB and his/her belongings because they feared it (tuberculosis) as a serious and contagious disease (Atre et al., 2015:63).

Dodor and Kelly (2009) reported that in Ghana community members indicated that fear of the disease created stigma, which led to participatory restrictions for community members who were TB infected. Dodor and Kelly (2009:172) asserted that “because of the fear of infection, most of the community members were of the view that TB patients should not be part of the society and should therefore be separated from the rest of the society’’. The perception of the need for separation of infected individuals existed to the extent that community members mentioned that they would not marry a TB patient and would also not encourage a family member to enter into a relationship with a TB patient. The main reason given for this position was the fear of infection. Another prime example of stigma and fear revealed in the study was that the majority of the community members indicated that they would not agree to the selection of a TB patient to represent them in any official capacity. This was because they understood the disease to be infectious and feared that such a community leader would infect them when talking to them as they would inevitably cough when talking. It should be noted that the study did not specifically report the perceptions of young adults.

A study of the stigmatisation of individuals with TB, reported outside of the African context by Moya and Lusk (2013) in the United States of America and Mexico, also suggested fear as one of the factors associated with tuberculosis stigma. In this study fear led to the isolation of TB sufferers from their loved ones and the perception that the person with TB was “filthy” (Moya and Lusk, 2013). Skinner and Classens (2016) conducted a study in five provinces in South Africa which indicated that the fear of tuberculosis was still seen as one of the factors that caused people with tuberculosis to be stigmatised and to be isolated by their communities and their loved ones. It could be argued that this fear could be caused by the communities’ negative perceptions of the disease as a result of pervading myths and misconceptions. One could also argue that many people’s fear of the disease

emanated from the association of the tuberculosis disease with HIV/AIDS. Nevertheless, the fear of the disease led to the hiding of the disease.

Cramm et al. (2010) revealed that a full 95% of their study respondents believe that people with TB tend to hide their TB status because they are afraid of what others may say (Cramm et al., 2010:10). One could argue that this may indicate fear of tuberculosis which may emanate from the fact that those with tuberculosis will be stigmatised and be blamed for acquiring the disease, thus they hide their tuberculosis status from other people. The hiding of the disease may also be caused by young adults and the community who may associate tuberculosis with HIV/AIDS. This interrelation is further discussed in the following section.

2.6.1.3 HIV/AIDS and tuberculosis

HIV/AIDS has been identified as one of the factors that have contributed greatly to the issue of perceptions of tuberculosis stigma among young adults and among the community, as argued above. Millet et al. (2013:542) confirmed in their study conducted in Barcelona, Spain that "the emergence of HIV has had an unprecedented impact on the epidemiology of infectious diseases in general and particularly on TB''. Therefore, it can be argued that the presence of HIV within the community has led to more stigma of tuberculosis since it (TB) is an infectious disease which is passed from one person to another through air. Courtwright and Turner (2010) revealed that in the areas of high HIV prevalence, where HIV and TB co-infection is common, the link between the two diseases has contributed to the stigmatisation of TB. It can be argued that the prevalence of HIV/AIDS within the rural settings has contributed to the tuberculosis stigma due to the co-infection which is common since people with HIV are at risk of being exposed to TB. This is also due to the fact that TB is one of the opportunistic diseases that the individual with HIV is exposed to and which could then lead them to be infected with TB.

Therefore, in the context of young adults and TB/HIV co-infection; Millet et al. (2013:452) confirmed and argued that "TB/HIV co-infection affects mainly young adults in the most productive years of their life, having a significant social and economic impact''. Therefore, HIV/AIDS can thus be identified as a mitigating factor

in an increasing tuberculosis and HIV co-infection in communities and in young adults.

Gebremarium et al. (2010:06) reported that in Ethiopia, many patients believed that they were susceptible to the stigma of TB. This was mainly due to the fact that people associated TB with HIV. Similarly, Shasha (2013:53), in a study conducted in the Nyanga area in South Africa, further supported TB/HIV co-infection stigmatisation by indicating that people suffering from TB are inclined to hide their diagnosis because people tend to associate TB with HIV.

In addition, Cramm et al. (2010:10) found that respondents in the Eastern Cape were under the misconception that all TB patients will also develop HIV. This perceived link can be explained by the fact that TB is the main cause of death among the estimated 5.5 million South Africans living with HIV/AIDS (>10% of the country's population) (Cramm et al., 2010:11). It can be noted that the perceived link also includes young adults, as Cramm et al. (2010) further adds that the co-infection rate approaches 73% in TB patients of all age groups. One could argue that this perceived link of HIV/AIDS and tuberculosis emanates from the level of tuberculosis knowledge that the community and young adults has.

2.6.1.4 Knowledge of tuberculosis

Knowledge about tuberculosis is one of the critical factors in the area of tuberculosis and stigma. It can be argued that apart from the fear of tuberculosis and the association of tuberculosis with HIV, lack of knowledge or having only limited knowledge of tuberculosis is one of the factors that has perpetuated tuberculosis stigma among the community.

A study by Zhang et al. (2016) conducted in China, explored the experiences of high school students with pulmonary tuberculosis, and found that typically the school students lacked knowledge regarding tuberculosis. According to Zhang et al. (2016:05), “despite undergoing several months of treatments, the sick students’ understanding of TB knowledge was still unsatisfactory’’.

However, a quantitative study by Renuka and Dhar (2012) which also focused on the knowledge and awareness of tuberculosis in India, indicated that 77% of students

were aware that TB was caused by bacteria, 85% were aware that it could spread from person to person, and 76% were aware that the lungs are the most commonly affected organs. In Renuka and Dhar's (2012) study, students seemed to have a basic knowledge of tuberculosis in relation to the transmission routes of the disease, while the study by Zhang et al. (2016) indicated that the students' knowledge of tuberculosis was unsatisfactory. Furthermore, both the abovementioned studies utilised similar samples as well as a similar sampling frame of 18 students (sample) in high school (sampling frame). This researcher argues that the high school students in those studies are in a similar category to young adults, which is the sample that was adopted by the current study.

The evidence from China and India was contradictory in terms of TB knowledge among high school students. Kambale's (2012) study focused on school learners who were in primary schools as opposed to high school students in the country of Malawi. Kambale reported that participants believed the causes of TB were bad luck, spirits and a heredity condition (Kambale, 2012). These beliefs were likely to perpetuate the stigma related to tuberculosis. Therefore, in the context of spirits and heredity scenarios, it could be argued that this was due to the prevailing cultural beliefs that existed within the society that made the society believe that the causes of TB were the result of bad spirits and witchcraft. Miller et al. (2017) further attested to this by stating that their study participants also believed and reported cultural beliefs about TB, which included TB being sexually transmitted, or inherited, or to be caused by curses or witchcraft.

Ismail and Josephat (2014:02) conducted a study in Tanzania where respondents aged between 15-19 years of age were less likely to accept that TB spread from person to person through the air when coughing, compared to those who were 45–49 years of age. The authors reported that this was likely to be because those of a younger age had lower levels of education, were more likely to be living in rural areas where they were not exposed to television or radio, and thus were all less knowledgeable about TB transmission (Ismail and Josephat, 2014:02).

Matebesi and Timmerman (n.d.05) reported that in the South African context, participants who had previously had TB and/or lived with a contact (someone who

had TB) were more likely to know what TB was, than someone who had no personal history of TB or no association with a close contact who had it.

Outside of those infected or exposed, the Soul City Institute (2015) found that there were still many who professed to have no knowledge of the disease at all. Moreover, Finlay et al. (2012) confirmed in a study conducted in South Africa, that people receiving treatment for tuberculosis had not received enough education about tuberculosis at the beginning of their treatment. Therefore, as a result of this, stigma was more likely to perpetuate among the community and young adults (Finlay et al., 2012). One could therefore argue that the community and young adults' perceptions and beliefs about tuberculosis could be one of the factors which have contributed to the perpetuation of the tuberculosis stigma.

2.6.2. Socially-Related Factors

2.6.2.1 Community perceptions and beliefs towards tuberculosis and people infected with tuberculosis

Community perceptions and their beliefs about tuberculosis and people with tuberculosis were also mitigating factors which contributed to the issue of tuberculosis stigma among the community and young adults. It could be noted in the study by Lee et al. (2017) that was conducted in Taiwan, that not disclosing one's illness to others was associated with tuberculosis stigma and depression. Moreover, the study indicated that the community's perspective towards tuberculosis included the different treatment of the TB patients, such as isolating the individuals with TB. One could argue that this attitude was associated with existing perceptions and beliefs among the community.

Cofie and Lius' (2014) study in Ghana revealed that TB was believed to be a spiritual disease, rather than a physical disease, and thus did not require medical attention. This perception had many social consequences, such as stigmatisation and the social isolation of TB patients and/or their families, diminishing marriage prospects for young TB victims, and sometimes for their family members as well (Cofie and Liu, 2014:26). Rundi (2010) also reported the impact of tuberculosis stigma to include a poor prospect of marriage for individuals with TB who were single.

In the African context, Sikwese (2012) also discussed some perceptions that individuals had of people with tuberculosis. The participants in Sikwese's study were between the ages of 18 to 49, which overlapped with the ages of the participants in the current study. Sikwese (2012) noted that individuals perceived tuberculosis as a disease that was dangerous and highly contagious, thus they disassociated themselves from individuals who were TB infected.

The Soul City Institute (2015) in South Africa also confirmed these perceptions and beliefs by indicating that TB was often described as dangerous, as a disease that killed and was thus associated with death. Thus death and danger were the prevalent terms that the community maintained to describe tuberculosis, and this formed their perceptions and beliefs about tuberculosis. As a result of this, people with tuberculosis were more likely to be subjected to stigmatisation. The perceptions and beliefs fall within the realm of myths and misconceptions. The Soul City Institute's study revealed that some of these myths and misconceptions were related to the prevention and transmission of tuberculosis, such as the misconception that TB was a sin or curse (Soul City Institute, 2015:17). This underlying perception impacted on beliefs related to the transmission of the disease, as well as the treatment of the disease, to the extent that some perceived tuberculosis as a disease that could not be medically cured.

Watermayer and Penn (2018) also added in their study in rural South Africa that some perceived beliefs about tuberculosis appeared to have a significant influence on tuberculosis knowledge and the perpetuation of tuberculosis stigma. This was because the community members and the individuals with tuberculosis often cited *"tindzage" or "mafulatsa",* a cultural disease manifesting in TB symptoms, as a result of not following cultural rituals correctly, especially when there was a death in the family (Watemayer and Penn, 2018:05). Therefore, one may argue that the beliefs that are held by the community are also one of the factors that have contributed to tuberculosis and its stigma, as these beliefs and perceptions have influenced the attitudes of the community and young adults towards tuberculosis and towards people infected with tuberculosis. This is discussed in the following section.

2.6.2.2 Attitudes towards tuberculosis and towards people infected with tuberculosis

The attitudes of young adults and the community seem to have contributed to the tuberculosis stigma in the rural South Africa. Attitudes in this context refer to the behaviour and actions that the young adults have conveyed or will convey towards tuberculosis and towards people with tuberculosis.

Kwedi Nolna et al. (2016) conducted a study in Cameroon, and found that the attitude of young adults and the community towards tuberculosis and towards people with tuberculosis was caused by various factors such as their knowledge of the disease, as well as fear of the disease. According to Kwedi Nolna et al. (2016:1202), "the majority of the respondents (65.9%) admitted to being afraid of getting infected with TB". Therefore, as a result of this fear, their attitudes were different towards people with TB.

According to Cramm et al. (2010:06), younger people, especially those who had tuberculosis, often mentioned that they had support from family and friends. Cramm et al. (2010), in their quantitative study conducted in South Africa years later, reported that while young adults had more positive attitudes towards people with tuberculosis, 95% of their study's respondents believed that people with tuberculosis tended to hide their TB status, as they were afraid of what others would say.

