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KWAZULU-NATALTM**

**INYUVESI
YAKWAZULU-NATALI**

**THE PSYCHOSOCIAL IMPACT OF HEARING LOSS ON THE
QUALITY OF LIFE OF ADULTS WITH MULTI DRUG-RESISTANT
TUBERCULOSIS**

BY

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2 September 2020

DECLARATION

I, Amanda Thusi, hereby declare that this dissertation submitted to the University of KwaZulu-Natal for the degree of Master of Communication Pathology (Audiology) is of my own original research. The following research has not been submitted to any other university or institute for examination purposes. All information obtained from other sources has been referenced accordingly and where direct quotes and definitions have been used, direct quotations have been documented and have further been referenced accordingly.

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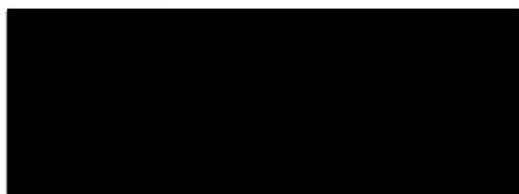
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DISSERTATION TITLE

The Psychosocial Impact of Hearing Loss on the Quality Of Life of Adults with Multidrug-Resistant Tuberculosis

As the candidate's supervisor,

- I AGREE to the submission of this thesis in the form of integrative material for examination.
- This is to certify that the contents of this thesis are the original research work of Ms. Amanda Thusi.



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ABSTRACT

Aminoglycosides used in the treatment of Multi Drug-Resistant Tuberculosis (MDR-TB) is an ototoxic agent, known to result in hearing loss. Hearing loss has been reported to have far-reaching psychological, physical, and social consequences, while the diagnosis of MDR-TB has negative impacts such as stigma, and financial implications. The effects of an acquired hearing loss with an MDR-TB diagnosis may, therefore, have an increased adverse impact on the overall Quality of life of an individual; however, there is minimal research in the area. A Qualitative Phenomenological research study was conducted on 10 participants, with a confirmed diagnosis of MDR-TB, and hearing loss. The researcher used a semi-structured questionnaire to collect data during face-to-face, audio-recorded interviews. Thematic analysis of results revealed that hearing loss in patients diagnosed with MDR-TB has a significant adverse impact on the patients' Quality of life. All participants were unable to return their 'normal' lives, i.e., life before the diagnosis of MDR-TB and hearing loss. Stigma, discrimination, psychological distress, adverse changes in family status and family relationships, financial constraints, and social challenges were some of the common issues reported by participants. Unemployment posed a significant challenge, resulting in participants having no economic stability due to MDR-TB, which was then worsened by the hearing loss; consequently, generating a great deal of stress. Participants reported feelings of worthlessness, a loss of identity, lack of motivation, feelings of embarrassment, and loss of independence. Cultural and ethnic factors also appeared to have influenced the participant's willingness to seek assistance for the psychosocial challenges they had been experiencing. Consequently, there is a significant irreversible social, psychological, and economic impact of hearing loss that has a direct impact on the Quality of life of MDR-TB patients and their families, which are likely to persist even after MDR-TB has been cured. There is a need for improved treatment methods that are less toxic to hearing together with psychosocial intervention strategies that equip patients diagnosed with MDR-TB and hearing loss to alleviate the adverse effects they experience. Without such interventions, the fight against the psychosocial impact of hearing loss in MDR-TB patients remains incomplete.

ISIFINGQO SO-CWANINGO

Imithi esebenziswa ukwelapha isifo seMDR-TB kuyenzeka idale ukungasebenzi kwezindlebe, lokhu kudala ukuthi abantu abaphethwe ilesi sifo bagcine sebengezwa kahle ezindlebeni. Izinhlupheko ezivela ngenxa yokungezwa ezindlebeni okudlaweyiMDR-TB kuyenzeka zibe nomthelelo omubi empilweni yomuntu. Kodwa, luncane ucwaningo kulendawo okuchaza ukuthi luncane ulwazi olukhona ngezinhlopheko ezihambiselana nemithi ilapha lesisifo. Iziguli ezine MDR-TB eziphinde zibe nenkinga yokuzwa ezindlebeni zibhekana nezinkinga eziningi eziqhubekayo noma ukwelashwa sekudlilile. Ucwaningo lwenziwe ngokusebenzisa indlela yocwaningo okuthiwa iQualitative Phenomenological. Imiphumela itholakale ngendlela yokubheka imiphumela ebizwa ngokuthi iThematic. Lwenziwe nabahlanganyeli aba yishumi. Bonke abahlanganyeli bebenesifo seMDR-TB esitholakale ngezindlela zokuhlola isikhwehlela. Indlela esebenzisiwe ukuthola ulwazi kubahlanganyeli beku ingxoxo okuthiwa yi semi-structured. Izingxoxo zenziwe ubuso nobuso futhi beziqophiwe. Zonke izingxoxo zenziwe ngumcwaningi. Imiphumela iveze ukuthi ukungezwa kwezindlebe kubantu abanesifo iMDR-TB kuyaphikisana nokuphila impilo egculisayo. Bonke abahlanganyeli abakwazanga ukubuyisela izimpilo zabo esimeni esifana nalesi abekade besiphila ngaphambi kokuthola isifo Imdr-tb. Izinkulumo ezimbi emphakathini, ukucwayiswa, ukuphatheka kabi emoyeni, ukushintsa kwezimo zomndeni nobudlelwane bomndeni, ukulahlekelwa imali kanye nokungamukelwa emphakathini kubalwe njengezinkinga ababhekane nazo. Abahlanganyeli basabe kakhulu ukulahlekelwa imisebenzi nemali obekungacacanga ngendlela yokungezwa ezindlebeni. Lokhu kusaba kudale ukuxineka okukhulu. Kuvelile ukuthi abahlanganyeli bazizwe bengabalulekile, engekho umuntu okhathazekile ngabo nangemizwa yabo. Baveze ukuba nokuphoxeka okukhulu. Izimo eziningi bezingeke zikwazi ukushintsha noma zishinthsheke. Izinto ezingeke zikwazi ukujikiswa ezihlupha umoya nezemali ezidalwe ukungenzwa kwezindlebe ngenxa yesifo iMDR-TB. Futhi lezinginkinga ababhekene nazo zenza ukuthi isimo sempilo singabe sihle bahlale bengabantu abaphelelewe ithemba. Abahlanganyeli baveze ukuthi bazizwa bengabalulekile, bengazazi ukuth bangobani, bengakwazi ukuzimela futhi benokuphoxeka okuningi. Futhi lezinginkinga ababhekene nazo zenza ukuthi isimo sempilo singabe sihle. Lezi izinkinga azibhekene nomuntu okuyena onesifo kuphela kodwa nemindeni yabo igcina isibhekene nazo, nayo imindeni kugcina isimo sempilo singasemnandi. Kube nzima ukuthi abahlanganyeli bakwazi ukuthi baphinde bathole imisebenzi ngemumva kokugula. Bonke abahlanganyeli bebengasebenzi ngenxa yesifo nenkinga yokuzwa. Futhi abakwazanga ukuthi baphinde bathole imisebenzi ngenxa yokungezwa kahle ezindlebeni. Okushaqisayo ukuthi zonke lezi zinkinga ziyaqhubeka noma umuntu esekuqedile ukwelashwa. Lokhu kudalwa ukuthi isimo sokungenzwa kwezindlebe sona aselapheki. Ngaphezulu kwalokho, baphinde balahlekelwa ithemba lokuthi bangakwazi na ukusebenza ngendlela efanele uma kwenzeka biyothola imisebenzi. Baveze ukuthi abantu abaningi ababaniki ithuba lokuzivezwa ngoba bevele bacabange

ukuthi umuntu omgezwa ezindlebeni akanalo ikhona lokusebenza ngendlela efanele. Kunesidingo esikhulu ukuthi kube khona izindlela zokwelapha isifo seMDR-TB ngamakhambi angabulali ukuzwa kwezindlebe. Kuphinde kubaluleke ukuthi imizamo yenziwe ukuthi abantu ababathwa ilesisifo bangalahlekelwa izimpilo zabo ngenxa yokugula emzimbeni nokungenzwa kwezindlebe. Lemizamo iyadingeke ukuze basizakale bakwazi ukunqoba izimo ezingemnandi ababhekana nazo. Ngaphandle kwalemizamo, ukulwisana nezinkinga ezibhekana nabantu abathola isifo seMDR-TB baphinde balahlekelwa ukuzwa ezindlebeni azisoze zaphela futhi asisoze zanqobeka.

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ABBREVIATIONS

BDQ	Bedaquiline
dB HL	Decibels in Hearing Levels
HL	Hearing loss
MDR-TB	Multidrug-Resistant Tuberculosis
OHC	Outer Hair Cells
PTB	Pulmonary Tuberculosis
QoL	Quality of life
TB	Tuberculosis
XDR-TB	Extensively-Drug Resistant Tuberculosis

CHAPTER 1: INTRODUCTION

1.1 Introduction

This chapter addresses the aspects related to the research problem and the rationale for the study, including a brief background regarding Multidrug-Resistant Tuberculosis (MDR-TB), hearing loss (HL), and Quality of life (QoL). These concepts are further expanded on in chapter two, together with available supporting literature. A summary of the chapters is also outlined, while key definitions utilized in the study are also presented.

1.2. Background and context to study

The World Health Organisation reported that approximately 466 million people worldwide have disabling hearing loss (WHO, 2018). It is further estimated that by 2050 over 900 million people will have disabling hearing loss. Hearing impairment is ranked as the 13th highest contributor to the global burden of disease and is projected to be the ninth leading contributor worldwide and seventh in high-income countries by 2030 (WHO, 2018). The prevalence of adult hearing impairment is substantially higher in low-income regions, especially in sub-Saharan Africa and in South and Southeast Asia (WHO, 2018). Hearing loss can be congenital or acquired. One type of acquired hearing loss is ototoxicity, resulting from aminoglycosides used in the treatment of MR-TB.

Drug-resistant TB is a public health threat, with the World Health Organization (2019) reporting that a total of 63 000 people died of tuberculosis (TB) in South Africa in 2018. It was estimated that around 301 000 people fell ill with TB in South Africa in 2018 (WHO, 2019). Based on the absolute number of cases, South Africa ranked eighth with 13% of the world's TB cases (WHO, 2019). The WHO Global TB (2019) report revealed that globally, an estimated 10.0 million people fell ill with TB in 2018, a number that has been relatively stable in recent years. The burden of the disease varies enormously among countries, from fewer than five to more than 500 new cases per 100 000 population per year, with the global average being around 130 (WHO, 2019). There were an estimated 1.2 million TB deaths in 2018. TB affects people of both sexes in all age groups, but the highest-burden is in men, who accounted for 57% of all TB cases in 2018. By comparison, women accounted for 32% and children for 11% (WHO, 2019). Geographically, most TB cases in 2018 were in the WHO regions of South-East Asia, Africa, and the Western Pacific, with smaller percentages in the Eastern Mediterranean, America, and Europe (WHO, 2019). Eight countries accounted for two-thirds of the global total: India, China, Indonesia, the Philippines, Pakistan, Nigeria, Bangladesh, and

South Africa. These and 22 other countries in WHO's list of 30 high TB burden countries accounted for 87% of the world's cases. In 2018, there were about half a million new cases of rifampicin-resistant TB, of which 78% had multidrug-resistant TB (WHO, 2019). Globally, 3.4% of new TB cases and 18% of previously treated cases had multidrug-resistant TB (MDR-TB) (WHO, 2019).