Similarly, a quantitative study by Lee et al. (2017) in China also confirmed that the majority of the community indicated that they would treat individuals with tuberculosis differently. This meant that the attitudes towards people with tuberculosis would result in some community members disassociating themselves from individuals who were TB-infected.

The Soul City Institute (2015:37) also confirmed in their study that they conducted in South Africa, that a significant number of people knew others with TB and, "in spite of the support expressed by some, attitudes of stigma and discrimination towards people with tuberculosis still linger[ed]''.

Dodor and Kelly (2009:172), in their study of attitudes and behaviours towards tuberculosis in Ghana, revealed that fear of infection and participatory restrictions were the prevalent factors that created stigma towards TB. The majority of the community members reported that they would not marry a TB patient and would not

encourage any family members to enter into such relationships either. They also revealed that the majority of communities were of the view that TB patients should not sell goods in the community because they could infect others with TB (Dodor and Kelly, 2009:172). Therefore, this researcher asserts that beliefs and perceptions about tuberculosis influence communities' and young adults' attitudes towards tuberculosis and towards people with tuberculosis.

2.7. Summary of the Literature

The above literature indicated that there were several underlying factors that perpetuated the stigma relating to tuberculosis, and these factors further influenced an individual's perceptions about tuberculosis. Drawing from the client-related factors, it was evident that the perceptions about tuberculosis and the existing stigma about tuberculosis led to delays in seeking care for tuberculosis, and fear of the disease was very prevalent. Several studies in international and African countries, as well as in South Africa itself, confirmed that fear of the disease was one of the factors which perpetuated stigmatisation, which in turn created different perceptions about tuberculosis among the community and in young adults. Furthermore, the literature also confirmed that the HIV/AIDS and tuberculosis interrelation by the community and by some of the young adults contributed greatly to the tuberculosis stigma. The literature findings confirmed that the interrelation between HIV/AIDS and tuberculosis was also caused by the lack of knowledge about tuberculosis in the community and among young adults.

However, reflecting back on the socially-related factors, the literature findings indicated that community perceptions and beliefs about tuberculosis were factors which were dominant in the area of tuberculosis perceptions and stigma. The literature findings also revealed that attitudes towards tuberculosis and towards people with tuberculosis contributed to the issue of tuberculosis and stigma in international countries, as well as in Africa and South Africa. Thus in the context of stigma, this researcher argues that individuals project their stigma onto other individuals with tuberculosis by having and by observing the aforementioned factors such as fear of the disease, misperceptions and beliefs, as well as negative attitudes towards TB and towards people with TB.

Following exposure to stigma and the various factors associated with stigma observed by young adults and the community, some of them ended up having a self-perceived stigma, which resulted in their fear of the disease and their subsequent stigmatisation of those with tuberculosis.

2.8. Justification for the Study

In order to address the requirements of this dissertation, the researcher reflected on published tuberculosis literature, which focused on the disease, perceptions about tuberculosis and the stigma related to tuberculosis. Several gaps were noted in the literature, and one of them was the lack of studies that focused exclusively on young adults who were between the ages of 20–35 years in South African rural areas, particularly in KwaZulu-Natal. Furthermore, in terms of research design, there were few studies which had adopted a qualitative approach in exploring the perceptions and stigma of young adults within the rural context. Therefore, as a result of this gap, the current study adopted a qualitative approach. The rationale in selecting this approach was that it enabled the study to explore and illicit in-depth information about the tuberculosis perceptions and stigma from participants, since the study was descriptive in nature and the aim was to explore tuberculosis perceptions and the stigma relating to tuberculosis among young adults within the rural areas of KwaZulu-Natal.

Chapter 03: Methodology

3.1. Introduction

The chapter will detail the research design, sampling strategy, data collection technique, methods of data analysis, as well as the trustworthiness and ethical considerations of the study.

3.2. Research Paradigm

The study will adopt the qualitative approach. The rationale in selecting the qualitative approach was that the approach enabled the study to elicit in-depth information about tuberculosis perceptions and stigma from the participants, as Terre Blanche et al. (2006:8) indicated that "qualitative research takes an in-depth approach to the case it studies in order to understand it more thoroughly". Therefore, with this approach, the study was able to obtain an in-depth view of the relevant data from the participants.

3.3. Study Context

The study was conducted in Ezitendeni, a community located within the KwaZulu-Natal Province in the Midlands cluster of the Inkosilangalibalele Local Municipality, under the UThukela District Municipality. The area is demarcated by agricultural farms surrounding the area (Umtshezi Integrated Development Plan, 2014). The community area of Ezitendeni comprises of families who are kinship family groups that share similar family ties and household groups which may comprise families that are not related. Reflecting on the availability of resources, the area comprises of the the school, Weenen Combined School, and other educational centres which are non-governmental organisations. There are also existing community structures and departments such as the Haviland Clinic, local business structures, Phila Centre and the Simunye Youth Development Project (Umtshezi IDP, 2014). Moreover, the "Umtshezi Municipality has a 33% unemployment rate and is dominated by low income households, with 27% having no income and the majority of those who are employed are involved in the agricultural sector. It follows that the majority of the unemployed are in the areas with high population concentration". The majority of the population can be considered functionally illiterate, as "70.5% of the population has a primary education and 18.8% have not been to school" (Umtshezi IDP, 2014: 02).

3.4. Research Design

The study focused on and selected a descriptive design as the design for the study. "Descriptive research refers to research studies that have as their main objective, the accurate portrayal of persons, situations or groups" (Burns and Grove, 2005:312). Therefore, the study utilised a descriptive design as the research study design to allow young adults to describe their experiences, perceptions and stigma relating to tuberculosis and to people who are diagnosed with tuberculosis.

3.5. Sampling Strategy

The study was guided by a non-probability, purposive sampling strategy. According to Terre Blanche et al. (2006:36), "non-probability sampling means that the probability of each person is unknown, or the unit being selected for sample is unknown". Purposive sampling involves the selection of participants who have the ability to produce rich-information and who serve the purpose of the research (Terre Blanche et al., 2006). Therefore, the current study selected participants who served the purpose of the study and who had the ability to provide in-depth and rich information about tuberculosis perceptions and stigma within the community of the Ezitendeni area. Guest et al. (2006) noted that data saturation for main themes was possible by the 6th interview, and for this reason, the study selected 12 participants who were between the ages of 20 – 35, and who comprised of 6 females and 6 males.

3.6. Data Collection

The study utilised semi-structured interviews as a way of collecting data. According to Terre Blanche et al. (2006:26), "semi-structured interviews include in-depth interviews and its purpose is to collect and generate in-depth subjective information from individuals". This information is generated through open-ended questions and prompts. Therefore, the study conducted one-on-one interviews with participants within the area of Ezitendeni. The interviews were conducted in the area where the participants resided. The interviews were recorded on a digital recorder and supplemented with written notes taken by the researcher. The interviews lasted for 45 minutes to 1 hour. The interviews were conducted from the 13th of September 2017 to the 16th of October 2017. Moreover, the interviewer utilised isiZulu and

English while collecting data through interviews. The data was then transcribed verbatim before analysis.

3.7. Data Analysis

According to Terre Blanche (2006), data analysis involves several steps which include familiarisation and immersion, inducing themes, coding and elaboration, as well as interpretation and checking. Therefore, the study also implemented these steps in order to ensure that the data analysis process was implemented appropriately.

3.7.1. Familiarisation and Immersion

This was "the process which involved the development of ideas and theories about [the] phenomenon being studied'' (Terre Blanche et al., 2006:322) which, in this context, was tuberculosis perceptions and stigma among young adults. Therefore, after the raw research data was transcribed, the researcher familiarised herself with and immersed herself in the data that was collected by working with the texts (field notes and interview transcripts) that were transcribed from the raw data. Conducting this process allowed the researcher to know more about the study and about the sets of interpretations that were likely to come out of the study on tuberculosis about stigma and perceptions.

3.7.2. Inducing Themes

Terre Blanche et al. (2006:322) describe induction as "a means to infer general rules or classes from specific instances". Therefore, this process involved induction following extraction of the themes which were found within the data that was collected by the study. These themes covered the array of issues which were prominent in exploring the tuberculosis stigma and perception among young adults. The themes also comprised of sub-themes, and these are presented in the findings chapter.

3.7.3. Coding

According to Terre Blanche et al. (2006:323), "coding involves working and outlining different sections of the data as being relevant to one or more themes''. Therefore, the researcher extracted sections and marked them differently as a way to distinguish each theme that was identified within the raw data. This involved any textual bit such as paragraphs, sentences, phrases or words. The codes and

relevant extracts were subsequently reviewed to ensure that the extracts fitted the codes and, where necessary, to further refine themes into subthemes.

3.7.4. Elaboration

This process involves capturing a fresh view of the data and also to carefully compare sections of the data within the text that appear to belong together (Terre Blanche et al., 2006). It further elaborates on the information which was obtained during the data collection process.

3.7.5. Interpreting and Checking

This was the last method that the study implemented in the process of data analysis. The study used well-selected, thick descriptions from the data to interpret the data in terms of the literature reviewed; in comparison to other data obtained, in the context of the subject position; as well as in terms of the theoretical framework and the researcher's underlying assumptions.

3.8. Trustworthiness

The study further ensured that trustworthiness was implemented. There were several processes that were implemented to ensure the trustworthiness of the study.

3.8.1. Credibility

Anney (2014) describes credibility as the confidence that can be placed in the truth of the findings. It can be argued that credibility establishes whether or not the research findings represent plausible information drawn from the participants' original views (Anney, 2014). Therefore, in order to ensure that the credibility was implemented, the study integrated strategies which prolonged engagement by actively engaging with the participants in the field with regards to tuberculosis perceptions and stigma. Furthermore, the researcher used debriefing sessions with the study supervisor to ensure the credibility of the study.

3.8.2. Transferability

Another process which was implemented was that of transferability. The process refers to the degree to which the results of qualitative research can be transferred to other contexts, with other respondents (Anney, 2014). To make it possible for researchers to assess transferability to other contexts, information regarding the study context, participants and processes has been detailed in this document.

3.8.3. Dependability

According to Babbie and Mouton (2006:278) dependability means “an inquiry must provide its audience with evidence that if it were to be repeated with the same or similar respondent in the similar context, its findings will be similar”. This is the process that the researcher conducted the inquiry audit which refers to an auditor such as examiner who examined the documentation of critical incidents such as interview records and investigator’s daily journal to ensure that the study conducted the interviews and has the evidence of the interviews.

3.8.4. Conformability

This is the last process that the researcher conducted in ensuring the trustworthiness of the study. According to Babbie and Mouton (2001: 278) “conformability denotes the degree to which the findings of a study are the product of its focus and not of the biases of researcher”. This process involved following procedure which is proposed by Babbie and Mouton (2001) and which is leaving audit trail that include raw data, data reduction and analysis process, data reconstruction and synthesis product, process notes, material relating to intentions and dispositions as well as instrument development information.

3.9. Ethical Considerations

The study was guided by the following ethical considerations:

3.9.1. Informed Consent

A request for informed consent (copy of consent form is attached as Appendix A) was issued to the study participants, and it was written in a manner which the participants understood. In addition to the form, during the verbal consent process, it was carefully explained to the participants that their participation was voluntary and that confidentiality would be maintained throughout the study.

3.9.2. Ethical Clearance

The study was approved on 02 June 2017 by the University of KwaZulu-Natal Humanities and Social Sciences Research Ethics Committee. The ethical clearance number for the study is HSS/0676/017M. During the study, the participants were informed that if they experienced problems with the researcher, they could notify the research ethics administration and the telephone number was provided. However, no problems were reported by the participants.