MDR-TB is a disease caused by *Mycobacterium tuberculosis* strains with resistance to isoniazid and rifampicin (WHO, 2014). Treatment of MDR-TB is generally for 18-24 months using second-line anti-tuberculosis drugs and the daily administration of an injectable drug for at least six months (Reuter et al., 2017). These drugs are primarily known as aminoglycosides.

1.3 Problem statement

Aminoglycoside treatment used for MDR-TB is likely to result in ototoxicity (Reuter et al., 2017). The effects of a hearing loss with an MDR-TB diagnosis may have an increased impact on the overall Quality of life of an individual. Hearing loss as a consequence of aminoglycoside use in the treatment of MDR-TB is a common complication, posing a significant challenge on the patient's Quality of life.

While some patients may be able to return to their lives as they had been before their diagnosis of MDR-TB, most patients may continue life with considerable social, psychological, and emotional challenges that are overlooked during the treatment of MDR-TB (Morris et al., 2013). Ototoxic hearing loss is permanent, and the societal impact of hearing impairment is profound (Tams, 2014). Assessing Quality of life can be used to demonstrate the importance that an individual places on specific aspects of their health or disease process. This information may be potentially useful in developing more appropriate therapies to assist in planning comprehensive strategies of care, which are essential in managing many chronic diseases. The provision of psychosocial interventions and rehabilitation for this patient population has not been documented in the South African context. There is minimal research in the area, which would, therefore, indicate a possible lack of awareness of the effect of aminoglycoside treatment on the Quality of life of individuals diagnosed with MDR-TB. The impact of the dual diagnosis of MDR-TB and ototoxic hearing loss on Quality of life needs to be considered in the health care system during treatment, as this data may drive improved national health care planning with regards to the treatment of patients diagnosed with MDR-TB.

1.4 Rationale for the Study

When life-threatening illness permits treatment with ototoxic drugs, preserving the Quality of the patient's life is often a treatment goal (Fausti et al., 2005). Hearing loss is indeed not a life-threatening condition; however, it is a severe threat to essential Quality of life unless intervention occurs early. The implementation of effective intervention requires a consideration of the impact of a hearing loss on the individual's Quality of life within the context of the MDR-TB diagnosis. However, there is a paucity of literature on the psychosocial impacts of hearing loss in patients diagnosed with MDR-TB. While studies have focused on the social, economic, and psychological impacts of MDR-TB and hearing impairment, these have been addressed as separate research areas. Furthermore, most studies reviewed focus specifically on the side effects of MDR-TB treatment while not considering the patient's overall Quality of life.

At present, much attention is being focused on the traditional microbiological and clinical indicators within the management of MDR-TB. Evaluation of the impact of MDR-TB treatment on patients' Quality of life has remained a neglected area. While most studies on MDR-TB prioritise the public health concerns of the disease, the human costs of MDR-TB have been overlooked. There is a need for research into the impact of both an MDR-TB diagnosis in combination with a hearing impairment, which may inform innovative psychosocial intervention to assist MDR-TB patients to cope better with their illness, improve treatment adherence, and treatment outcomes as well as the overall Quality of life (Peterson & Rogers, 2015). Researchers in developed countries have called for the use of aminoglycosides to be banned due to their adverse effects. However, awareness must be created about the devastating impact of aminoglycosides on an individual's hearing and, thus, their ability to communicate effectively. In doing so, appropriate measures can be put into place to manage aminoglycoside-induced ototoxicity effectively in order to maximize the affected individual's Quality of life (Peterson, & Rogers, 2015). Although a new, less toxic drug, Bedaquiline, has been implemented as a shorter regimen for the treatment of MDR-TB, some patients are not candidates for the treatment.

It is, therefore, not possible to completely remove aminoglycosides from the treatment regimen in the near future. Furthermore, there are a significant number of people who have already been treated with aminoglycosides and now present with permanent hearing loss. This permanent hearing loss can significantly reduce Quality of life as it can have a detrimental effect on relationships, mental and physical health, income as well as personal safety. Additionally, being diagnosed with MDR-TB and undergoing treatment imposes significant psychological, social, and

economic stress on patients (Morris et al., 2013), which may be exacerbated with the diagnosis of a hearing loss. Therefore, a comprehensive assessment of the patients' health status should entail an assessment of the overall impact of MDR-TB and hearing loss on health and patients' perception of well-being. Besides routine clinical assessments, this assessment can be done by measuring the Quality of life. Assessment of Quality of life should also be accompanied by the relevant interventions to help participants cope with changes during and after treatment, and should be informed by evidence-based research. However, a perusal of literature has revealed that there are no studies addressing the psycho-social impact of hearing loss in this patient population within the South African context, which provided the impetus of the current study, which addresses the following research question:

How does a hearing loss impact on the Quality of life of patients diagnosed with MDR-TB?

1.5 Aim and Objectives of the Study

The study aims to describe the psychosocial impact of hearing loss on the Quality of life of adults with MDR-TB. The study objectives are as follows

- To explore the psychological and emotional impact of hearing loss in adults with MDR-TB.
- To describe the experiences of the social impact of hearing loss in adults with MDR-TB.
- To describe the experiences of the economic and vocational impact of hearing loss in adults with MDR-TB.

1.6. Conceptual Framework

A conceptual framework is an understanding of how the research problem will be explored, the specific direction the research will undergo, and the relationship between the different variables in the study (Grant & Osanloo, 2014). This is best summarised as “*a system of concepts, assumptions, and beliefs that support and guide the research plan, specifically, the conceptual framework lays out the key factors, constructs, or variables, and presumes relationships among them*” (Grant & Osanloo, 2014, p.17). A conceptual framework offers many benefits to research. For instance, it helps the researcher to identify and construct a worldview on the phenomenon being investigated (Grant & Osanloo, 2014). Moreover, it explains the natural progression of a phenomenon that is being researched and offers a structure of connected concepts that provide a picture of how ideas in a study are related to one another (Grant & Osanloo, 2014).

The conceptual framework employed in the present study draws from the World Health Organization Quality-of-Life Scale (WHO, 2010), depicted in Figure 1.1 below. The scale identifies Quality of life through specific domains, namely: physical, psychological, social and environmental relationships. The scale identifies a further domain as ‘older specific facets’. These facets include areas of past, present and future activities; participation; and intimacy which are important aspects in the life of an individual. Based on the framework, Quality of life is directly influenced by these relationships. Important concepts from the model were employed in the present study as they are closely related to the studied phenomenon. The conceptual framework guided the researcher towards the development of the research objectives which allowed the researcher to explore the different aspects of Quality of life.

Objective 1 was guided by the psychological and environmental relationships, objective 2 was guided by the social relationships of Quality of life and objective 3 was guided by the physical relationships of Quality of life. Furthermore, concepts from the framework were selected to assist in the development of the data collection instrument i.e., the interview schedule. The conceptual model has emerged to help guide the deeper analysis of the study and the concepts create a holistic view of Quality of life, and in so doing, achieve the aim of the study.

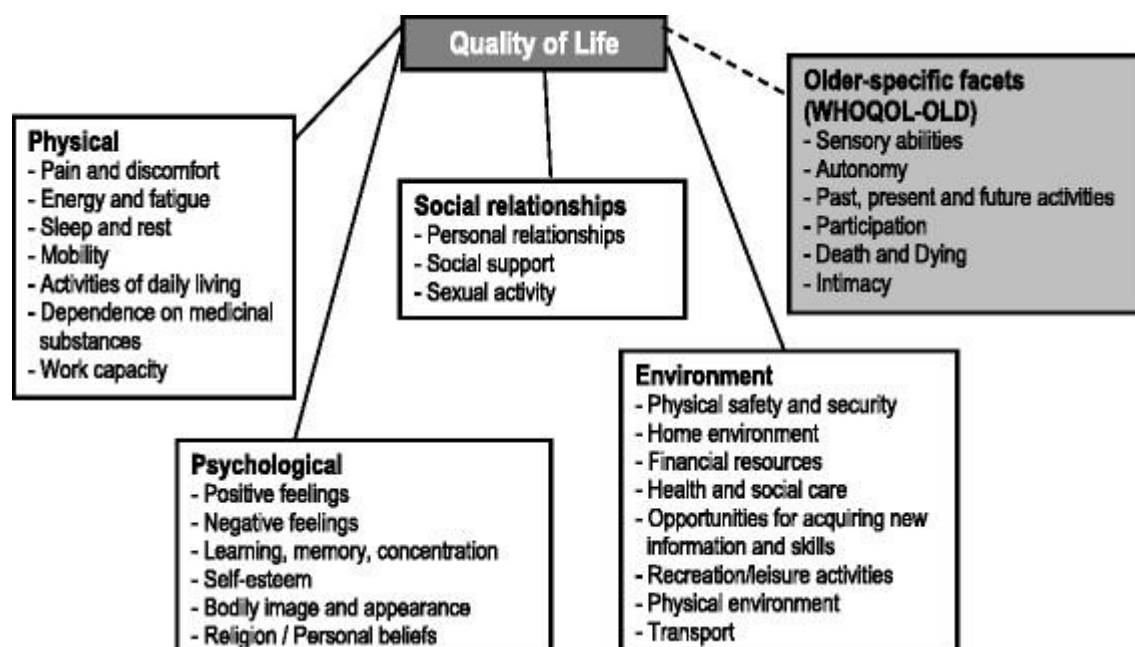


Figure 1.1: World Health Organization Quality-of-Life Scale. Sourced from: “Analyses of Their Item Response Theory Properties Based on the Graded Responses Model” by WHO, 2010, p.229

In addition to the conceptual framework above, the researcher took further consideration to the psychosocial aspects of hearing as they are multidimensional. Preminger (2007) describes the reactions to hearing loss as cognitive, emotional, interpersonal, physical responses and behavioural. “The emotional reactions refer to the stigma surrounding hearing loss and may include shame and embarrassment; cognitive reactions may include a low self-esteem which may be worsened by the challenges experienced in difficult listening situations; interpersonal reactions may be inclusive of social withdrawal and intimacy in relationship(s); behavioural reactions may include self-isolation; and physical reactions may include health problems that can be worsened by hearing loss such as headaches and sleep problems” (Preminger, 2017, pg.113). These impacts further determine how an individual reacts psychosocially to his or her hearing loss (Preminger, 2007). The psychosocial reactions to hearing loss are not only experienced by the individual with hearing loss but by his/her significant others as well (Preminger, 2007). It was important to consider these reactions to hearing loss as they guided the researcher towards the development of questions relevant to psychosocial impacts of hearing loss in the data collection instrument.