The participants were also informed of the following rights:

3.9.3. Beneficence

Beneficence imposes a duty by researchers to minimise harm and to maximise benefits (Polit and Beck, 2008:170-171). The researcher was constantly alert to any issues that could possibly have harmed the participants' physical or mental conditions. The involvement of the participants did not put them at any disadvantage at any point during this study, nor did it expose them to any manipulation. The interviews were conducted in the comfort of the participants' homes. Participants were given a choice to answer the questions in English or Zulu.

3.9.4. Respect for Human Dignity

This principle includes the right to self-determination and the right to full disclosure (Polit and Beck, 2008:171-172). Each participant received an informed consent letter which contained the information pertaining to the study, and the purpose of the study and the roles and rights of the participants were explained in a language with which they were comfortable. Participants were encouraged to ask questions. The contact details of the researcher were included in case they had any queries. Participation was voluntarily. The participants could choose to leave the study at any time.

3.9.5. Principle of Justice

According to this principle, participants had the right to fair treatment and a right to privacy (Polit and Beck, 2008:173-174). Confidentiality and privacy were ensured. Participants were asked to sign consent forms which described the study, promised confidentiality and indicated that the subjects could withdraw their participation at any given time. All data obtained was managed by the researcher and the research supervisor only. The name of the participant did not reflect anywhere on the transcribed data; instead the names of participants were replaced with pseudonyms and an asterisk. The data was stored securely in the discipline/department, accessible only to the researcher and the researcher's supervisor. It will be destroyed within five years after the completion of the study.

3.10. Study Limitations

These were anticipated potential limitations of the study:

3.10.1. Fear and Honesty

The participants might not have shared their point of view honestly during the study with regard to tuberculosis, due to fears that they might have had about tuberculosis and the perceptions relating to it.

3.10.2. Availability of the Participants:

Some participants were not available on the day that was set for individual interviews. However, amendments were made to adjust the time in which the participants were available for interviews.

3.11. Conclusion:

The aim of this chapter was to provide and present the methodology which guided the study. The chapter further outlined the data analysis which was carried out to analyse the data that was provided by the study. Moreover, the chapter also outlined the ethical considerations that were implemented within the study and which guided the study.

Chapter 04: Findings

4.1 Introduction

The chapter presents and discusses the findings of the current study. The chapter starts with an overview of the themes and sub-themes that emerged from the thematic analysis and then details each theme. However, the study will first outline and depicts the demographic data and characteristics of participants who were part of the study.

4.2. Characteristics of the Participants

The following is the demographic data of the participants who were part of the study that was conducted with the aim of exploring the perceptions and stigma of tuberculosis among young adults in rural areas of South Africa. This demographic data depicts the characteristics of the participants which include the gender, age group, educational level as well as the occupation of the participants. It should be noted that all these participants reside in one demographic area which is the Ezitendeni area.

Table 4.2.1 Characteristics of the participants

Name	**Gender**	**Age Group**	**Educational Level**	**Occupational /Employment Status**
Zah*	Female	30-35	Secondary completed	Employed
Thembeka*	Female	20-25	Tertiary (some)	Tertiary student
Tshitshana*	Female	30-35	Secondary completed	Part-time employment
Yolanda*	Female	26-30	Secondary (some)	Employed
Phaka*	Female	26-30	Tertiary completed	Employed
Lethiwe*	Female	20-25	Tertiary (some)	Tertiary student
Nele*	Male	30-35	Tertiary (some)	Tertiary student
Thobe*	Male	26-30	Secondary (some)	Employed
Steh*	Male	26-30	Secondary completed	Employed
Mzokhona*	Male	20-25	Secondary (some)	Self-employed
Lindo*	Male	20-25	Secondary	Unemployed

			completed	
Siya*	Male	20-25	Tertiary (some)	Tertiary student

4.3. Emerging Themes

The following were the main themes that emerged within the study. These themes generated the sub-themes. The main themes were: young adults' knowledge of tuberculosis, their reactions should they discover they were personally infected with tuberculosis, their experiences with tuberculosis-infected people, their perceptions towards the TB-infected people living within the community, and the possible stigma that they may maintain about tuberculosis.

Table 4.3.1. Emerging Themes and Sub-Themes

Theme	Sub-Theme
4.3.1. Young adults' knowledge of Tuberculosis	• Understanding of the disease • Knowledge about transmission of Tuberculosis • Knowledge about the treatment of Tuberculosis
4.3.2. Young adults' views on being diagnosed with Tuberculosis	• Reaction to Tuberculosis infection
4.3.3. Young adults' experiences with Tuberculosis-infected people	• Young adults' family members • Community members
4.3.4. Young adults' possible stigma of Tuberculosis	• Lack of knowledge • Fear of the disease • Reaction of fear and discrimination of Tuberculosis • HIV/AIDS and Tuberculosis
4.3.5. Young adults' perceptions of TB infected people living in the community	• Community attitudes towards people living with Tuberculosis • Young adults' attitudes towards people living with Tuberculosis

4.3.1. Young Adults' Knowledge about Tuberculosis

This theme was used to explore the young adults' knowledge by tapping into their perceptions and understanding about the disease which is tuberculosis. The theme further explored the young adults' knowledge about tuberculosis by exploring the young adults' knowledge in terms of the transmission and treatment of the disease.

4.3.1.1. Understanding of the disease

The aim was to obtain young adults' understanding of the disease in terms of their own description of the disease. Therefore, the findings indicated that some young adults had an understanding of the tuberculosis disease, as they specifically described it.

> *According to my understanding, TB is the disease that can be spread via the air. It not exactly like other diseases which can be spread from flesh to flesh…TB is the disease where you don't know where or how you acquired it because it something that is spread via the air…'* (Zah*).

The participant went on to note that a person cannot do anything specific to prevent tuberculosis, especially if that person lives with an individual who is infected with tuberculosis, since the person is at a higher risk of being infected with tuberculosis. This would not be the same as someone who needs to prevent HIV, where there is a need to insist on condom use with the aim of protecting and preventing HIV. Therefore, as tuberculosis is spread through the air, this may be the contributing factor to fears around the disease, as reducing the risk is not under an individual's control. This fear was elaborated as quoted below:

> *What I know about TB is that it is something which can be treated; it is not like HIV… and TB is something that you cannot prevent because you can even get it in the street while you are taking a walk…'* (Siya*).

TB was commonly associated with the chest but as the responses below indicate, there were still differences in the accuracy of additional knowledge provided by the participants, with one incorrectly indicating that it could not be cured, and a second correctly identifying that when untreated, the condition could be fatal.

> *What comes to my mind is that TB is something which is associated with the chest or disease which is not cured…'* (Yoh*).

> *I could say TB is a chest-related disease…which is infectious. I could say again that this disease is very much dangerous if you don't treat it, as one can end up dying because of it… (Phaka*).*

In addition, some participants correctly identified additional symptoms associated with the disease:

> *It is a chest-related disease; its symptoms include fever, sweating, being unable to eat… (Thobe*).*

However, there were some of the participants who attempted to describe tuberculosis even though they were not specific in their description of the disease.

> *I can say that it is a disease which badly affects people in a bad way; a disease which makes the person weak in health…* (Lindo*).

Therefore, with regard to the general understanding of the disease, it could be argued that the aforementioned responses indicate that the participants did not have full understanding of the disease.

4.3.1.2. Knowledge about tuberculosis transmission

In exploring the knowledge of tuberculosis, the study first explored the knowledge of tuberculosis transmission. The findings indicated that the participants were aware that tuberculosis is a disease which is transmitted from one person to another person, particularly where there is poor cough hygiene and close proximity in a shared space.

> *Most of the time it is through coughing…if someone coughs and does not close his/her mouth, that is where TB germs flow easily and affect others… (Zah*).*
>
> *I think you acquire it if someone who has TB coughs and spreads it to another person who inhales the TB germs…especially if they are in the same space…(Thembeka*).*
>
> *From what I know is that TB is infectious, especially if we share a space or if we are in the same room… and when you cough, and you don't cover your mouth. It is where TB is being spread… (Phaka*).*
>
> *A person can get TB if there is someone who is coughing and who does not close his or her mouth…or in other cases, it someone who coughs out the sputum or if someone inhales the TB germs from someone who has TB…'(Mzokhona*).*

While being correct, some participants emphasised fewer common routes of transmission.

> *It could be dust…or other harmful things that one inhales which are detrimental to his/her chest…or an infant who becomes infected by TB because of his or her mother who is TB infected… (Yoh*).*

Reflecting from the abovementioned response, the participant mentioned dust as one of the factors that increases the risk of TB infection. Therefore, it could be

argued that this is more common to industrial workers who are exposed to silica tuberculosis which is caused by silica dust. Yarahmad et al. (2013:35) noted that "workers are at risk of exposure to silica dust in various industries including mining, tunnel construction, casting, glass production, sandblasting, ceramic production, shingle production and cement and concrete manufacturing". Yet other participants reported that they were not able to describe the transmission of the disease.

> *To be honest, I don't know what cause TB…but I know that it is coughing which is long overdue… (Lettie*).*
>
> *I am really not sure about that part… what I know is that if someone has TB, it can be spread to another person… I do not know how it is spread to another person…(Nele*).*

As the following response was not correct in the proposed preventative measure of drinking milk, it is noted here as a negative case.

> *If you are someone who stays at a dusty place or maybe working with woods that produce dust… you just need to get something that will cover your face so that you will not be affected by the dust…if you work with wood that draws dust, you end up inhaling the dust… if you have been working in a dusty place, it better to drink milk, as it helps in neutralising and in cleaning the dust that you have inhaled… (Thobe*).*

It can be argued that this participant's suggestion about preventing tuberculosis can be regarded as one of the myths, as there is no existing research which has confirmed that one can prevent tuberculosis by drinking milk.

4.3.1.3. Young adults' knowledge about tuberculosis treatment

Some of the participants indicated that they are well aware of the tuberculosis treatment.

> *I think I do have a bit of the treatment information… what I know is that there is a treatment that you should take which is a 6 month treatment but I do not know on how one should take the treatment… but I know that you take it for 6 months, and after that 6 months, the TB is treated… (Phaka*).*
>
> *Yes, it is usually 6 month's treatment… (Lethie*).*
>
> *I think there is a treatment; it's 6 months where they say they can treat you properly…after that time, it needs extra attention to be treated but what I know is that within 6 months, you can cure it… (Nele*).*
>
> *There is a treatment for TB, as I have mentioned earlier on that it's a treatable disease…but I don't really know that well the name of TB treatment but there is a treatment for TB that you take for 6 months… (Siya*).*
>
> *There is a treatment in my knowledge but they usually say it's a six month treatment where you take a treatment for six months…after six months that individual can be treated… (Mzokhona*).*

The abovementioned findings indicate that the participants were aware of the typical overall treatment duration, but that they were unsure about the specific names of the medication used or when it should be taken. Furthermore, one may argue that the knowledge of long period treatment which is 6 months may contribute to the fear of infection and therefore stigma.

Despite the aforementioned findings from these participants, there were participants who were unsure about the duration of the tuberculosis treatment.

> *Yes, there is a treatment for TB, the treatment may be similar to the HIV/AIDS treatment since it is pills (TB treatment) that you take each day…although I do not have enough knowledge on what the duration for taking the treatment is… (Lindo*).*

However, there were some of the participants who went in-depth in describing the process of treatment for tuberculosis which is also treated within the hospital. This was due to the fact that some participants were previously exposed to tuberculosis treatment programmes and some have undergone the tuberculosis treatment itself.

> *The treatment for TB is available…if it is a normal TB, the treatment is there but if it is MDR-TB, that is where you have an uncontrollable TB and it is where you are not allowed to sit with people since you can infect them…that is when you are being taken to a TB hospital (King Dinuzulu Hospital). And from there, you take the treatment up until you finish your medical treatment…another thing is that sometimes you unable to diagnosed TB in the sputum bottle… I am saying this, as I once had TB, and I had a situation where they were unable to trace and diagnose TB from my sputum; they ended up referring me to X-ray and that is where it was identified… (Thobe*).*

The above participant was one of the tuberculosis patients who was referred and who underwent the tuberculosis treatment within a hospital setting. Nevertheless, the other participant revealed an interesting perspective when it comes to tuberculosis treatment which includes a 6 months treatment and MDR tuberculosis treatment.