1.7 Terminology

Aminoglycosides: “Groups of antibiotics that are used to treat many gram-negative bacterial, staphylococcal, and mycobacterial infections” (WHO, 2016, p.12).

Hearing Loss/ Hearing impairment: “A partial or total inability to hear sound in one or both ears” (Tambs, 2014, p.8).

Multidrug-Resistant Tuberculosis: A disease caused by *Mycobacterium tuberculosis* strains that is resistant to isoniazid and rifampicin drugs (WHO, 2016).

Ototoxicity: Damage to hearing or balance function, which can result as a side effect of a drug or chemicals (Tambs, 2014).

Psychosocial: The psychosocial approach looks at individuals in the context of their psychological, social, environmental, physical, and mental wellness (WHO, 2014).

Quality of life: “An individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns. It is a broad-ranging concept affected in a complex way by the person’s physical health, psychological state, personal beliefs, and social relationships” (WHO, 2010, p.2).

1.8 Outline of Chapters

Chapter 1 – Introduction

This chapter contextualises the study and highlights the study problem and rationale for the study. It provides a brief description of each subsequent chapter. Additionally, common terminologies used in the research dissertation are defined.

Chapter 2 – Literature Review

The chapter reviews the theoretical aspects of Multidrug-Resistant Tuberculosis, the role of aminoglycoside use within the MDR-TB regimen, the effects of aminoglycosides on hearing as well as the psychosocial aspects in the life of the patient with MDR-TB. A description of the studies reviewed in the area is also presented. The Quality of life of patients diagnosed with MDR-TB who further develop a hearing loss is critically examined.

Chapter 3 – Methodology

This chapter describes the methodological framework employed in this study. The chapter provides information related to the aims and objectives of the study, the study design, sample size, sampling method, and description of the investigative procedures used in this study, followed by the results of the pilot study. Data analysis is also described in detail. The chapter concludes with a discussion of the ethical and legal considerations of the study.

Chapter 4 – Results and Discussion

This chapter is a presentation and discussion of the results obtained in this study. The results of the study have been analysed qualitatively and are presented according to the themes. Furthermore, the results are discussed with reference to relevant literature, and the discussion aims at providing possible explanations for the findings obtained.

Chapter 5 – Conclusion, Limitations, and Recommendations

This concluding chapter provides a summary of the findings as well as clinical and research implications. Limitations and recommendations for future studies are also provided.

1.9 Summary

This chapter presented an overview of the study. According to the literature available, there is minimal research into the psychosocial impacts faced by patients with MDR-TB who further acquire a hearing loss. Therefore, the present study aims to describe the psychosocial impact of hearing loss on the Quality of life of adults with MDR-TB. The findings of this study may, therefore, provide the evidence for more holistic management of the MDR-TB patients, including psychosocial interventions.

CHAPTER 2: MULTIDRUG-RESISTANT TUBERCULOSIS, HEARING LOSS AND QUALITY OF LIFE

2.1 Introduction

The ensuing chapter provides an overview of the theoretical aspects of MDR-TB, the treatment regimen, and the incidence of the adverse side effect of hearing loss, which may lead to several psychosocial problems that influence Quality of life. Therefore, the chapter aims to provide an understanding of how the multiple challenges faced by MDR-TB patient's impact their overall Quality of life.

2.2 Multidrug-Resistant Tuberculosis

Drug-resistant tuberculosis is an airborne communicable disease. It was recognised as a significant public health threat in industrialised countries in the early 1990s following several outbreaks of MDR-TB (Gandhi & Weissman, 2012). These outbreaks were noted to have been mainly through the transmission of drug-resistant tuberculosis in congested, institutional settings with inadequate infection control, with the main reasons for the continual exposure and spread of MDR-TB being mismanagement of TB treatment and person to person transmission (Gandhi & Weissman, 2012). Inappropriate or incorrect use of antimicrobial drugs or the use of unsuccessful formulations of drugs and premature treatment disturbance can cause drug resistance, which can be transmitted, especially in crowded settings such as hospitals (Gandhi & Weissman, 2012).

MDR-TB can be as a result of the failure of drug-sensitive TB treatment with the development of resistance (acquired MDR-TB) or as a result of the direct transmission of a multidrug-resistant strain (primary MDR-TB) (Ahmad et al., 2016). The development and spread of MDR-TB and drug-resistant strains in the community may be the result of many factors. Globally, these factors have included challenges with TB programme-related factors such as poor management of patient's treatment, shortages of drug supply, drug quality, unavailability of anti-tuberculosis drugs without prescription, lack of uniformity between the public and private health sector regarding treatment guidelines, and poorly managed and supported national TB control programmes (Ahmad et al., 2016). These transmissions have significantly contributed to the global transmission of MDR-TB.

In some countries, it is becoming much more difficult to treat MDR-TB. Treatment options are limited and expensive, the recommended medicines are not always available, and patients

experience many adverse effects from the drugs (WHO, 2018). In some cases, even more severe drug-resistant TB may develop. Extensively drug-resistant TB (XDR) is a form of multidrug-resistant TB with additional resistance to more anti-TB drugs that respond to even fewer available medicines (WHO, 2018). Drug resistance can be detected using specialised laboratory tests which test the bacteria for sensitivity to the drugs or detect resistance patterns; these tests can be molecular in type or else culture-based (WHO, 2018). Molecular techniques can provide results within hours and have been successfully implemented even in low resource settings such as South Africa (WHO, 2018).

South Africa has a high burden of MDR-TB. Until 2008, like many countries in the world, South Africa adopted an inpatient model of care whereby patients were hospitalised in a centralised specialised hospital for MDR-TB for the first six months of treatment (Loveday, 2017), to allow the facilitation of daily injections and close monitoring of adverse events and adherence. Following discharge, and for the remaining period of treatment, patients were discharged to their homes to complete treatment at their local healthcare facility and return to the centralised hospital for monthly outpatient visits (Loveday, 2017). However, by 2008 the increasing burden of drug-resistant tuberculosis, together with limited hospital bed capacity, resulted in long waiting times and high mortality while patients waited to access treatment (Loveday, 2017). Patients were discharged before the end of the initial injectable phase of treatment to facilities unfamiliar with MDR-TB treatment, resulting in poor treatment outcomes and high default rates (Loveday, 2017).

The WHO World TB Report (2019), estimates that 11000 people fell ill with MDR-TB in South Africa in 2018, although the actual number might be as high as 16000 (WHO, 2019). According to the Global Burden of Disease study 2015, TB is the fifth leading cause of years of life lost and disability-adjusted life years in South Africa (GBD, 2016). South Africa, a country with high TB, MDR-TB, and HIV burden, contributes approximately 10% of global MDR-TB cases diagnosed and reported, with treatment success similar to the global rate at 54% and mortality at just above 20% (Brigden et al., 2019). TB prevalence (all forms) in South Africa is estimated at 398.6 per 100,000, and the incidence of MDR-TB at 25 per 100,000 (Brigden et al., 2019). The current percentage of new cases with MDR-TB in South Africa is reported to be 3.4% (Brigden et al., 2019). Drug-resistant TB statistics for South Africa in the year 2019 can be seen in Table 2.1 below:

Table 2.1

Drug-resistant statistics for 2019 Sourced from: “Drug-Resistant TB Care in South Africa” (WHO, 2019, p.222)

Drug-Resistant TB Care 2018	New Cases	92%
	Previously treated cases	94%
	Laboratory confirmed cases	13199
	Patients started on treatment	9668
	Multi Drug-Resistant Tuberculosis cases tested for resistance to second-line drugs	7469

While drug-resistant tuberculosis was first identified in the 1980s, treatment was only rolled out across South Africa in 2001 (Jenkins et al., 2011). Following the publication of the 2008 updated World Health Organisation guidelines, the standardised treatment used in South Africa was improved with the inclusion of more drugs (Jenkins et al., 2011). Treatment of MDR-TB previously required *“18-24 months using second-line anti-tuberculosis drugs, and the daily administration of an injectable drug, i.e., aminoglycosides for at least 6 months, which are more toxic and less well tolerated than the first-line medications”* (Jenkins et al., 2011, p. 4).

2.3 MDR-TB and Aminoglycosides

The first-line drugs that are used to treat TB include isoniazid, rifampicin, ethambutol, and pyrazinamide (WHO, 2014). However, due to MDR-TB being resistant to isoniazid and rifampicin, treatment of the condition cannot rely upon the use of these medications and, therefore, a combination of second-line drugs may be used as a treatment option (WHO, 2014). Aminoglycosides are the second-line drugs that were commonly used for the treatment of MDR-TB. Aminoglycosides were used to treat many gram-negative bacterial, staphylococcal, and mycobacterial infections, and were recommended as they have an intense action against multidrug-resistant gram-negative bacilli. They were, therefore, considered to be a vital component in the treatment of MDR-TB (WHO, 2014).

Second-line drugs used in the treatment of MDR-TB included Kanamycin, Amikacin, and Capreomycin (Reuter et al., 2017). The aminoglycosides are classified as a Group 2 drug (meaning injectable drugs) (WHO, 2014). Depending on the individual susceptibility of the patient with MDR-TB, first-line oral drugs were combined with second-line injectable aminoglycosides (WHO, 2014). Due to the use of a combination of the second-line drugs, the patient may be exposed to more side effects, as each drug presents with a different type of side effect (WHO, 2014). Table 2.2 below

describes the second-line injectable drugs that were previously used in anti-tuberculosis treatment as well as the side effects of each drug.

Table 2.2

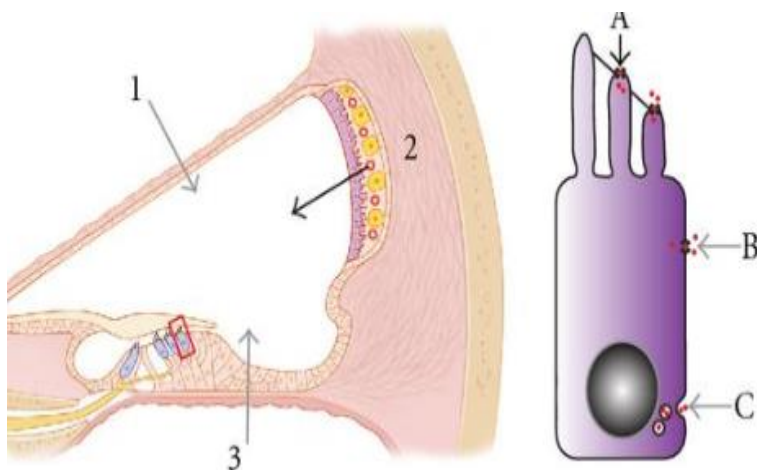
Second-line drugs used in anti-tuberculosis treatment. Adapted from: ‘The devil we know: Is the use of injectable agents for the treatment of MDR-TB justified’ (Reuter et al., 2017, p.11).

Aminoglycoside Antibiotics	Use	Side Effects
Amikacin	Used to treat several infections, including Multidrug-Resistant Tuberculosis. The cost of therapy is higher than Kanamycin.	Primarily known for causing cochleotoxicity.
Kanamycin	Used to treat severe bacterial infections and Tuberculosis. It is not a first-line treatment. It is an oral antibiotic, or by injection into a vein/muscle. It is recommended for short term use only. Preferred treatment method as the cost of therapy is the cheapest.	Permanent, irreversible bilateral loss of hearing, loss of balance, or both. May also result in renal failure.
Capreomycin	Given in combination with other antibiotics for the treatment of Tuberculosis. Second-line treatment used for Multidrug-Resistant Tuberculosis. It is given by injection into a vein or muscle. The cost of therapy is substantially higher.	Hearing loss, tinnitus, and decreased renal function.

As seen in Table 2.2., above, Aminoglycosides, despite being extremely effective in the treatment of MDR-TB, have known dose-related adverse effects, mainly nephrotoxicity (renal impairment) and ototoxicity. Fortunately, renal impairment is usually reversible (Bardien et al., 2009); however, ototoxicity is permanent.

2.4 Mechanism of Aminoglycoside-Induced Ototoxicity

Ototoxicity is the property of being toxic to the auditory system, and sometimes the vestibular system, which can result as a side effect of a drug (Tambs, 2014). The specific mechanisms of the hair cell toxicity are unclear but may be summarised by Huth et al., (2011), as in figure 2.1 below:



Proposed mechanisms of aminoglycoside transport in the inner ear. Possible entry sites for aminoglycosides into the scala media include via (1) the Reissner's membrane, (2) stria vascularis, and (3) basilar membrane. Published work supports the notion of entry via the Reissner's membrane and the stria vascularis through and between the marginal cells. At the hair cell level, aminoglycosides can potentially enter via mechanotransducer channels located on stereocilia of hair cells (A), endocytosis on the apical or basolateral membranes (A, B, or C), TRP channels (A, B or C), or ATP receptors (A).

Figure 2.1: Proposed mechanism of aminoglycoside transport in the inner ear. Sourced from: "Mechanism of Aminoglycoside Ototoxicity and Targets of hair cell protection" by Huth et al., 2011, p.13

According to Bardien et al. (2009), ototoxicity is due to the death of the outer hair cells in the organ of Corti of the cochlea and type 1 sensory cell in the vestibular organ. Aminoglycoside induced hearing loss can occur intermittently or in a dose-dependent manner (Bardien et al., 2009). When the vestibule and/or semi-circular canals are affected by ototoxicity, the symptoms cause difficulties with seeing and processing images. The body subconsciously tries to compensate for the imbalanced signals being sent to the brain by obtaining visual cues to support the information it is receiving, resulting in dizziness, oscillopsia, and vertigo (Bardien et al., 2009). Aminoglycosides gradually accumulate in the endolymph and perilymph of the inner ear, and the half-life in these fluids is 5 to 6 times greater than that of plasma half-life (WHO, 2008). Back-diffusion is dependent on the concentration of the aminoglycoside in plasma; hence, ototoxicity is more likely to occur in patients with persistently elevated concentrations in plasma (WHO, 2008).

Despite their ototoxic effects, aminoglycosides were still used in South Africa as essential components of the drug regimens because they were the cheapest and most accessible injectable drugs, as recommended by WHO (2013) guidelines. However, according to the WHO Global TB report (2019), there is now a new drug regimen for the treatment of MDR-TB. Bedaquiline (BDQ) is a drug used in new effective regimens for the treatment of MDR/XDR-TB. It replaces the injectable agents in the short regimen and is given for a minimum duration of six months unless withdrawn early due to related toxicity or other contra-indications (WHO, 2019). Research suggests that BDQ is superior to aminoglycoside injectable in terms of safety and efficacy in the treatment of MDR-TB; thus, a modified shorter regimen, including BDQ is considered more effective than the previous injectable-containing regimen (WHO, 2019). However, not all patients diagnosed with MDR-TB may be eligible for treatment with Bedaquiline. The exclusion criteria for MDR-TB treatment through the use of Bedaquiline are described by WHO (2019), as follows:

- “Any previous exposure to second-line anti-TB medicines for more than one month regardless of treatment outcome.
- All Pre-XDR and XDR TB,
- Any additional suspected resistance to second-line TB medicines,
 - Close contacts of patients with pre-XDR or XDR-TB,
 - Close contacts of patients with MDR- TB,
 - Close contacts of patients in whom Rifampicin Resistant (RR)/MDR-TB treatment has failed,
- Complicated and/or severe forms of extra-pulmonary RR/MDR-TB disease – e.g., meningitis, osteoarticular, pericardial effusion.
- RR/MDR-TB with extensive disease, e.g., extensive bilateral cavitary disease.
- Any other situation in which the clinician is uncertain of a patient’s eligibility for the short treatment regimen” (p. 18).

Despite the inability of the drug Bedaquiline to be used as a treatment option for all patients diagnosed with MDR-TB, the new guidance envisages that most MDR-TB patients can be treated with entirely oral drug regimens lasting 18–20 months. The standardized, shorter MDR-TB regimen (with treatment duration of 9–12 months) can be offered to eligible patients who agree to the shorter treatment, but this requires a daily injectable agent for at least four months (WHO, 2019). This is an indication that the treatment of MDR-TB still requires the use of injectable aminoglycosides.

Permanent ototoxic hearing loss may develop after a single dose of injectable agents, and progress even after discontinuation of the injectable drugs (Reuter et al., 2017). Aminoglycosides are

known to persist in the inner ear tissues for six months or longer after administration (Bardien et al., 2009). The incidence of hearing loss associated with aminoglycosides is reported to be time and dose-dependent, related to concentrations in the inner ear (Appana, Joseph, & Paken, 2016). Ototoxicity may also be influenced by patient susceptibility, as well as factors related to the cumulative effects of the drug over time.

2.5 Ototoxicity from Aminoglycoside use

Ototoxicity is a common side effect during the treatment of several life-threatening health conditions. Often, when treating such conditions, the focus tends to be on saving the patient's life rather than preserving their hearing (Ramma, Schellack, & Heinze, 2019). A recent review of literature on the incidence of hearing loss among MDR-TB patients revealed that between 2.6% and 61.5% of persons treated for MDR-TB had documented a hearing loss and when the hearing of MDR-TB patients was formally tested every six weeks regardless of symptoms, more than fifty percent of patients had documented hearing loss; thus suggesting that this is an alarmingly common occurrence (Reuter et al., 2017). Even in studies on the shortened MDR-TB regimen, in which the injectable agent may be given for four months, hearing loss was reported in as many as 44% of patients in one cohort (Reuter et al., 2017). This review noted that in most observational cohorts of MDR-TB, formal assessments of hearing were not performed. Thus, these studies most likely underestimated the magnitude of the incidence of hearing loss in patients treated with second-line agents.

A further review of studies has revealed a high incidence of hearing loss among patients using second-line agents for the treatment of MDR-TB. As can be seen from the studies reviewed in Table 2.3 below, there are discrepancies in the percentage of aminoglycoside-induced hearing loss throughout the studies, and this may be due to the type of drug used, treatment duration, patient susceptibility as well as audiological tests used for the monitoring of hearing status.

Table 2.3

Studies on the incidence of aminoglycoside-induced hearing loss during treatment for MDR-TB

Author (Year)	Country	Drug used	No. of participant	Ototoxicity (%)	Type of testing used	Study Design	Comments
Hong et al. (2020)	South Africa	Kanamycin	379	63%	Pure tone Audiometry, Patient reports	Prospective	Audiograms every month during the 6-month intensive phase.
Hysell et al. (2018)	Bangladesh	Kanamycin	36	77,8%	Air conduction pure tone audiometry and speech audiometry.	Prospective	At the highest frequencies, hearing loss was severe and progressed to involve frequencies crucial for the perception of conversational speech in nearly a third of patients.
Abla et al. (2017)	Indonesia	Kanamycin	33	90,9%	Tympanometry, Otoacoustic Emissions (OAE), Air conduction pure tone audiometry.	Retrospective	Treatment for two months. The administration of Kanamycin injection for two months or more was considered to have a risk for ototoxicity.
Arnold et al. (2017)	United Kingdom	Amikacin initially treated with	One hundred consecutive participants at	55%	Air conduction Pure tone audiometry	Retrospective	The total duration of treatment with an injectable agent was 178 days. Two endpoints

		Capreomycin	four MDR-TB treatment centres.				relating to hearing were chosen: an audiogram definition (ototoxicity) and a definition encompassing audiogram results and patient-reported hearing impairment. Ototoxicity was reported to be higher in those on Amikacin than those on Capreomycin
Appana et al. (2016)	South Africa	Kanamycin	Fifty-two adults	100%	Case history, medical history review, otoscopic examination, immittance audiometry, pure tone audiometry, speech audiometry, distortion product otoacoustic emissions	Prospective	High and ultra-high frequencies were most affected. Speech discrimination scores deteriorated over time.
Kavallieratos (2012)	South Africa	Kanamycin	68	100%	Distortion Product Otoacoustic Emissions and Pure Tone Audiometry	Retrospective	All participants showed a change in hearing function. Changes were seen in both DPOAE function and Pure Tone

							Average thresholds, following long-term treatment for MDR-TB.
Kennedy (2009)	Ireland	Kanamycin	13	61,5%	Air conduction pure tone audiometry	Prospective	Audiograms every six weeks
Duggal and Sarkar (2007)	India	Amikacin, Kanamycin, Capreomycin	64	18%	Air and bone conduction pure tone audiometry	Longitudinal	The participant's age range was 17-65 years. Testing frequencies were 250- 8000Hz.
De Jager and van Altena (2002)	Netherlands	Amikacin, Kanamycin, Streptomycin	61	18%	Air conduction pure tone audiometry	Retrospective	Classification of a hearing loss defined as 15 dB at two adjacent frequencies or 20 dB at one frequency. Testing frequencies were 250-8000 Hz.