> *There is a treatment for TB where you should do check-ups and then you go to a hospital; what the department is now doing is that if you have stayed for more than a week without seeing the clinic or hospital and if your TB is infection is above than the normal TB, they put you in a programme in hospital to treat you…the Department of Health has also implemented a programme where one with TB can obtain his medication at hospital, not at home, so that he can finish the medication at the hospital, so as to avoid one to finish off the medication at home, as it could make the individual be unable to finish the medication if he/she is at home…' (Steh*).*

In summary, despite the fact that some participants were unsure about the duration of the treatment which is 6-month treatment, typically participants were aware of the tuberculosis treatment. Moreover, exploring the knowledge of the young adults about

tuberculosis served as the fundamental route in exploring the perceptions of tuberculosis and the possible stigma that young adults may hold about tuberculosis and people with tuberculosis.

4.3.2. Young Adults' Views on being diagnosed with Tuberculosis

The study explored young adults' views on being diagnosed with tuberculosis. The aim of exploring their views was to obtain their in-depth subjective views and feelings with regards to tuberculosis infection in their lives. Furthermore, it was also to establish their perceptions of being infected with tuberculosis and the possible stigma that they may have regarding tuberculosis.

4.3.2.1. Reaction to tuberculosis infection

The participants within the study indicated their views and reaction should they be diagnosed as infected with tuberculosis. The participants had a variety of responses. Some participants mentioned that they would not be worried about it, while some indicated that they will be afraid.

> *I won't have much stress because I am aware that TB is treatable. I could visit the clinic where I could obtain 6 months TB treatment…' (Tshitshana*).*

However, others indicated that they would feel afraid due to the fact that they have previously witnessed other people dying because of tuberculosis, but they similarly, would take action to start dealing with the disease upon their lives.

> *I could be afraid due to the fact that I have seen other people passing away because of TB…but along the way, I think, I can accept the situation and start taking the steps in dealing with the disease… (Phaka*).*

One male participant revealed that it will be hard at first to accept the results at first but knowing about tuberculosis will eventually encourage him to seek medical assistance.

> *It will be hard but since I am aware and educated about TB, I will come to my senses and be alert that TB can be treated. I can take that six-month treatment… (*Siya*).

Others similarly indicated that their reaction would be practical (i.e. they will seek medical assistance to treat tuberculosis).

> *So, for me, it will be to visit clinic and do medical check-ups and if I got TB, I would then follow the proper instructions which will assist me in taking up the treatment… (*Steh*).

Therefore, the aforementioned reactions indicate that although few of the participants thought that they would be afraid, and some shocked, if they discovered that they have tuberculosis, they would take the necessary steps to deal with the disease.

4.3.3. Young Adults' Experiences with Tuberculosis-Infected People

The theme focused on the experiences of young adults with regard to their interaction with TB-infected individuals. The aim of exploring this area was to obtain in-depth and subjective experiences of young adults who lived or interacted with people who are infected with tuberculosis. Therefore, in exploring this area, some of the participants revealed that they have interacted with people who are TB-infected within the family and community.

4.3.3.1. Young adults' family members

Some participants within the study revealed that they have interacted with their family members who had tuberculosis. Although this interaction typically exposed the young adults in experiencing tuberculosis in an indirect way, this experience was one of the ways in which the young adults obtained an in-depth knowledge about tuberculosis.

> *I had a grandfather who stayed on the other side of my home. He had TB and we were always there for him. We would usually go and clean up his room that he was staying in; he was old and frail and he was unable to do most of the things by himself. During my interaction with him, I did not have that fear; I touched him and came close to him because I did not pay much attention to what he had… (Lethie*).*
>
> *I have talked to a lot of people who told me that they once had TB…but I remember there were two children from my family who had TB but I was able to talk to them without fearing that they will infect me, as they were already taking up the treatment for TB… (Siya*).*
>
> *We once lived with someone who had TB and that individual died due to TB… after that incident, the social workers referred us to the doctor who further did medical check-ups on us, as we have lived with the someone who had TB and it was found that we did not have the TB disease…during the time where the deceased was alive, I was able to talk to him and I had a good relationship with him… (Mzokhona*).*

It should be noted that in the last verbatim statement, the participant referred to the uncle that they lived with who had tuberculosis and who thus passed on due to tuberculosis. Therefore, this was where the family had to be screened for tuberculosis so as to check and assess those who might have been infected. Nevertheless, it is evident that the abovementioned individuals had an experience of tuberculosis even though they did not have tuberculosis themselves. Through living

with people who were TB-infected, they experienced the disease which influenced their perception about tuberculosis and people with tuberculosis.

4.3.3.2. Community members

Some of the participants revealed that they never lived nor did they interacted with people who are infected with tuberculosis in the family environment. However, they have interacted with people who are infected with tuberculosis within the community.

> *Since I am someone who is involved in the community, we do have situations where we usually do profiling, where you usually find out that some households tend to hide someone who has TB. However, in my case, I could say that I do not have a problem with people who have TB …' (Steh*).*
>
> *I once had an experience with someone who had TB…and I never avoided her because of the medical condition that she had….even though I knew that she had TB, we continued to have a good interaction…' (Yoh*).*
>
> *Yes, I once had interrelations with someone who had TB for quite a long time, as we worked together…things between us were okay… I was able sit with her and interact with her even though they mentioned that she had TB… nothing changed between us… (Phaka*).*

Apart from the young adults interacting with people who had tuberculosis, the findings further revealed that there were participants who indicated that they never had experienced nor did they interact with people who had tuberculosis.

> *If I could speak the truth, I will say, I have never interacted with someone who has TB because from my knowledge, most of the people tend to hide their sickness or some are unable to reveal their TB status to others… (Lindo*).*
>
> *I have never had experience with someone who has TB, even in this community, I have never interacted with someone who has TB… (Tshitshana*).*
>
> *No, I have not been in a situation where I had to interact with someone who has TB…even within the community, I have never interacted with someone who has TB…(Nele*).*

Therefore, the findings from the above were an indication that there were participants who had interacted with people who were infected with tuberculosis, both in the community and family environment. These participants typically indicated that they have never stigmatised people with tuberculosis.

On the other hand, the findings also indicated that there were participants who indicated that they never interacted with people who had tuberculosis. This may be because, as noted in the literature review, the individuals may have hidden their sickness or some were unable to reveal their TB status to others. Therefore, it could be argued that the hiding of the disease emanated from the fear that the

tuberculosis-infected individuals may have had due to the fear of discrimination and isolation that they could possibly experience from the community. However, it could be argued that the implications of hiding the disease may also result in TB-infected people having insufficient support from other community members, and this may make them be less motivated to attend health facilities for health support, as a result of hiding the disease from other people, so that their tuberculosis status would remain unknown.

4.3.4. Young Adults' Possible Stigma of Tuberculosis

The main objective of the study was to explore the stigma among young adults which they may have with regard to tuberculosis. The aim of focusing in this area was to explore the stigma that the young adults may have towards people with tuberculosis. Therefore, in exploring this area of stigma to young adults, the study identified some of the mitigating factors which made the young adults stigmatise people with tuberculosis who were living within the area.

4.3.4.1. Lack of knowledge

Several participants from the male and female groups indicated that they did not stigmatise people with tuberculosis, however, it was evident that the lack of complete knowledge about tuberculosis was one factor which triggered young adults to indirectly discriminate or stigmatise people with tuberculosis.

> *I do not recall stigmatising anyone with TB but there is a stigma, especially if you lack knowledge about TB… (Zah*).*
>
> *'Not really, because I was not aware that TB could kill you…honestly, I knew nothing about TB, but when I became fully aware about it, I then considered it as a serious disease…so stigma wise, I did not have it… (Lethie*).*

The above extract illustrates the tension between ensuring that the severity of the TB left untreated is completely understood and the need to ensure that these messages do not unwittingly increase the stigma.

Nevertheless, it should be noted that the existing high levels of illiteracy level of among young adult adults within the area as outlined by the Umtshezi IDP (2014), may have contributed to them being less knowledgeable about tuberculosis within the area and this was one of the factors that was outlined by the participants which made some of the other young adults in the area to be less knowledgeable about tuberculosis.

> *There was never a time where I found myself stigmatising or discriminating someone with TB… I guess maybe it is because it is something that I did not pay attention to…and looking at the community, I think most of the people discriminate others with*

TB because they do not have the full knowledge about TB or they are not well-educated about tuberculosis…(Lindo).*

4.3.4.2. Fear of the disease

In addition to the abovementioned factor about the stigma of tuberculosis, fear of the disease was identified as one of the factors which perpetuated the stigma of tuberculosis among young adults as well as the community. Some of the participants indicated that they were afraid of people with tuberculosis. To some participants, this was one of the ways in which people with tuberculosis were stigmatised.

Although I have never stigmatised anyone with TB, many people stigmatise people with TB because they are afraid that they will get TB… (Thembeka).*

I did find myself being afraid of people who have TB in the area, and the reason could be that I was not fully aware about TB. I was hearing people speak about it and some describing how is it spread. I think that was one of the reasons I had to run away from it because I did not want to be infected….and I was also afraid of being stigmatised, as people who have tuberculosis tend to be stigmatised, therefore, I was also afraid that people will look at me differently if I had TB… (Nele).*

This extract illustrates that the fear of the disease, together with an incomplete knowledge about the disease, resulted in the participant indirectly stigmatising those who had tuberculosis by isolating himself from those who had tuberculosis.

However, one particular participant noted that it was knowledge of the most common transmission routes that made them more conscious of the behaviour of others around them.

Yes, I won't lie, I do have that little fear about the people with TB but it is more of the fact that I am concerned about my health; it like if someone is going to cough next to me, I do have that attention to see if he or she has closed their mouth while coughing because I am very sensitive to that. I am very concerned about my health… (Siya).*

Therefore, reflecting to the abovementioned statement by this participant, it may be argued that the fear of the disease was also related to the participant being healthily cautious about his life.

4.3.4.3. Reaction of fear and discrimination of tuberculosis.

In addition to the fear of the disease, some of the participants outlined some of the reactions of fear and discrimination of tuberculosis that they have observed within the community.

There are some people in the community who still discriminate against those who have tuberculosis, and some do not associate themselves with TB-infected people… (Thobe).*

There is still that element of discrimination within the community. Some are being gossiped about in some of the public areas such as the taverns due to the fact that they have TB... (Lindo).*

I think in this area, people are not treated well if their TB status is positive…people tend to be cautious and afraid of someone who has TB… in one of the places, I was once being cautioned in an unfriendly way to not sit next to a particular individual who had TB… (Phaka).*

The reactions of community members reported by the participants varied from simple avoidance and gossiping to the outright encouragement of discrimination.

4.3.4.4. HIV/AIDS and tuberculosis

One of the critical factors in the issue of the stigma of tuberculosis was the relationship between tuberculosis and HIV/AIDS. The study findings revealed that this is was one of the factors that triggers stigma among young adults and the community. Participants revealed that many people (including them) had a perception that if one has tuberculosis, that infected individual is also HIV positive.

The stigma about TB is that it is usually linked to HIV/AIDS; most people still believe that a person with TB has HIV/AIDS, and a lack of knowledge about TB is the source of TB stigma in the area… (Steh).*

I had this belief that if someone has TB, the first thing that came to my mind is that the person has HIV because most of the people in the community (including myself) associate TB with HIV… (Tshitshana).*

It could be argued that one of the key indicators that caused several community members to link tuberculosis and HIV/AIDS is weight loss.