From the studies highlighted in table 2.3 above, the incidence rate of ototoxicity ranges from 18% to 100%, with most studies focusing on Kanamycin. Furthermore, shifts in the hearing threshold were more evident in the high frequencies ($\leq 4000\text{Hz}$). Low-frequency sounds are responsible for the perception of speech in quiet, whereas higher frequency sounds are responsible for the perception of speech in noise (Rademaker-Lakhai et al., 2006). Ultra-high frequencies allow for the perception of music as well as an appreciation of certain natural sounds (Rademaker-Lakhai et al., 2006). Therefore, patients on MDR-TB treatment who develop an aminoglycoside-induced hearing loss may experience increased difficulty with speech discrimination, as everyday communication interactions generally encounter background noise to some degree.

A hearing loss resulting from ototoxicity can, therefore, negatively impact the affected individual. An individual's ability to perform daily tasks is not only influenced by his/her hearing ability, but also by other situational factors such as background noise, room acoustics, and his/her familiarity with the environment or situation (Dobie & van Hemel, 2004). Such factors are important even in individuals who present with normal hearing, but the effects are magnified when hearing is impaired. In a noisy environment, it may be more challenging to maintain a conversation or to give and receive information, especially with poor lighting and limited visual cues (Dobie & van Hemel, 2004). It is important to note that audiological word recognition score testing is conducted in a sound-treated booth and does not represent communication in everyday situations unless speech in noise tests are used. This, therefore, indicates the increased challenges patients could face with speech discrimination outside of a sound-treated room, which would consequently lead to limited communication ability.

Decreased communication ability is highly expected as an ototoxic hearing loss may occur at any stage of treatment; thus, emphasizing the importance of ototoxicity monitoring throughout treatment. Considering the progression of hearing loss over treatment duration, audiological monitoring of patients on MDR-TB treatment is of paramount importance (Appana et al., 2016). The monitoring of hearing loss is essential for two reasons. First, if detected early, it may be possible to alter the treatment regimen to either stop or reduce the dose of the responsible drug, increase the dosing interval or retain current therapy while increasing the frequency of audiological monitoring to identify further deterioration; thus, preventing progression of hearing loss to the point where it would impact on communication (Jenkins et al., 2011). Second, if significant hearing loss has developed and is detected, interventions can be implemented to assist in communication (Jenkins et al., 2017). The choice of intervention depends mainly on disease severity and response, the duration for which the injectable has already been given, the drug resistance profile of the individual as well as the

availability of alternate drugs. In addition, the nature of the hearing loss and the speed at which it has occurred must be considered (Jenkins et al., 2011), through ototoxicity monitoring.

Ototoxicity monitoring, which is within the scope of practice of the Audiologist, is the continuous assessment of the auditory system functioning that provides information about the effects of toxic agents on the auditory system (American Speech-Language-Hearing Association [ASHA], 2006). Audiologists need to be aware of their role in ototoxicity monitoring, which includes conducting audiological assessment before, during, and after administration of ototoxic drugs (Khoza-Shangase & Stirk, 2016), in addition to setting up the ototoxicity monitoring programme, as well as informing doctors of the development of a hearing loss (Paken, Govender, Pillay & Sewram, 2020). Additional responsibilities include counselling patients and their families, providing compensatory communication strategies training, and providing amplification (Health Professions Council of South Africa, 2018). However, in many developing countries such as South Africa, audiological services are limited, and often, the hearing loss goes undetected (Khoza-Shangase & Stirk, 2016).

Devastatingly, hearing aids and cochlear implants are not available in most settings with high MDR-TB rates. Even if available, they are far inferior to normal hearing as they do not replace or replicate human hearing, irrespective of the physical and financial costs they involve (Reuter et al., 2017). Permanent hearing loss is also a long-term condition that can have substantial psychosocial consequences. Perhaps the most substantial of these consequences are communication difficulties and social isolation (Selimoglu, 2007). Adoga et al. (2019) identified the implications of disabling hearing loss in adults acquired through the use of aminoglycosides, as setbacks in family, social life, and in employment conditions, resulting in isolation and frustration. Adoga et al. (2019) further stressed the importance of emotional stability in the diagnostic and rehabilitative processes in order to address the difficulties arising from social and familial factors, which may impact the patient's Quality of life.

2.6 Quality of Life

The Constitution of the World Health Organisation defines health as a state of complete physical, mental, and social well-being; not merely the absence of disease and follows that the measurement of health and the effects of health care must include not only an indication of the severity of diseases but also an estimation of well-being (WHO, 2014). Quality of life has been challenging to define and to measure because different cultural, ethnic, religious, and personal values influence the way that an individual is affected by disease and its outcomes. WHO (2014) describes the domains of quality of life as follows:

- **“Subjective satisfaction:** Global quality of life as assessed by the individual
- **Physical environmental factors:** Standard of housing or institutional living arrangements, control over physical environment, and access to facilities.
- **Socio-economic factors:** Income and wealth, nutrition and overall standard of living.
- **Social environmental factors:** Family, social networks and support. Levels of recreational activity and contact with statutory and voluntary organisations.
- **Cultural factors:** Age, gender, ethnicity, religious beliefs and background.
- **Health status factors:** Physical well-being, functional ability and mental health.
- **Personality factors:** Psychological well-being, morale, life satisfaction and happiness”
(WHO, 2014, p.4)

The term ‘Quality of Life’ extends both to the impact of treatment and side effects and to the recognition of the patient as an individual, as a “*whole person, body, mind and spirit*” (Pukelien & Starkauskiene, 2011, p. 11). Quality of life can only be described by the individual and can be further understood as the degree of satisfaction or dissatisfaction felt by an individual about various aspects of their lives (WHO, 2014). Alternatively, Quality of life can be regarded as the provision of the necessary conditions for happiness and satisfaction (WHO, 2014). Quality of life can be further described as the degree to which an individual is healthy, comfortable, and able to participate in or enjoy life events (Jones et al., 2006). The term ‘Quality of life’ can refer to both the experience an individual has of his or her own life and the living condition that the individual finds him/herself in (Jones et al., 2006). Hence, Quality of life can be said to be highly subjective. Whereas one individual may associate Quality of life with wealth or overall life satisfaction, another person may define it in terms of having the ability to live a good life with emotional and physical well-being (Jones et al., 2006). A disabled person may report a high quality of life, whereas a healthy person without a disability may report a low quality of life. Within the area of health care, Quality of life is viewed as multidimensional, encompassing emotional, physical, material, and social well-being (Jones et al., 2006). It represents an aspect of health that is different from the generally used medical and biological methods of assessment, such as blood tests and clinical judgement. These tests have generally dominated health care and medicine, mostly because they are objective. The measurement of Quality of life is subjective and entails the subjective views of the patients directly, and this should be used by health care professionals to supplement traditional assessments (Jones et al., 2006). The measurement of Quality of life should, therefore, also be used during assessments and management of MDR-TB.

2.7 MDR-TB and Quality of Life

The MDR-TB disease has a negative and all-encompassing impact on the affected individual's health status in terms of the physical, psychological, and social aspects (Guo et al., 2009). Even after the MDR-TB patients had completed their treatment and were considered microbiologically 'cured,' their Quality of life remained poor in comparison to the general population (Guo et al., 2009). The on-going impairment in Quality of life may be partly due to the persistent physical symptoms and residual physiological damages from the disease and/or treatment. Furthermore, few qualitative studies have shown that the social stigma attached to the diagnosis of MDR-TB in some cultures is significant (Guo et al., 2009). People with MDR-TB may feel isolated from their family and friends or experience the fear and anxiety of disclosing their diagnosis to others. All these consequential impairments may take a long recovery time (Guo et al., 2009). Psychological health takes into account several dimensions of the individual's mood and emotional well-being. The most common emotion expressed by patients is the feeling of hopelessness and fear, once diagnosed with MDR-TB, as reflected in the feeling that the MDR-TB treatment is the final option for a patient, which validates their inherent fears of the effectiveness of MDR-TB treatment in providing them with a cure for their disease (Seedat et al., 2009). Patients often feel distressed and discouraged when having to change and adapt their lifestyle to accommodate the long course of therapy required for MDR-TB.

Many patients reported living an isolated life with a lack of participation in their 'normal' routine, which resulted in them feeling less valuable, sometimes leading to depression and a perceived loss of self-identity, low self-esteem as well as feelings of guilt, and isolation (Seedat et al., 2009). Most patients are worried, scared, frustrated, or disappointed by the diagnosis of MDR-TB, and most of them do not initially accept their diagnosis (Sharma et al., 2012). The impact of stigma has led to divorce, cancellation of impending marriages, breakdown of family relationships, and also isolation within the family (Loveday et al., 2017). Many patients admitted to isolation facilities feel bored, lonely, or abandoned. After discharge, most of these patients are not received back into their homes. Even after patients have completed treatment, many of them avoid visiting their acquaintances, colleagues, or even their spouses (Sharma et al., 2012). These changes may have a significant impact on an individual's psychological and mental state.

The psychological effects of MDR-TB have further been reported by patients to include feelings of hopelessness and fear with initial diagnosis as well as a fear of death. Some patients feel as though they are a burden to their families, while many participants also report having been distressed

to have to change their living behaviours substantially. While some patients may be able to maintain their pre-MDR-TB lives to a limited extent, most patients report losing their sense of identity (Morris & Quezada, 2013). Loss of identity was noted to have further psychological impacts not only on the individual but on family members as well, in that many patients and their carers expressed their anxieties in not knowing what side-effects to expect and how to deal with them if they occurred. This lack of knowledge also meant that patients were unsure whether they should seek medical help, whether they were indeed experiencing a side-effect or a symptom of MDR-TB and whether or not the side-effect would pass (Morris & Quezada, 2013). Knowledge about the disease and treatment was reported as being necessary for patients in helping them come to terms with their diagnosis and to understand their treatment journey (Laxmeshwar et al., 2019).

Patients and family members generally lacked knowledge about MDR-TB, its treatment, and side-effects (Khanal et al., 2017). The majority of respondents did not know about MDR-TB before their diagnosis. Some had heard about drug-sensitive TB from their family or acquaintances that had been previously diagnosed with TB. Limited knowledge about MDR-TB and its treatment seemed to fuel patients' anxieties. Those who had previously been treated unsuccessfully for drug-sensitive TB were particularly fearful and lacked any faith in the potential for MDR-TB treatment to cure their disease (Khanal et al., 2017). Inadequate information, as well as concerns and confusion, led to further psychosocial stress for patients and their family members (Khanal et al., 2017).

In a study by Thomas et al. (2016), twenty-three per cent of MDR-TB patients had defaulted on treatment due to financial constraints, and there was also a reduction in salary due to work absenteeism, while some income had to be spent on costs associated with treatment. MDR-TB has a substantial adverse economic impact on patients due to the long duration and complexity of treatment (Thomas et al., 2016). MDR-TB was found to contribute significantly towards stress and anxiety as most patients were no longer able to work after diagnosis, and those who continued to work received less income due to absence at work. This inability to work creates economic vulnerability as patients are no longer able to earn an income (Thomas et al., 2016).