Therefore, the study findings suggested that a lack of knowledge, fear of the tuberculosis disease as well as the tuberculosis/HIV/AIDS interrelation are the main sources of stigma which young adults and the community may have towards people with tuberculosis, and these are the sources which cause young adults and the community to stigmatise people with tuberculosis.

4.3.5. Young Adults' Perceptions of TB-Infected People Living in the Community

The study further explored the perceptions of young adults with regard to TB-infected people who are living within the community. The aim of exploring this area was to obtain an in-depth sense of the perceptions of young adults as well as the way in which they view people who are infected with tuberculosis. There are several responses which emerged within the findings which pointed out that people with tuberculosis are still discriminated against within the community.

4.3.5.1. Community attitudes towards people living with tuberculosis

In exploring this area of young adults' perceptions about people with tuberculosis, the study first looked at young adults' observations in terms of the attitudes which are conveyed by the community towards the people living with tuberculosis in the area. The aim was to get their in-depth overview about the way in which people with tuberculosis are treated within the community.

> *Not so well, they discriminate against you and it's like if you have TB or HIV, you are not a person but an animal… (Zah*).*
>
> *There are some who are still discriminated against about having TB, and some tend to be afraid of those who have TB…' (Thobe*).*
>
> *I think people are still afraid most of the time… and it may be because they are afraid that they will be infected with the disease….' (Mzokhona*).*

The abovementioned were some of the findings which indicated that tuberculosis was still regarded as a stigma, as people who were infected with it were stigmatised by both young adults and the community in the area. One may argue and add that the stigma that is experienced by the TB-infected individuals as pointed out by the participants may have emanated from the aforementioned factors which are the fear of the disease and the interrelation of tuberculosis and HIV/AIDS. These sources of stigma could be driving factors which made the community afraid of tuberculosis and thus discriminate against those who have tuberculosis. However, although there was an existing stigma towards people with tuberculosis, the young adults further revealed that some individuals with tuberculosis experience no stigma of tuberculosis, as some community members have an understanding that people with tuberculosis are part of the society. The young adults further explained that people with tuberculosis should be treated well within society.

> *If someone has TB within the community, we should treat him/her fairly just like we treat others. We should not discriminate or treat him/her unfairly….' (Mzokhona*).*
>
> *I think that we should treat them well; there is no need to say, 'I can't speak to you because you have TB'… (Tshitshana*).*
>
> *We have to treat them fairly; if someone has TB, we should be able to treat them just like other people within the community… (Yoh*).*

4.3.5.2. Young adults' attitudes towards people living with tuberculosis

The study also explored the attitudes of young adults toward people who are infected with tuberculosis. The findings revealed that the participants typically expressed positive attitudes towards people living tuberculosis, and it was indicated that they had no problem with people living with tuberculosis within the area.

In my own personal view, if there is someone who has TB within the society, that person should not be excluded because he/she is part of society… we should provide support to him/her…' (Yoh).*

The person should be part of the society regardless of his/her health status. What we can do is that we should be against the stigma of treating other people unfairly based on their health status…so every person who has HIV or TB should be part of society…' (Steh).*

The individual who has TB should be part of the community because everyone has a right to life… (Mzokhona).*

Although these participants accepted the individuals with tuberculosis, there were participants who indicated that the individuals with tuberculosis should also take it upon themselves to deal with tuberculosis which also includes taking up the tuberculosis treatment.

I would say that everyone deserves to be in the community but if they have TB, they must look after themselves… and they should go to the clinic, so that they could be assisted… (Nele).*

I have two answers for that; firstly, in my own honest opinion, I would say that those people with TB should remain here within the society. However, on the other hand, I will say that the person who has found out that he/she has TB, must do a proper follow up and adhere to the TB treatment, especially when the community is encouraging them to take the treatment…(Siya).*

4.4. Conclusion

In conclusion, the chapter aimed at presenting the research study findings which emerged during the data collection process. The findings revealed young adults' knowledge of tuberculosis, their views and reactions on being infected with tuberculosis, their perceptions of TB-infected people living in the community, the stigma of tuberculosis as well as their experiences with tuberculosis-infected people. These were the main themes which emerged within the study.

Chapter 05: Discussion

5.1. Introduction

This chapter discusses the findings of the study as in light of the objectives of the study, and the existing evidence from other contexts summarised in the literature review. It also discusses the findings, as they relate to the theoretical framework that guided the study. The chapter also focuses on outlining and proposing some of the recommendations that could be implemented in the area of tuberculosis and stigma.

5.2. Summary of the Study Findings

The main objectives of the study were to explore the knowledge and awareness of young adults with regard to tuberculosis, to assess the perceptions of young adults with regard to tuberculosis, to understand the experiences of young adults toward people who are diagnosed with tuberculosis, as well as to explore the possibility of stigma among young adults towards those with tuberculosis.

5.2.1. Young Adults' Knowledge of Tuberculosis

As reflected on in the previous chapter, the focus of this theme was to explore the knowledge about tuberculosis transmission, and the knowledge about the treatment of tuberculosis.

5.2.1.1. Young adults' awareness of tuberculosis

The findings confirmed that young adults were generally aware thereof, and they had an understanding of the disease. The participants emphasised that, typically, tuberculosis is a chest- and lung-related disease. The findings were consistent with the Soul City Institute's (2015:14) study which also indicated that "TB is generally understood by most groups to be a disease of the lungs''. However, the findings also confirmed that young adults generally understood the disease of tuberculosis as the disease that can be spread through air. These findings were also consistent with Kambale's (2012) study which confirmed that "81% of learners mentioned that tuberculosis is spread by droplets through coughing and sneezing'' (Kambale, 2012:21). This description of tuberculosis as the disease that is spread through air was supported by the findings from Sikwese's (2012) study which revealed that the participants understood the disease as a disease that is transmitted through air. However, Renuka and Dhars' (2012) study further revealed that "tuberculosis was

understood as a disease which is caused by smoking and overcrowding, respectively'' (Renuka and Dhar, 2012:336).

Therefore, it could be argued that this description of the disease is mostly understood as a mode of transmission for the disease. However, the participants from the study described the disease as a lung- and chest-related disease, and that the disease that can be spread through air.

5.2.1.2. Knowledge about tuberculosis transmission

The findings indicated that the young adults had knowledge about tuberculosis transmission. Some of the participants within the study revealed that tuberculosis is transmitted from one person to another person through coughing and sharing the same space with the infected person. The sharing of the same space with the infected person was one of the findings which is supported by Sikwese's (2012) study which revealed that the "respondents explained that one can get TB by sleeping in the same room with a person who is infected with TB''. Moreover, the findings of the study were also consistent with Kambale's (2012) study which found that most of the participants knew that "TB is spread by droplets through coughing and sneezing''.

While Renuka and Dhar (2012:335) found that "male students were better informed when it comes to tuberculosis transmission'', there were no apparent differences in the knowledge level between young women and men.

5.2.1.3. Knowledge about the treatment of tuberculosis

The findings indicated that some of the young adults were aware of the treatment for tuberculosis. It can be noted that the treatment that the young adults mentioned was the treatment of tuberculosis which was for 6 months. The findings were supported by the findings from data collected among high school students in India (Renuka and Dhār, 2012:335) which revealed that students knew that tuberculosis was preventable and that treatment was free. They knew about DOTS and that the treatment was for 6-9 months. It can be noted that this study, by Renuka and Dhar (2012), indicated that students knew about the DOTS (which is known as Directly Observed Treatment Service) as opposed to the current study findings which suggested that young adults mentioned the treatment for tuberculosis which is for six

months and there was no evidence in the current study findings that young adults were aware of DOTS.

5.2.2. Young Adults' Views on being diagnosed with Tuberculosis

The study explored how young adults would react to being diagnosed with tuberculosis. Some of the participants revealed that they will not be worried about being diagnosed with tuberculosis since they will seek medical assistance. This reaction was also confirmed by Sikwese's (2012) study which indicated that "respondents would not be worried because tuberculosis is treatable''.

However, this current study found that some participants would react with apprehension and felt worried about being diagnosed with tuberculosis. This reaction was parallel with the findings of Sikwese's (2012) study which confirmed that some of the participants would be worried about being diagnosed with tuberculosis, due to the severity of the disease which includes persistent coughing, and because it could result in death. Sikwese (2012:13) confirmed this by revealing that some respondents mentioned that they feared that they would die. However, de Andre et al. (2015) further supported these findings by presenting emotional repercussions which are "the feelings resulting from the diagnosis, illness and treatment process''.

5.2.3. Young Adults' Experiences with Tuberculosis-Infected People

The study aimed at exploring young adults' experiences with tuberculosis-infected people. In exploring this area, the findings identified two of the sub-themes which assisted in generating the subjective experiences of young adults with tuberculosis-infected individuals.

5.2.3.1. Young adults' family members

In exploring the experiences of young adults with tuberculosis-infected people, the findings from the study revealed that the participants have interacted with people who have tuberculosis, particularly people who are family members. The findings also confirmed that the young adults had positive interactions with their family members who were TB-infected. However, the findings of this study differed to the study findings of Matebesi and Timmerman (nd) which suggested that some participants experience hostility towards their families as a result of having tuberculosis (Matebesi and Timmerman, nd).

5.2.3.2. Community members

The study further explored the experiences of young adults with community members who are infected with tuberculosis. The findings indicated that while some of the participants interacted with community members who had tuberculosis, there were participants who revealed that they have never interacted with people who have tuberculosis. However, the participants mentioned that one of reasons they were not certain whether they had interacted with community members who have had tuberculosis was a result of those infected hiding the disease from others. Therefore, the findings revealed that the hiding of the disease emanated from the fear that the tuberculosis-infected individuals had due to the discrimination and isolation that they could possibly experience from the community. The findings of the study by Atre et al. (2015) indicated the similar outcomes which revealed that "the majority of respondents anticipated that persons with TB would hide their condition and experience diminished self-esteem due to the disease'' (Atre et al., 2015:63). This is supported by earlier research by Cramm et al. (2010) who also noted that 95% believe people with TB tend to hide their TB status because they are afraid of what others may say. Therefore, it can argued that the social stigma of the disease, which included the fear of disease, was the reason that led some of the young adults to be unable to interact with the community members.

5.2.4. Young Adults' Possible Stigma of Tuberculosis

The findings confirmed the possible stigma of tuberculosis which is displayed by the community and the possible stigma that the young adults were aware of. Reflecting back to the concept of stigma, Moya and Lusk (2013:549) describe stigma as "a social process that exists when elements of labelling, stereotyping, separation, loss of status and discrimination occur in a power situation which allows them to''. Therefore, the study findings identified some of the mitigating factors which made the young adults indirectly stigmatise people with tuberculosis who are living within the area.

5.2.4.1. Lack of knowledge

The findings confirmed that the lack of knowledge was one of the fundamental factors which led the community and some of the young adults to stigmatise people with tuberculosis. Moreover, reflecting back to the current study findings, it was confirmed that several participants from the male and female groups did not

stigmatise people with tuberculosis. These findings interlinked with the findings of the study from Promtusananon and Peltzer (2005:75) which indicated that “respondents had a limited knowledge about the causes of tuberculosis’’. It can be argued that the lack of knowledge was likely to be a result of the overall low levels of education in the community.

5.2.4.2. Fear of the disease

The study findings identified the fear of the disease as one of the critical factors related to the stigma of tuberculosis among the community and young adults. The findings indicated that some young adults within the study feared the disease, and to some participants, this was one of the ways in which people with tuberculosis were stigmatised. This supports the findings of Atre et al. (2015) who also revealed that “respondents reported that the community may isolate the person with TB and his/her belongings because they fear it as a serious and contagious disease” (Atre et al., 2015:63). The findings were further confirmed by Dodor and Kelly (2009) by indicating that the “fear of infection and participatory restrictions were some of the factors which created stigma towards TB’’ (Dodor and Kelly, 2009:172). The findings further revealed that “because of the fear of infection, most of the community members were of the view that TB patients should not be part of the society and should therefore be separated from the rest of society’’ (Dodor and Kelly, 2009:172). Furthermore, it can be argued that as a result of the fear of the disease, there was a barrier in effective tuberculosis health care. Dimitrova et al. (2006) reported that the stigma created not only fear, but a significant barrier to effective access to tuberculosis care. This was due to the fact that ‘’tuberculosis was seen as an infectious, dangerous and threatening condition’’ (Dimitrova et al., 2006:271). One may argue that the fear of the disease may have contributed to the stigma being the barrier for effective health care among the community and young adults. Therefore, it can be argued that the fear of the disease among young adults and the community indirectly played a role in stigmatising those who have tuberculosis within the community which prevents them accessing effective health care.

5.2.4.3. HIV/AIDS and tuberculosis

The association of HIV/AIDS with tuberculosis was one of the themes which were confirmed by the study findings with regard to the tuberculosis stigma among the community and young adults. The findings revealed that the perceptions that those

infected with tuberculosis were also likely to be HIV positive was one of the factors that triggered stigma towards some young adults and among the community. Other studies also supported the existing notion of tuberculosis and HIV/AIDS. According to the study by Turner (2010:36), “in areas of high HIV prevalence, where HIV and TB co-infection is common, the link between the two diseases has contributed to the stigmatisation of TB’’. The findings suggested that in areas of HIV prevalence, tuberculosis can be perceived as the marker for someone who is HIV positive, and this may have contributed to stigma being transferred to individuals (Turner, 2010). A study by Cramm et al. (2010) further revealed that 54% of the respondents believe TB patients will also develop HIV’’ (Cramm et al., 2010:03). Matebesi and Timmerman (nd:08) further revealed that “the presence of the stigma was linked to HIV/AIDS, as the participants revealed that someone who has TB is believed to have HIV/AIDS’’. Therefore, it can be noted that in this particular factor, which is similar to the other studies, the participants in the study expressed similar notions about HIV/AIDS and tuberculosis interrelation which resulted in the stigmatisation of tuberculosis-infected patients.

5.2.4.4. Reaction of fear and discrimination of tuberculosis.

The findings revealed that the participants observed reactions of fear and discrimination of tuberculosis within the community. Isolation, fear and discrimination were the key demonstrations of stigma and thus of a reaction of fear and discrimination. The findings of the study interlinked with the Brazilian study conducted by de Andre et al. (2015) which indicated self-segregation as one of the reactions to tuberculosis stigma and discrimination as well as the fear. According to de Andre et al. (2015:06), this “behaviour was highlighted in the study of psychosocial experiences of patients with TB which indicated medical leave from work as a resource of self-segregation’’. It further argued that this was “not only because of their health condition but also because of the desire to avoid social and emotional embarrassment’’ (de Andre et al., 2015:06).

Outside of formal employment, stigma also had the potential to impact on the livelihoods of those in informal employment. Dodor and Kelly (2009) found that the “majority of community members are of the view that TB patients should not sell in the community because they can affect others’’ (Dodor and Kelly, 2009:172). Therefore, it can be argued that the study confirmed that as a result of the reaction of

fear of tuberculosis, some community members resorted to isolating and segregating others who were infected with tuberculosis, thus discriminating them due to the tuberculosis infection.

5.2.4.5. Perceived community attitudes towards people living with tuberculosis

The findings indicated that the stigma which is projected by the community towards the individuals with tuberculosis still exists. The findings from Dodor and Kelly (2009) revealed that the fear of infection and participatory restrictions created stigma towards tuberculosis. Moreover, because of the fear of the infection, most of the community members were of the view that "TB patients should not be part of society and should therefore be separated from the rest of society'' (Dodor and Kelly, 2009:172). These findings were supported by the findings of the Soul City Institute (2015) study which confirmed that in spite of the support expressed by some, attitudes of stigma and discrimination towards people with tuberculosis still linger. In the same vein, Kwedi Nolna et al. (2016) further added that the negative attitudes towards individuals with TB was largely influenced by the fear, as the majority of respondents in that study indicated to being afraid of getting infected with TB. Nevertheless, the findings confirmed that some individuals with tuberculosis experience no stigma of tuberculosis when the community had an understanding that individuals with tuberculosis are part of society. The findings were also parallel with the study findings of Musoke et al. (2013) which indicated that community members had positive attitudes towards people who are TB positive.

5.2.4.6. Young adults' attitudes towards people living with tuberculosis

The findings revealed the young adults subjective overview and attitudes towards people living with tuberculosis within the rural area. The findings confirmed that the participants showed a mainly positive attitude towards people living with tuberculosis. Therefore, the current study findings were supported by the Soul City Institute (2015) findings which also suggested that the participants from the study showed positive attitudes towards individuals with tuberculosis. The participants indicated that they showed these attitudes by taking care of the relatives, and by supporting those with tuberculosis to visit health care facilities for treatment.

5.3. Social Cognitive Conceptual Framework

The study was guided by the social cognitive theory. Bandura (2001:57) indicated that the "social cognitive theory explains human behaviour in terms of a dynamic three-way reciprocal model in which personal factors, environmental influences and behaviour continually interact''. The basic premise of the framework is that people can learn, not only through their own experiences, but also by observing the actions of others and the results of those actions. Therefore, it can be argued that the study also indicated the views which were expressed by young adults in being diagnosed with tuberculosis, the experiences of young adults with individuals who are infected with tuberculosis as well as the attitudes of young adults towards the individuals who have tuberculosis. Therefore, it can be argued that the views and the attitudes that young adults had towards tuberculosis were informed by the internal stimuli suggested by the cognitive framework which suggested that people are neither driven by inner forces nor automatically shaped and controlled by external stimuli (Bandura, 2001:58). For that reason, it can be inferred that the views expressed by the young adults and the attitudes that they conveyed towards tuberculosis and towards the individuals with tuberculosis, were influenced by internal forces which can be interpreted as the experiences and the perceptions that the young adults had with regard to tuberculosis. Moreover, these internal perceptions and the experiences of young adults towards tuberculosis automatically shaped their attitudes towards tuberculosis as well as to individuals who had tuberculosis.

5.4. Perceptions and Stigma of Tuberculosis

The fundamental goal of the current study was to explore the perceptions and stigma of tuberculosis among young adults. Therefore, reflecting to the findings and to the perceptions that were presented by the study, it can be argued that there were several factors which led to the influences which consecutively perpetuate unfitting perceptions and stigma of tuberculosis. Nevertheless, Bos et al. (2013) argued that the origin of stigmatisation lies in cognitive representations that people (perceivers) had regarding those who possess the stigmatised conditions (targets). Therefore, one may infer that the existence of stigma regarding tuberculosis was due not only to the underlying factors of tuberculosis stigma, but through cognitive representations such as the tuberculosis disease which can thus elicit stigma and unfitting perceptions that could be rapt to individuals with tuberculosis.

Therefore, the reaction of fear and discrimination was largely influenced by the existing public stigma which represented people's social and psychological reactions to someone they perceive to have a stigmatised condition which, in this instance, is tuberculosis. So, the findings revealed that the participants observed reactions of fear and discrimination of tuberculosis within the community. Isolation, fear and discrimination were the key indications of the demonstration of stigma and thus of the reaction of fear and discrimination. One may argue that the reaction of fear and discrimination may also led to self-segregation which indicated isolation of oneself as the individual from other people who have the tuberculosis disease. Studies such as the one by de Andrade et al. (2015) revealed self-segregation as one of the reactions to the tuberculosis stigma and discrimination as well as the fear.

Therefore, one may contend that the presence of self-segregation could be due to self-stigma. This relates to individuals with tuberculosis who separate themselves from loved ones or community members due to their own fear of infecting others with tuberculosis and tuberculosis stigma. Nevertheless, apart from the reaction of fear of the disease and self-stigma, stigma by association, which in this study was identified as HIV/AIDS and tuberculosis interrelation, further influenced some community members to demonstrate unfitting perceptions and stigma of tuberculosis.

Therefore, one may deduce that based on the findings of the previous studies on tuberculosis perceptions and stigma, and through the findings of the current study revealed through young adults, the stigma and perceptions of tuberculosis still exist. Furthermore, the findings of the study revealed that young adults did not hold or demonstrate stigma towards the individuals with tuberculosis. Nonetheless, they were aware about the stigma of tuberculosis which existed within the community. However, the findings revealed that the young adults hold unfitting perceptions of tuberculosis such as the perceptions that tuberculosis and HIV/AIDS are interrelated in the manner that someone who has tuberculosis thus has HIV/AIDS. It should be noted that these perceptions that were held by young adults were due to a lack of knowledge about tuberculosis, as the primary findings indicated.

5.5. Limitations of the Study

The anticipated limitation that the study could encounter was that the study lacks generalizability, as it utilised a small, purposively selected sample which consisted of 12 participants. As a result, the study findings may not be generalised to the whole population.

5.6. Recommendations

Therefore, based on the aforementioned research findings, the study proposed the following recommendations to be made with regard to the perceptions and stigma of tuberculosis among young adults.

5.6.1. Awareness Campaigns on Tuberculosis among Young Adults

The study suggests that more awareness campaigns about tuberculosis should be implemented at the communities where the young adults reside. These campaigns can also be implemented at TVET (Technical and Vocational Education and Training) colleges, universities, schools and other institutions that have larger numbers of young adults. It was evident in the study findings that although young adults typically knew about tuberculosis, they were, however, not fully aware about the other factors that relate to tuberculosis such as the treatment of tuberculosis and other critical aspects of tuberculosis. Therefore, conducting these awareness campaigns to young adults will help in making the young adults be more aware that tuberculosis is a critical disease that requires serious attention. Furthermore, conducting these awareness campaigns could also assist in deconstructing the negative ideologies and perceptions of tuberculosis that young adults and the communities may have regarding tuberculosis.

5.6.2. Future Studies

The study recommends that the future studies on tuberculosis and stigma could focus on conducting the quantitative based studies which will utilise both samples of male and female young adults. The aim could be to compare the findings of both samples. This could also help in determining the trends that relate to tuberculosis perceptions and stigma among young adults who are residing in rural settings. The study could also extend to older individuals who are in the age group of 40–60, as the aim will be to explore their perceptions of tuberculosis and the possible stigma of tuberculosis that could exist.

5.7. Conclusion

In conclusion, the main aim of the study was to explore the perceptions and stigma of tuberculosis among young adults. The objectives were to explore the awareness of young adults with regard to tuberculosis, to assess the perceptions of young adults with regard to tuberculosis, to understand the experiences of young adults toward the people who are diagnosed with tuberculosis, and to explore the possibility of a stigma among young adults with regard to tuberculosis. However, the study was able to achieve these objectives, as the findings indicated the general understanding of tuberculosis among young adults, and the young adults' knowledge about tuberculosis which included the knowledge about the transmission of tuberculosis. The findings further indicated the young adults' perceptions of tuberculosis and being diagnosed with tuberculosis, young adults' attitudes towards people infected with tuberculosis, the possible stigma of tuberculosis among young adults as well as their experiences with tuberculosis-infected individuals. Therefore, it can be concluded that the young adults had tuberculosis perceptions which included unfitting perceptions which were due to a limited knowledge of tuberculosis. Moreover, the study findings revealed that the young adults did not uniformly hold, nor did they demonstrate stigma towards the individuals with tuberculosis. However, they were aware about the existing stigma in the community that is attached to tuberculosis within the rural area of KwaZulu-Natal.

Reference List

Anney, V.N. 2014. Ensuring the quality of the findings of qualitative research: looking at trustworthiness criteria. *Journal of Emerging Trends in Educational Research and Policy Studies (JETERAPS). 5(2): 272-281*.