Although MDR-TB diagnosis and treatment services are free for patients in countries such as Ethiopia and Indonesia, patients have other direct and indirect costs, and the financial impact is significant for most patients (van den Hof et al., 2016). Despite the free provision of health care services by public health services in South Africa, patients bear high costs when accessing diagnosis

and treatment services for MDR-TB (Ramma et al., 2015). The economic barriers include inaccessibility of treatment, the distance away from the hospital, transport costs, and costs incurred during hospitalization (Ramma et al., 2015). Many patients and their families still face high financial costs related to seeking and accessing care for their TB illness. Financial difficulties associated with the costs of treatment are higher during the intensive phase of treatment for outpatients (Ramma et al., 2015).

The estimated costs of MDR-TB patient diagnosis and treatment are higher than those for other TB patients, mainly due to the extended period for treatment (van den Hof et al., 2016). Aggravating this situation, MDR-TB patients more often lose their jobs. If the patient is the breadwinner of the family, the combination of lost income and extra costs, generally, is catastrophic. A too high financial burden may cause patients to avoid the diagnosis, not to start treatment, or stop treatment, leading to prolonged transmission of the disease to others (van den Hof et al., 2016). Patients stopping treatment as soon as they feel better may need retreatment, which is more expensive, takes longer, and is more toxic than initial treatment (van den Hof et al., 2016). It can be said that societal pressures and negative views about MDR-TB may also be a contributing factor to patients not completing the long treatment course.

The social impacts of MDR-TB have been identified to present as the patient's perception of self, inability to continue participating in their usual social activities, as well as stigma and discrimination from family and friends. Stigma and discrimination have been reported as a major concern facing MDR-TB patients, as it negatively impacts the patient in accessing healthcare facilities in their neighbourhood (Loveday et al., 2017). The effects of stigma included: experiences of social seclusion or rejection from family members, friends, neighbours, and/or health providers; internalized shame; financial instability; discrimination; and its repercussions (Loveday et al., 2017). Social acceptance and support are very minimal for MDR-TB, unlike other diseases (Loveday et al., 2017). It was also reported that MDR-TB patients would voluntarily separate themselves from their family for fear of spreading the infection to other members, which may result in feelings of isolation.

There is abundant literature on the psychosocial impact of MDR-TB documented internationally and within the South African context. However, these impacts are on-going (Loveday et al., 2017), indicating that minimal or inadequate interventions have been put in place to support

patients diagnosed with MDR-TB. Table 2.4 below highlights studies on the psychosocial impact of MDR-TB.

Table 2.4

Studies on the psychosocial impact of MDR-TB

Reference	Country	Method	Sample Size	Findings	Implication
Kendal et al. (2013)	South Africa	Retrospective	225	Housing and economic insecurity were associated with decreased Quality of life and a higher risk of treatment default	Socioeconomic support was crucial in improving treatment outcomes.
Mauch et al. (2013)	Dominican Republic	Cross-Sectional	20	MDR-TB patients had significantly lower Quality of life scores in comparison to patients with drug-susceptible TB	There is a greater need for psychosocial support for MDR-TB patients
Vega et al. (2004)	Peru	Case Study	75	The prevalence of depression and anxiety was high among MDR-TB patients	Recommendation on the use of anti-depressant medication in conjunction with MDR-TB treatment to address psychiatric issues

While studies have shown that MDR-TB has significant psychosocial impacts, the impacts may be worsened by a hearing loss, which may lead to a further decline in Quality of life.

2.8 Quality of life and Hearing Loss

There is much evidence demonstrating the long-term detrimental impact of hearing loss on Quality of life, and the ability to lead productive lives. Hearing loss is often described as an invisible disability that can reduce a person's Quality of life and can have far-reaching psychological, physical, and social consequences (Jennie et al., 2014). Hearing loss is the third most common cause of years lost to disability globally (Jennie et al., 2014). There are multiple consequences to losing one's hearing that last far beyond the treatment and monitoring performed by TB programmes.

When hearing loss occurs, it is a challenging and unusual experience, and rapid onset hearing loss, as seen in MDR-TB patients, is more confusing than a gradual loss of hearing (Kaland & Salvatore, 2002). Adults who acquire hearing impairment have families and jobs through which they relate and identify their lives, and neither of these includes hearing loss (Kaland & Salvatore, 2002). Hearing loss can considerably affect the relationships with communication partners. Individuals with hearing loss can find it challenging to take part in family gatherings and to converse with family members (Jennie et al., 2014). Relationship changes are noted in families whereby they do not understand hearing loss and the communication challenges brought on by hearing loss. They believe that the person with the hearing impairment is not trying hard enough to listen; which in turn leads to the individual becoming impatient and frustrated (Jennie et al., 2014). Persons with hearing loss are more likely to be bullied or physically assaulted, more likely to be depressed and socially isolated, and less likely to find work (Jennie et al., 2014).

Heffernan et al. (2016) describe the representations of psychosocial experiences of adults with hearing loss as cognitive, emotional, and coping. Hearing loss was found to have various negative connotations, including unintelligence, and unfriendliness which aligns with the stigmatisation of hearing loss and its impact on one's sense of identity (Heffernan et al., 2016). Individuals with hearing loss had primarily negative emotional responses to the condition, including frustration, embarrassment, and loneliness. Coping representations suggest that individuals with hearing loss who attend many social events could appear, on the surface, to have a high degree of social functioning. However, they could feel isolated and dissatisfied (Heffernan et al., 2016). This inability to participate in valuable and meaningful interactions may negatively impact the individual's Quality of life.

Late-deafened adults often reported that hearing loss had negatively changed their understanding of their identity and often led to an identity crisis (Jennie et al., 2014). Also, people with hearing loss can have experiences of stigma, as the condition has various negative stereotypes, including incompetence, cognitive impairment, and social impairment (Selimoglu, 2007). As the rate of MDR-TB diagnosis in South Africa increases, patients who acquire a hearing loss due to aminoglycoside treatment are at a higher risk of facing these consequences. Furthermore, there are greater levels of anxiety and depression among patients with hearing impairment than in the general population, which have a substantial negative impact on Quality of life (Jennie et al., 2014).

Quality of life is a global imperative, regardless of whether the patient has a life-threatening disease or not (WHO, 2018). The sense of hearing can significantly influence an individual's Quality of life as hearing loss in adults may reduce communication ability with spoken language, and participation in social and vocational activities (Appana et al., 2016). Assessing health-related Quality of life is essential for documenting the burden of chronic disease, tracking changes in health over time, and assessing the effects of treatment (Ron et al., 2011). Although in medical practice, the method of assessing patient health status and disease is by laboratory or clinical tests, it becomes impossible to separate the disease from the individual's personal and social context, especially in chronic and progressive diseases (Sharma et al., 2012). It is, therefore, particularly relevant to gain insight into the impact on the Quality of life of MDR-TB diagnosed patients who present with a hearing loss due to the disease debilitating course and long term effects of hearing loss.

There are multiple consequences of losing one's hearing that last far beyond the treatment and monitoring performed by TB programmes. Moreover, the on-going use of injectable agents requires a significant amount of logistical support. It may contribute to difficulties faced by persons who are unable to return to work, school, or perform other activities of 'normal' life while on treatment. Being diagnosed with MDR-TB and undergoing treatment imposes significant psychological, social, and economic stress on patients, which may be further compounded by a hearing loss. Quality of life is, therefore, likely to be further diminished by higher anxiety and depression owing to a diagnosis of hearing impairment in the patient with MDR-TB. MDR-TB and its treatment have been reported to have impacted on the patients' contact with family and broader social networks and this, in turn, impact on their psychosocial well-being (Khanal et al., 2017). Younger patients seemed particularly affected by this restriction on their social networks. Several participants also explained how relatives stopped visiting them due to fear of transmission, and this added to their emotional stress. Family members also commented on how the fear of infection affected family relations for patients (Khanal et al., 2017). MDR-TB remains a major public health problem in South Africa, and there needs to be a better understanding of the impact of MDR-TB, the ototoxic side effect on hearing as well as its treatment outcomes on Quality of life.

2.9 Summary

MDR-TB is a global concern and has impacted significantly on the lives of individuals diagnosed. This literature review has highlighted the theoretical aspects of MDR-TB, the role of aminoglycoside use within the MDR-TB regimen, and the effects of aminoglycosides on hearing as well as the psychosocial effects of MDR-TB diagnosis in the affected patient. The chapter has, further, revealed that there is a lack of literature into the psychosocial impacts of both MDR-TB and

hearing loss on Quality of life both internationally as well as in the South African context. The lack of literature has led to the formulation of this study, to inform the literature on the psychosocial impacts of hearing loss within the MDR-TB population, to identify the challenges experienced by patients in order to bring awareness and possibly advocate for the provision of psychosocial interventions to improve their overall Quality of life outcomes.

CHAPTER 3: METHODOLOGY

3.1 Introduction

The following chapter focuses on the research methodology, which guided the research process. It includes the aims and objectives of the study, the study design, a description of the study population, the sampling technique used, data collection instruments, and the procedure used to collect the data. A description of the data analysis is provided. Furthermore, issues relating to the validity and reliability of the study, as well as the ethical and legal considerations, are also discussed.

3.2 Research Aim and Objectives

The study aimed to describe the psychosocial impact of hearing loss on the Quality of life of adults with MDR-TB.

In order to achieve the aim of the study, the following objectives were formulated:

- To explore the psychological and emotional impact of hearing loss in adults with MDR-TB.
- To describe the experiences of the social impact of hearing loss in adults with MDR-TB.
- To describe the experiences of the economic and vocational impact of hearing loss in adults with MDR-TB.

3.3 Research Approach and Study Design

A qualitative research approach utilising Phenomenological analysis design was used to conduct this study. *“Qualitative research is an inquiry process of understanding based on distinct methodological traditions of inquiry that explore a social or human problem. The researcher builds a complex, holistic picture, analyses words, reports detailed views of informants and conducts the study in a natural setting”* (Creswell, 1998, p.15). Qualitative research uses non-statistical methods to develop concepts, which help us to understand social phenomena in natural settings where they occur, emphasizing the meanings, experiences, and views of the participants (Cottrell & McKenzie, 2011). Using a qualitative research method is useful in empowering participants by including them in the research process and thus making their voices heard (Neergard, Olesen, Anderson, & Sondergaard, 2009). Qualitative methods are typically more flexible as they allow the researcher to be spontaneous and adapt their interaction with the different participants (Berg, 2001). Qualitative methods use open-ended questions, which allow participants to respond in their own way and provide more information (Berg, 2001). Participants are, therefore, able to provide more detailed responses. In turn, the researcher has the opportunity to respond to what participants say immediately and ask additional questions that may be relevant to the information provided by the participant (Berg, 2001).