Atre, S., Kudale, A., Morankar, S., Gosoniu, D. and Weiss, M.G. 2011. Gender and community views of stigma and tuberculosis in rural Maharashtra, India. *Global public health*. *6*(1): 56-71.

Babbie, E. and Mouton, J., 2001. 'Objectivity and Trustworthiness in Qualitative Research', in The Practice of Social Research, Oxford and New York: Oxford University Press, pp.274-278.

Bandura, A. 2001. Social cognitive theory: an agentic perspective*. Annual review of psychology*. 52(1): 1-26.

Brown, L., Trujillo, L. and MacIntyre, K. 2001. *Interventions to reduce HIV/AIDS stigma: What have we learned?* New Orleans, LA: Horizons Project.

Bos, A.E., Pryor, J.B., Reeder, G.D. and Stutterheim, S.E. 2013. Stigma: advances in theory and research. *Basic and applied social psychology*. 35(1): 1-9.

Brieger, W.R,. 2006. Definitions of Community. *John Hoskins Bloomberg School of Public Health* lecture (10): 1-5. Available online at http://ocw.jhsph.edu/courses/SocialBehavioralFoundations/PDFs/Lecture10.pdf. [Accessed 19 November 2017]

Burns, N. and Grove, S.K. 2005. *The practice of nursing research: conduct, critique, and utilisation*. 5th ed. St Louis: Elsevier Saunders.

Courtwright, A. and Turner, A.N. 2010. Tuberculosis and stigmatisation: pathways and interventions. *Public health reports*. 125(4): 34-42.

Cramm, J.M., Finkenflügel, H.J., Møller, V. and Nieboer, A.P. 2010. TB treatment initiation and adherence in a South African community influenced more by perceptions than by knowledge of tuberculosis. *BMC public health*. 10(1): 72.

Cofie, R. and Liu, A. 2014. *Knowledge, Myths and Misconceptions of Ghanaians about Tuberculosis*. International Journal of Advanced Physiology and Allied Science. North America.

Dimitrova, B., Balabanova, D., Atun, R., Drobniewski, F., Levicheva, V. and Coker, R. 2006. Health service providers' perceptions of barriers to tuberculosis care in Russia. *Health Policy and Planning*. 21(4): 265-274.

de Andrade, E.D.T., Hennington, É.A., de Siqueira, H.R., Rolla, V.C. and Mannarino, C. 2015. Perspectives of patients, doctors and medical students at a public university hospital in Rio de Janeiro regarding tuberculosis and therapeutic adherence. *PloS one*. 10(9): e0137572.

Dodor, E.A. and Kelly, S. 2009. 'We are afraid of them': attitudes and behaviours of community members towards tuberculosis in Ghana and implications for TB control efforts. *Psychology, health and medicine*. 14(2): 170-179.

Finlay, A., Lancaster, J., Holtz, T.H., Weyer, K., Miranda, A. and van der Walt, M. 2012. Patient and provider-level risk factors associated with default from TB treatment, South Africa, 2002: A case-control study. *BioMed Central*. 12 (1) 56: [Online]. Available at: [http://www.biomedcentral.com/1471-2458/12/56/] [Accessed 1 June 2012].

Freitas, I.M., Crispim, J.D.A., Pinto, I.C., Villa, T.C.S., Brunello, M.E.F., Pinto, P.F.P.S. and Arcêncio, R.A. 2012. Knowledge and perception about tuberculosis of patients' families under directly observed treatment at a health service in Ribeirão Preto-SP, Brazil. *Texto and Contexto-Enfermagem*. 21(3): 642-649.

Fogel, N. 2015. Tuberculosis: a disease without boundaries. *Tuberculosis*. 95(5): 527-531.

Gebremariam, M.K., Bjune, G.A., and Frich, J.C. 2010. Barriers and facilitators of adherence to TB treatment in patients on concomitant TB and HIV treatment: a qualitative study. *BMC Public Health*. 10 (1), 651.

Guest, G., Bunce, A., Johnson, L. 2006. How many Interviews are enough? An experiment with data saturation and variability. *Family Health International*. 18(1): 59-82.

Hossain, S., Quaiyum, M.A., Zaman, K., Banu, S., Husain, M.A. and Islam, M.A. 2012. Socioeconomic position in TB prevalence and access to services: results from a population prevalence survey and a facility-based survey in Bangladesh. *PLoS ONE*. 7(9): [17-26]. [Online] Available at: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3459948/ [Accessed 18 October 2018].

Ismail, A. and Josephat, P. 2014. Knowledge and perception on tuberculosis transmission in Tanzania: multinomial logistic regression analysis of secondary data. *Tanzania journal of health research*. 16(1): [02-03]

Kambale, S. 2012. *Assessment of the knowledge and perceptions about tuberculosis among primary school children in NTCHEU district, Malawi*. (Doctoral dissertation, University of the Western Cape).

Kurspahić-Mujčić, A., Hasanović, A. and Sivić, S. 2013. Tuberculosis related stigma and delay in seeking care after the onset of symptoms associated with tuberculosis. *Medicinski Glasnik*. 10(2): [16-17]

Kwedi Nolna, S., Kammogne, I. D., Ndzinga, R., Afanda, B., Ntone, R., Boum, Y., & Nolna, D. 2016. Community knowledge, attitudes and practices in relation to tuberculosis in Cameroon. *The International Journal of Tuberculosis and Lung Disease*, *20*(9), 1199-1204.

Lee, L.Y., Tung, H.H., Chen, S.C. and Fu, C.H. 2017. Perceived stigma and depression in initially diagnosed pulmonary tuberculosis patients. *Journal of clinical nursing*. 26(23-24): 4813-4821.

Long, N.H., Johansson, E., Diwan, V.K. and Winkvist, A. 2001. Fear and social isolation as consequences of tuberculosis in VietNam: a gender analysis. *Health policy.* 58(1): 69-81.

Lindsay, P.H. and Norman, D.A. 2013. *Human information processing: An introduction to psychology*. [London]: Academic Press.

Macq, J., Solis, A. and Martinez, G. 2006. Assessing the stigma of tuberculosis. *Psychology, health and medicine*. 11(3): 346-352.

Millet, J.P., Moreno, A., Fina, L., Del Baño, L., Orcau, A., De Olalla, P.G. and Cayla, J.A. 2012. Factors that influence current tuberculosis epidemiology. *European Spine Journal*. 22(4): 539-548.

Manderson, L. 1992. Community participation and malaria control in Southeast Asia: defining the principles of involvement. *The Southeast Asian journal of tropical medicine and public health*. 23(1): 9-17.

Matebesi, Z. and Timmerman, C. The TB patient: qualitative evidence of perceived factors affecting treatment compliance. *Joint research project on tuberculosis control in the Free State, South Africa: From infection to cure*. Available from: https://www.ufs.ac.za/docs/librariesprovider20/centre-for-health-systems-research-development-documents/documents/the-tb-patient-qualitative-evidence-of-factors-affecting-compliance-1.pdf?sfvrsn=2. [Accessed 11 November 2017].

Moya, E.M. and Lusk, M.W. 2013. Tuberculosis stigma and perceptions in the US-Mexico border. *salud pública de méxico*. 55(1): s498-s507.

Musoke, P. and Mayanja-Kizza, H. 2013. Burden of tuberculosis disease among adolescents in a rural cohort in Eastern Uganda. *BMC infectious diseases*. 13(1): 349.

National Department of Health. 2014. *Joint Review of HIV, TB and PMTCT programmes in South Africa: Main Report. April*. [Online]. Available at: http://www.health-e.org.za/2014/04/14/report-joint-review-hiv-tb-pmtct-programmes-south-africa/. [Accessed 12 November 2017].

National Department of Health. 2009. *TB Guidelines*. [Online]. Available at: http://familymedicine.ukzn.ac.za/Libraries/Guidelines_Protocols/TB_Guidelines_2009. sflb.ashx [Accessed 21 March 2019].

National Institute for Communicable Diseases. 2014. *South African Tuberculosis Drug Resistance Survey (2012-14). Division of National Health Laboratory Service. Communiqué. South African Family Practice.* [Online]. Available at: http://www.nicd.ac.za/.../Update%20on%20DRS%20Survey%20to%20all%20Stakeholders. [Accessed 14 November 2017].

National Youth Development Policy Framework of South Africa. 2015. [Online] Available at: file:///C:/Users/User/Downloads/NYP%20Policy%202020%20Report%20(1).pdf. [Accessed 12 October 2017]

Polit, D.E. and Beck, C.T. 2008. *Nursing Research. Generating and Assessing Evidence for Nursing Practice*. 8th ed. Philadelphia: Wolters Kluwer Health/Lippincott Williams and Wilkins.

Promtussananon, S. and Peltzer, K. 2005. Perceptions of tuberculosis: attributions of cause, suggested means of risk reduction, and preferred treatment in the Limpopo province, South Africa. *Journal of Health, Population and Nutrition*. Vol. 21 (1): 74.

Pungrassami, P., Kipp, A.M., Stewart, P.W., Chongsuvivatwong, V., Strauss, R.P. and Van Rie, A. 2010. Tuberculosis and AIDS stigma among patients who delay seeking care for tuberculosis symptoms. *The International journal of tuberculosis and lung disease*. 14(2): 181-187.

Renuka, M. and Dhar, M. 2012. Knowledge and awareness of tuberculosis among high school students of Mysore City. *Al Ameen Journal of Medical Sciences*. 5(3): 333-336.

Rundi, C. 2010. Understanding tuberculosis: perspectives and experiences of the people of Sabah, East Malaysia. *Journal of health, population, and nutrition*. 28(2): 114.

Shasha, A.C.N. 2013. *Patient experiences and perceptions of non-compliance with TB treatment*. (Doctoral dissertation, Stellenbosch: Stellenbosch University).

Skinner, D. and Claassens, M. 2016. It's complicated: why do tuberculosis patients not initiate or stay adherent to treatment? A qualitative study from South Africa. *BMC infectious diseases*. 16(1): 712.

South African National Tuberculosis Association (SANTA). 2017. *What is Tuberculosis?* [Online]. Available at: http//:www.santa.org.za/latent-tb.html . [Accessed 20 March 2017].

Statistics South Report. 2013. *Morbidity and Mortality patterns among the youth of South Africa*. [Online]. Available at: http//:http://www.statssa.gov.za/?page_id=3839. [Accessed 15 October 2017].

Stutterheim, S.E., Pryor, J.B., Bos, A.E., Hoogendijk, R., Muris, P. and Schaalma, H.P. 2009. HIV-related stigma and psychological distress: the harmful effects of specific stigma manifestations in various social settings. *Aids*. 23(17): 2353-2357.

Sikwese, S.E. 2012. *Community perceptions of tuberculosis and people diagnosed with tuberculosis in a rural community in Malawi*. Doctoral dissertation, [University of Witwatersrand].

Soul City Institute. 2015. *TB Formative Research. July. Siyahlala Informal Settlement, Western Cape*. [Online]. Available at: www.soulcity.org.za/projects/tuberculosis/research/tb-formative-research-final-report--docx.pdf. [Accessed 20 January 2018]

Terre Blanche, M. and Durrheim, K. 2006. Histories of the present: social science research in context. *Research in practice: Applied methods for the social sciences*. 2(1): 1-17.

Tolossa, D., Medhin, G. and Legesse, M. 2014. Community knowledge, attitude, and practices towards tuberculosis in Shinile town, Somali regional state, eastern Ethiopia: a cross-sectional study. *BMC public health*. 14(1): 804.

Umtshezi Municipality. 2014. *Integrated Development Plan*. Umtshezi Municipality. [Online]. Available at: file:///C:/Users/User/Downloads/KZN234%20Umtshezi%20IDP%202014-15.pdf. [Accessed 12 July 2017].