Phenomenology is the study of the common meanings, which are shared by study participants in order to create an understanding of the participants' experiences of a phenomenon (Lester, 1999). This type of research mainly focuses on the individual's perceptions of his/her experiences (Lester, 1999). Phenomenology aims to understand the way individuals see themselves in their environment. By understanding the meanings that individuals place on their particular experiences, a phenomenon is obtained (Lester, 1999). Therefore, it can be said that phenomenology leads in some way into at least some background conditions of individual experience (Rodriguez & Smith, 2018).

The type of Phenomenological design identified for the research study was transcendental phenomenology. It is descriptive, focuses on the discovery and description of the lived world, and is characterised by the following procedures:

- a) "Identify a phenomenon to study,
- b) Bracket out researchers' experience,
- c) Collect data from participants who have experienced the identified phenomenon,
- d) Analyse data and develop categories and themes of identified statements and quotes,
- e) Develop a textural (what) and structural (how) descriptions of the participants' experiences,
- f) Develop a combination of the textural and structural descriptions in order to convey the essence of their experiences of the identified phenomenon" (Edmonds & Kennedy, 2013, pg. 10).

3.4 Study Site

The study was conducted at Sizwe Tropical Disease Hospital in the city of Johannesburg, Gauteng province. The hospital was selected due to its large referral base. Sizwe Tropical Hospital is utilised for the centralised management of all patients with MDR-TB from the five health districts, i.e., City of Johannesburg, Ekurhuleni Metro, City of Tshwane, West Rand, and Sedibeng (Statistics South Africa [Stats SA], 2014), as reflected in Figure 3.1, below. Patients are admitted for the intensive phase of treatment and are discharged to district clinics to continue treatment after one sputum culture-negative conversion (Stats SA, 2014). They are expected to report back to Sizwe Tropical Disease Hospital after three months for review.

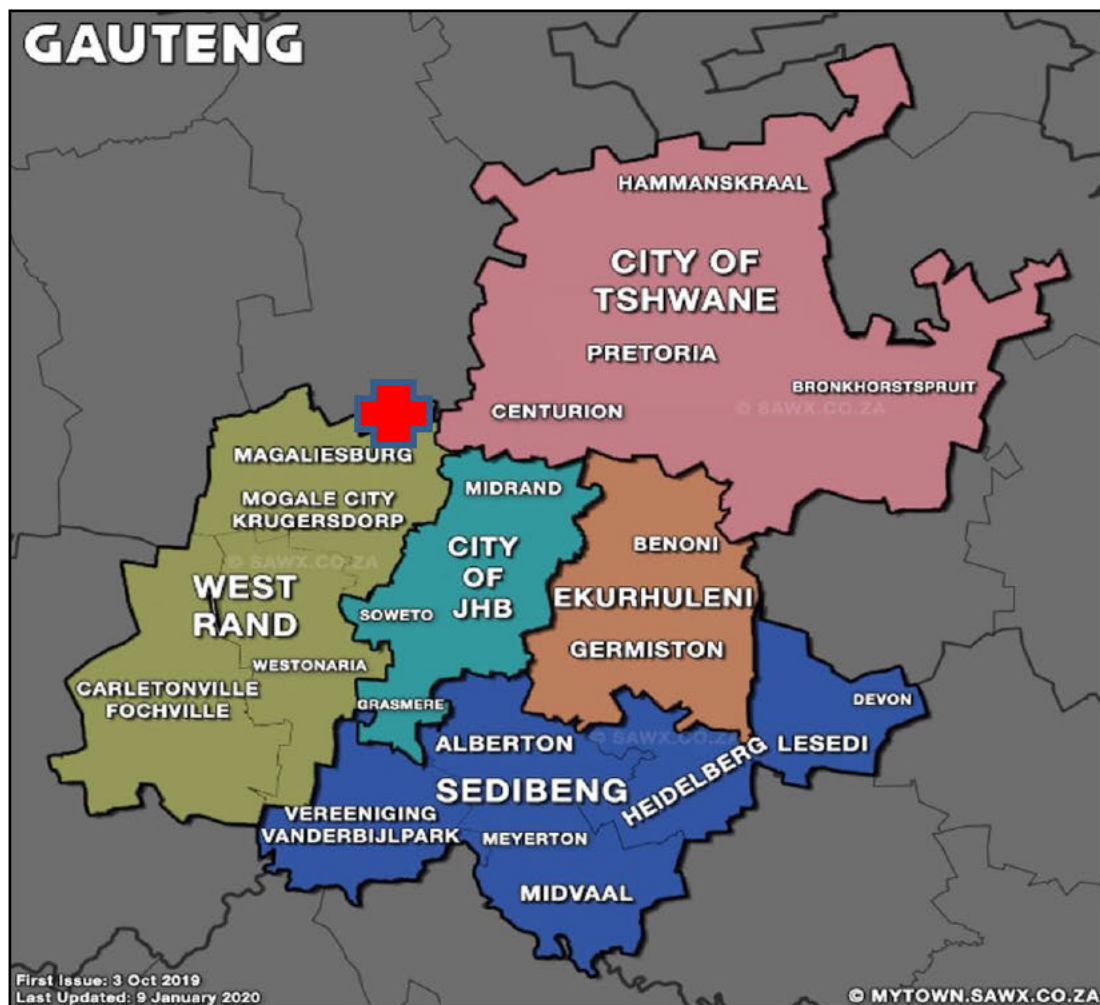


Figure 3:1: Location of Sizwe Tropical Disease Hospital within Gauteng Province

Downloaded from: https://en.wikipedia.org/wiki/List_of_municipalities_in_Gauteng

3.5 Study Population

The study population included patients at Sizwe Tropical Disease Hospital who had acquired a hearing loss due to treatment for MDR-TB.

3.6 Sampling

3.6.1 Sampling Method

A purposive sampling method was used to conduct this study. Purposive sampling is synonymous with qualitative research (Small, 2009). Choosing to engage in purposive sampling indicates that the researcher identifies sampling as a means of choosing with whom and where they are to conduct the research study (Small, 2009); thus, implying that the researcher's sample must be linked to the objectives of the study. The main goal of purposive sampling is to focus on particular

characteristics of a population that are of interest, which best enables the researcher to answer the research question (Small, 2009). Purposive sampling is most appropriate when the chosen data collection instrument is a semi-structured interview, as the focus is on obtaining an in-depth description of the case (Babbie, 2010). Therefore, participants who would be able to provide rich information need to be chosen for the study, as they could relate a great deal about the psychosocial impacts of hearing loss on the quality of life in the context of an MDR-TB diagnosis.

3.7 Participant Selection

Participants for the study were selected based on the criteria identified as suitable for achieving the aims of this study. Therefore, before conducting the research study, the following inclusion and exclusion criteria were stipulated, ensuring that only a particular group were selected.

3.7.1 Participant inclusion criteria

The following criteria were used to include participants in the study:

- The participants had to have a laboratory-confirmed diagnosis of MDR-TB.
- All participants had to have normal baseline audiograms.
- The participants had to have been between 20 and 40 years of age, to ensure a fairly homogenous group who may have similar interests in terms of community and work life.
- The participant had to have been on the injectable agents (Kanamycin, Amikacin, Capreomycin) drug regimen, as these drugs are known to have ototoxic side effects.
- The participant had to have completed or been on their MDR-TB medication for at least six months to allow enough time for exposure to their daily activities to identify psychosocial impacts.
- The participant had to have acquired a hearing loss during their course of MDR-TB treatment, as reflected by audiometric test results in his/her medical file.
- The participant had to be alert, cooperative, and able to participate fully in an interview.

3.7.2 Participant Exclusion Criteria

The following criteria were used to exclude participants in the study:

- Participants were excluded if they had a pre-existing hearing loss, not due to ototoxicity resulting from aminoglycoside treatment.
- Participants who were not medically stable to speak.
- Participants who were not fluent isiZulu and/or English speakers, as interviews were conducted in isiZulu or English.

- Participants who presented with vestibulotoxicity, as the focus of the study was only on the ototoxic hearing loss and vestibulotoxicity may further impact the quality of life.

3.8 Study Participants

Ten participants contributed data to the study. This was considered an acceptable sample size, as Morse (2014) suggests at least 5-15 participants for phenomenological studies. Participants were aged between 26 to 40 years and comprised of seven males and three females. Eight participants (80%) chose to have the interview conducted in isiZulu, while two participants (20%) had their interviews conducted in English.

3.9 Data collection

3.9.1 Data collection method

Face-to-face semi-structured interviews were conducted with each participant. The use of semi-structured interviews allowed the researcher to have a good understanding of the information collected as well as flexibility over the overall flow of questions. A semi-structured interview allows an individual to answer questions on their own terms rather than the standardised interview. However, it still provides a good structure for similarity when compared to a focused interview (May, 1997). Kumar (2005) views the interview as the most suitable approach for studying sensitive areas, as the interviewer can prepare participants before asking sensitive questions and explain the questions to them in person.

While the interview process is a valuable means of collecting in-depth data, it does have limitations; namely, it can prove to be a time-consuming process. The interaction between the interviewer and the participant can differ as each interview is unique, and the quality of the responses obtained from different interviews may vary significantly (Kumar, 2005). The quality of data collected may also be influenced by the skill of the interviewer, depending on whether it is their first time or if they have experience with conducting interviews. The risk of bias is high due to fatigue, as well as becoming too involved with interviewees (Abawi, 2013). In addition, it might be challenging to obtain reliable data on a research subject if the participant sample size is small, unlike the quantitative approach whereby the sample size is much larger and, in certain circumstances, may yield more reliable data (Abawi, 2013). In qualitative research, data is collected at the site where the participants experience the phenomenon (Creswell, 2013). Therefore, data collection for the current study was at the hospital where patients had been hospitalised. All interviews were conducted by the

researcher. The researcher conducted one interview per day. Furthermore, to reduce the impact of the limitations mentioned above on the quality of data collected, the interviewer took careful consideration not to interview patients if they were tired or unwell. Patients were notified at the beginning and during the interview that should they need to discontinue or pause for a break, they were allowed to.

3.9.2 Data Collection Equipment

In addition to semi-structured interviews, field notes were taken down during the interview process. Field notes were taken regarding facial expressions, emotions, and informal observations such as body language. The researcher also made notes regarding the ease at which participants answered questions to gather if they were scared, or teary, or had other emotional responses during the interview process. These notes assisted the researcher to gain more insight into the information provided by the participants as well as gain a deeper understanding of their experiences. This information also assisted when analysing the findings of the study as well as reporting on the impact of the results on the quality of life of participants.

All interviews were audio-recorded using a 16GB Voice recorder USB Dictaphone digital audio. The Dictaphone had features of digital noise reduction to effectively filter the noise around the recording environment, thus supporting better clarity of sound and memory play. The Dictaphone also had a highly sensitive dual omnidirectional microphone to enhance sound source acquisition and high-quality recording for 96 hours. All interviews were then uploaded and saved onto NVIVO 12 software.