Waako, J., Verver, S., Wajja, A., Ssengooba, W., Joloba, M.L., Colebunders, R., Musoke, P. and Mayanja-Kizza, H. 2013. Burden of tuberculosis disease among adolescents in a rural cohort in Eastern Uganda. *BMC infectious diseases*. 13(1): 349.

Watermayer, J. and Penn, C. 2019. Community perspectives on tuberculosis care in rural South Africa. *Health and social care in the community*. 27(1): 182-190.

World Health Organisation. 2014. *Global tuberculosis report 2014. Geneva: World Health Organisation. WHO/HTM/TB/2014.08*. [Online]. Available at: http://reliefweb.int/report/world/global-tuberculosis-report-2014 [Accessed 12 June 2017].

World Health Organisation. 2015. *Global tuberculosis report 2015*. [Online]. Available at:https://apps.who.int/iris/bitstream/handle/10665/191102/9789241565059_eng.pdf?sequence=1&isAllowed=y. [Accessed 13 September 2017].

Woith, W.M. and Rappleyea, M.L. 2016. Emotional representation of tuberculosis with stigma, treatment delay, and medication adherence in Russia. *Journal of health psychology*. 21(5): 770-780.

Yarahmadi, A., Zahmatkesh, M.M., Ghaffari, M., Mohammadi, S., Labbafinejad, Y., Seyedmehdi, S.M., Nojomi, M. and Attarchi, M. 2013. Correlation between silica exposure and risk of tuberculosis in Lorestan Province of Iran. *Tanaffos*. 12(2): 34.

Yin, X., Yan, S., Tong, Y., Peng, X., Yang, T., Lu, Z. and Gong, Y. 2018. Status of tuberculosis-related stigma and associated factors: a cross-sectional study in central China. *Tropical Medicine and International Health*. 23(2): 199-205.

Zhang, S., Li, X., Zhang, T., Fan, Y. and Li, Y. 2016. The experiences of high school students with pulmonary tuberculosis in China: a qualitative study. *BMC infectious diseases*. 16(1): 758.

APPENDIX A: INFORMED CONSENT

Consent to Participate in Research

I……..have been informed about the study entitled (Exploring perceptions and stigma of tuberculosis among young adults in a rural area of KwaZulu-Natal) by Siphesihle Khumalo.

I understand the purpose and procedures of the study.

I have been given an opportunity to answer questions about the study and have had answers to my satisfaction.

I declare that my participation in this study is entirely voluntary and that I may withdraw at any time without affecting any of the benefits that I usually am entitled to.

I have been informed about any available compensation or medical treatment if injury occurs to me as a result of study-related procedures.

If I have any further questions/concerns or queries related to the study I understand that I may contact the researcher at:

Cellphone contact: 0790511668 or

Email address: siphesihle013@gmail.com.

If I have any questions or concerns about my rights as a study participant, or if I am concerned about an aspect of the study or the researchers then I may contact:

HUMANITIES & SOCIAL SCIENCES RESEARCH ETHICS ADMINISTRATION
Research Office, Westville Campus
Govan Mbeki Building
Private Bag X 54001
Durban
4000
KwaZulu-Natal, SOUTH AFRICA
Tel: 27 31 2604557- Fax: 27 31 2604609
Email: HSSREC@ukzn.ac.za Additional consent, where applicable

I hereby provide consent to:

Audio-record my interview / focus group discussion	YES / NO
Video-record my interview / focus group discussion	YES / NO
Use of my photographs for research purposes	YES / NO

_____ _____
Signature of Participant **Date**

_____ _____
Signature of Witness **Date**
(Where applicable)

APPENDIX B: APPROVAL FOR THE STUDY

UNIVERSITY OF KWAZULU-NATAL
INYUVESI YAKWAZULU-NATALI

19 July 2017

Mr Siphesihle Khumalo (212500388)
School of Built Environment & Development Studies
Howard College Campus

Dear Mr Khumalo,

Protocol reference number: HSS/0676/017M
Project title: Exploring perceptions and stigma of tuberculosis among young adults in a rural area of KwaZulu-Natal

Approval Notification – Expedited Application

In response to your application received on 02 June 2017, the Humanities & Social Sciences Research Ethics Committee has considered the abovementioned application and the protocol has been granted **FULL APPROVAL.**

Any alteration/s to the approved research protocol i.e. Questionnaire/Interview Schedule, Informed Consent Form, Title of the Project, Location of the Study, Research Approach and Methods must be reviewed and approved through the amendment/modification prior to its implementation. In case you have further queries, please quote the above reference number.

PLEASE NOTE: Research data should be securely stored in the discipline/department for a period of 5 years.

The ethical clearance certificate is only valid for a period of 3 years from the date of issue. Thereafter Recertification must be applied for on an annual basis.

I take this opportunity of wishing you everything of the best with your study.

Yours faithfully

[redacted]

.....
Dr Shenuka Singh (Chair)

/ms

Cc Supervisor: Dr Kerry Vermaak
Cc Academic Leader Research: Professor O Mtapuri
Cc School Administrator: Ms Nolundi Mzolo

Humanities & Social Sciences Research Ethics Committee
Dr Shenuka Singh (Chair)
Westville Campus, Govan Mbeki Building
Postal Address: Private Bag X54001, Durban 4000
Telephone: +27 (0) 31 260 3587/8350/4557 **Facsimile:** +27 (0) 31 260 4609 **Email:** ximbap@ukzn.ac.za / snymanm@ukzn.ac.za / mohunp@ukzn.ac.za
Website: www.ukzn.ac.za

APPENDIX C: QUESTIONS FOR INDIVIDUAL SEMI-STRUCTURED INTERVIEWS

1. What do you know about TB?
2. How do you know if someone has T.B?
3. What are your views/thoughts about people with T.B?
4. What are the local names for TB?
5. How do you perceive to be your reaction if you were diagnosed with TB?
6. What are your experiences with people with T.B?
7. How did you relate with them (people with TB)?
8. How must people with TB be treated within the community? Why?
9. What do you think about TB and Cure?
10. What do you believe are the reasons why people diagnosed with TB delay in seeking care and treatment?

APPENDIX D: SCHEDULE OF REVISIONS

College of Humanities
Schedule of Revisions Completed Post-Examination
Masters/PhD
(Please enumerate and describe, in the form below, the concerns expressed or revisions required by the examiners as well as how the concerns/revisions were addressed/effected in the revised dissertation. Please add numbers if more are needed.)

Student Name: Siphesihle Khumalo
Student Number: 212500388
Degree: Master of Population Studies
Title of Dissertation: Exploring perceptions and stigma of tuberculosis among the young adults in a rural area of KwaZulu-Natal

#	**Concern Expressed/Revision Required (verbatim, source, by whom, page reference)**	**My understanding of the concerns**	**Actions taken (detailed description, new page reference if applicable)**
	Concerns: Examiner 1 (Internal)		
1			
2			
3			
4			
5			
#	**Concern Expressed/Revision Required (verbatim, source, by whom, page reference)**	**My understanding of the concerns**	**Actions taken (Detailed description, new page reference if applicable)**
	Concerns: Examiner 2		
1	**General:** bold headings and sub-headings and remove underlining Acronyms and abbreviations should be written in full once first time and only use abbreviation with subsequent appearance.	I understood the concern noted by the examiner and I will revise it as per examiner's instruction.	The bold headings, sub-headings and Acronyms was revisited and revised as by the examiner's request.
2	**Topic:** add 'a' to rural	The candidate understood the suggestion mentioned by the examiner on the topic of the study and will revise it as per examiner's instruction.	The topic was revised and the 'a' was added on the topic.
3	**Acronyms / abbreviation:**	The candidate has noted	The section was observed and

	- all abbreviations should be written in full first time and only use abbreviations for subsequent appearance - Abbreviations should be arranged alphabetically - DOTS – correct is Directly Observed Treatment Short-course (also in 5.2.1.3)	and understood the observation made by the examiner on Acronyms/abbreviation.	reworked as per examiner's request.
4	**Table of content** – remove pg on page numbers and only show the first page - Abstract and table of content appear in the table of content but missing - Delete 4.2.1 and the first 4.3.1 these are tables and should appear under list of tables - Structure of the dissertation- chapters to include headings	The candidate noted the concerns suggested by the examiner and will revisit the table of content to include and readjust the table as well as the structure of the dissertation.	The table of content was reworked and readjusted as well as the structure of the dissertation for the study.
5	**Chapter 2:** **2.3.3 1.** Table to be named properly as 'Table 2.1 TB Incidences per Province' and include under list of tables 2.3.3 Delete all the abbreviations including those in the table not necessary	The candidate understood the concern noted by the examiner and will revise the sections as per examiner's instruction.	The chapter was revisited to rework and adjust to the concerns suggested by the examiner.
6	**Chapter 3:** research paradigm – Start by statement indicating that the study used qualitative approach then rationale and delete qualitative approach in the subheading. Population of the study and data collection tool: is missing to be added Trustworthiness: incomplete add confirmability and dependability.	The candidate noted the gaps identified by the examiner and will include the missing information on this chapter of this study.	The missing gaps were identified and the information for conformability and dependability was further added to the chapter.
7	**Chapter 4** pg 38 correct age categories overlapping * to be explained whether refer to pseudo names or what pg 41 Delete last paragraph 'reflecting on the above.. transmission	The candidate noted the overlapping age categories and will rearrange the categories to suit the study needs as per examiner's request. However, with regards to the following	The overlapping categories were corrected and the use of * refers to the pseudo names of the participants. The paragraph in pg. 41 and pg. 47 are supporting the statements mentioned by the participants and

	of TB' this is discussion. pg 47- delete 'therefore, reflecting…eyes of society. p48 delete first paragraph -discussion.	examiner concerns, my understanding of the concern is that the paragraph in pg 41 and pg 47 are supporting the statements mentioned by the participants and the aim is to provide a clear and precise meaning of the what the participants has mentioned.	the aim is to provide a clear and precise meaning of what the participants has mentioned.
8	**Chapter 5:** Delete all subheadings (subthemes) and remain with themes only - delete objectives in the conclusion.	The candidate noted the concerns mentioned by the examiner. However, the understanding of the candidate is that these subthemes are providing a clear description of the findings that the study has gathered/explored. The presence of subthemes also helps the reader to have a clear understanding of the theme that has been explored by the study. Furthermore, the inclusion of objectives to in the conclusion is to give a reader on what the purpose and the main objectives were and also to provide a clear conclusion of the study based on the objectives of the study.	The subthemes are providing a clear description of the findings that the study has gathered/explored. The presence of subthemes also helps the reader to have a clear understanding of the theme that has been explored by the study. Furthermore, the inclusion of objectives to in the conclusion is to give a reader on what the purpose and the main objectives were and also to provide a clear conclusion of the study based on the objectives of the study.
9	**Referencing** – in-text referencing to be consistent, some having page numbers while some did not - some in text references not in the reference list: Turner, 2010, WHO TB Report, 2013, NDoH TB Report 2013, Soul city Institute, 2014,	The candidate understood and noted the concern indicated by examiner on referencing issue and will address it.	The reference section was revised and edited by including some of the studies that were not included on reference list.
10			
11			
#	**Concern Expressed/Revision Required (verbatim, source, by whom, page reference) My understanding of the concerns**		**Actions taken (Detailed description, new page reference if applicable)**
1			

APPENDIX E: LETTER OF EDITING

Pauline Fogg
54 Grundel Road
Carrington Heights
Durban
4001
074 782 5234

26 April 2020

Letter of Editing

This report serves to state that the dissertation submitted by Siphesihle Khumalo has been edited.

The dissertation was edited for errors in syntax, grammar, punctuation and the in-text referencing system used.

The edit will be regarded as complete once the necessary changes have been effected and all of the comments addressed.

Thank-you for your business.

P Fogg

Pauline Fogg