3.9.3 Data Collection Instrument

A semi-structured interview schedule (Appendix A1 and A2) was used to collect data. The data collection instrument was developed by amending existing tools by Newman et al. (1991) and Kelly (2015). The interviewer has some freedom to probe further on additional questions in response to what may be seen as significant responses while allowing the development of rapport and empathy between the researcher and the participant (Ryan & Cronin, 2009). The researcher sought to use language that was easy to understand and relevant to each of the participants being interviewed. The interview schedule was, therefore, translated to isiZulu as isiZulu is the second most commonly spoken language in Johannesburg, Gauteng (Alexander, 2018). The interview schedule was back-translated into English by another Audiologist, who had good knowledge about the topics covered in

the interview schedule. The questions were open-ended, giving participants the ability to express their thoughts and feelings (mainly when sensitive issues were being discussed) while offering more detail on the research subject (Sarantakos, 1988).

The interview questions were developed following the aim of the study. The interview schedule (Appendix A1 and A2) was structured into four sections. Table 3.1 below provides an overview of the interview schedule with motivations for each section.

Table 3.1

Motivations for each area in the interview schedule

Section	Motivation
Biographical Details	In order to obtain a holistic view of the participant, and to understand the answers provided by the participant, participants were asked to share biographical information. There may be possible influences that biographical details have on the information received; hence, these factors need to be acknowledged.
Medical History	It was important to gain insight into participant's medical history in order to note the duration of illness as well as the onset and progression of hearing loss. This information allows the researcher to understand better the participant's medical journey as well as present medical and audiological status.
Psychological and Emotional Impact	The questions in this section allowed the participants to express their feelings, thoughts, and emotions regarding their overall quality of life.
Social Impact	This section allowed the researcher insight into the societal impacts that participants experienced due to their MDR-TB and hearing loss. Information obtained, assisted in describing how MDR-TB and hearing loss impacted relationships.
Employment and Economic Status	The questions presented in this section allowed the researcher to describe the impact that the diagnosis of hearing loss and MDR-TB may have on their employment and consequent finances.

The research objectives were achieved through specific questions in the data collection instrument, as indicated in Table 3.2.

Table 3.2

Questions related to each objective

Objective	Questions
To explore the psychological and emotional impact of hearing loss in adults with MDR-TB.	3-5
To describe the experiences of the social impact of hearing loss in adults with MDR-TB	6-8
To describe the experiences of the economic and vocational impact of hearing loss in adults with MDR-TB	9-11

3.10 Data Collection Procedure

- Prior to commencing the research study, full ethical clearance was obtained from the University of KwaZulu-Natal Biomedical Research Ethics Committee BE274/19 (Appendix B).
- Permission to conduct the study at Sizwe Tropical Disease Hospital was obtained from the Gauteng Department of Health (Appendix C), and the Hospital Chief Executive Officer (Appendix D). Once permission was obtained, the recruitment process began.
- The resident Audiologist was involved in the recruiting of patients. This method of recruitment was selected as patients had developed a relationship of trust with the Audiologist. The Audiologist made patients aware of the research study as they attended their Audiology follow-up appointments during the month of data collection. Those participants who met the inclusion criteria were then invited to participate.
- Participants were given an information leaflet (Appendix E1 and E2) informing them of the nature and purpose of the study, and the requirements for participation. If they were willing to participate, they were required to sign an informed consent form (Appendix F1 and F2), a copy of which was retained by the participant.
- Interviews, using the interview schedule (Appendix A1 and A2) were conducted with the participants. All participants were asked the same questions from the questionnaire, but the structure of the questions was adapted depending on the answers provided by each participant. The interviews ranged from 35 to 45 minutes per participant.
- Interview times varied and were scheduled at times, suitable for both participants and the researcher.
- Each interview was conducted and audio-recorded by the researcher. Interviews were held in a quiet, private room in a comfortable environment where seats were carefully arranged and where suitable lighting was available, to reduce the risk of any ambient noise, as background noise could have affected the patient's ability to hear. Lighting and seating arrangements were necessary, as some patients were dependant on lip reading for communication.

- Infection prevention and control practices were implemented during the interview stage of the data collection process. The interviews were conducted with a vulnerable population, and it was essential to maintain a safe environment by reducing the risk of the potential spread of disease. Gloves were not required as there was no physical contact between the researcher and the participants during the interview process. All windows were left open to provide natural ventilation since MDR-TB is an airborne disease, and the researcher did not have any illness at the time, which may have caused weakened immunity as that could have created the susceptibility to infection.
- After the interview, the researcher assigned pseudonyms to all participants.
- Data collection took place between October and November 2019. The audio-recorded interviews were fully transcribed verbatim. The interviews that were conducted in IsiZulu were translated into English and then transcribed verbatim.
- Transcription of interviews was done through the NoNotes.com transcription service.

3.11 Pilot Study

A pilot study was conducted at Sizwe Tropical Disease Hospital before the main study. The pilot study included four patients from Sizwe Tropical Disease Hospital. These were patients diagnosed with MDR-TB as well as a hearing loss. The patients who participated in the pilot study were not included in the main study. The pilot study aimed to do a trial run of the main study that would identify any possible limitations that could hinder the quality and validity of the results obtained (Blessing & Chakrabarti, 2009). A pilot study allows the researcher to make adjustments during the primary investigation to ensure that maximum and efficient data relating to the study is obtained (Blessing & Chakrabarti, 2009). Participants were informed that following the interview, they would be required to complete the pilot study survey (Appendix G1 and G2). This survey provided the researcher with feedback on the data collection instrument so that appropriate changes could be made.

3.11.1 Results from the pilot study

The results obtained from the pilot study indicated that the data collection method and tool was appropriate. No concerns were reported by participants with regards to the time taken to complete the questionnaire; however, the interviewer acknowledged that the duration of interviews could have been extended for the collection of information-rich data. All participants reported that the questions were easy to understand and respond to. Therefore, no changes were made to the content. The results and recommendations from the pilot study are shown in Table 3.3, below.

Table 3.3

Results and recommendations from the pilot study

Aspect	Results	Recommendation
1. Time taken to administer the interview	The time taken to administer the interviews varied between 20-35 minutes per interview. However, the researcher identified that the duration of questioning was not effective as there was minimal probing of questions.	Time was adjusted for interviews in the main study to allow for more probing in order to obtain more in-depth information.
2. Clarity of the questions asked	All participants reported that the questions were clear and easy to understand.	No adjustments were made to any questions in the interview schedule.
3. Terminology used in the interview	All participants reported no challenges with the terminology or language used in the interview.	No adjustments were made to the terminology used during the interviews.
4. To determine whether any additional questions needed to be included in the interview schedule	All participants reported that the questionnaire addressed all areas that impacted their quality of life.	No additional questions were required.

3.12 Data Analysis

The study aimed to describe the psychosocial impact of hearing loss on the Quality of life of adults with MDR-TB. Thus considering the above aim, the Inductive Thematic Analysis approach was considered the most appropriate for data analysis.

3.12.1 Overview of inductive thematic analysis

The chosen method of data analysis was inductive thematic analysis. *Thematic analysis is a method for identifying, analysing, and reporting patterns (themes) within data. It minimally organises and describes your data set in (rich) detail* (Braun & Clarke, 2006, p.6). The thematic analysis intends to understand people's everyday experiences of reality, in great detail, in order to gain an understanding of the research phenomenon in question. Thematic analysis reports on participants' experiences, their meaning, and their reality. Therefore, it can be used as a method to reflect reality or reveal the surface of reality (Braun & Clarke, 2006). Inductive analysis is the process of coding the

data without trying to fit it into a pre-existing phenomenon or the researcher's assumptions. In this sense, this form of thematic analysis is data-driven (Braun & Clarke, 2006). An inductive approach to thematic analysis means the themes identified are strongly linked to the data themselves.

Transcribed and translated qualitative data obtained from the interview process were entered into the NVIVO software programme. The data was then coded, analysed, interpreted, and verified. The codes applied are keywords, which are used to categorise or organize text and are considered an essential part of qualitative research (Sarantakos, 1998). A code is a keyword linked to a quotation that allocates the specific data segment with a translated meaning (Saldana, 2013). The code assists the researcher in the analysis process by detecting patterns, categories, and themes and also assists the researcher in finding the quotes and phrases more efficiently, through the help of the programme being used (Saldana, 2013).

3.12.2 Coding

The data was analysed, categorised and organised into themes and further sub-themes, which emerged through the coding process. Categories were created through organising and classifying the various codes into groups that share certain features. Coding is not the complete process of data analysis; however, it is a process of organising data so that underlying messages may become apparent to the researcher (Saldana, 2013).

3.12.2.1 Open coding

The first stage was open coding, which required reading and rereading the data in order to have an idea of how patterns could be coded, which was then followed by a naming process. The naming process is called "conceptualizing the data," whereby the name stands for or represents an event (Saldana, 2013). The name given to each theme is one that is most related to the study and gets the reader's attention when they first see it (Saldana, 2013).

3.12.2.2 Axial coding

Axial coding was the next process and involved looking at connections and similarities between the themes so that themes, which were linked or related to each other, could be grouped. This is the process of classifying categories, which have a similar meaning to one another. These themes

should be internally consistent but yet different from one another (Strauss & Corbin, 1990). When the categories were compared to one another, themes were generated with sub-themes.

3.12.3 Generating Themes

“A theme captures something important about the data in relation to the research question and represents some level of patterned response or meaning within the data set” (Braun & Clarke, 2006, p.10). Themes illustrate how the various categories relate to each other and are an outcome of the process of coding and categorisation (Saldana, 2013). The themes, which emerged, were assigned a specific code accordingly. The next stage involved interpreting the data by identifying any recurring themes and highlighting any similarities and differences in the data. The final stage of analysis involved data verification. This is a process of ensuring validity by rechecking the transcripts and codes again (Sarantakos, 1998). Finally, all themes, from the combined participant’s themes, were presented and comprised the final presentation.

3.13 Reliability and Validity

Reliability is defined as “believable and trustworthy and is the overall consistency of a measure” (Carlson, 2009). Reliability is vital in research, as it ensures that the research study is conducted in a manner whereby the results obtained are trustworthy (Morse, 2002). Verification is the process of checking, making sure, and being confident. These mechanisms are integrated throughout the research process in order to identify and correct any errors before they are built into the developing study (Morse, 2002). The validity of a study determines whether the research study measures what it is meant to measure or how truthful the results obtained are; it also determines whether or not the study was able to answer the research questions (Hall & Blackmore, 2007). Validity is important because it can assist the researcher to determine what types of materials and instruments to use, and ensure that researchers use methods that are ethical, and cost-effective (Hall & Blackmore, 2007). In the present study, reliability and validity were addressed as follows:

- Content validity refers to the extent to which a measure represents all aspects of a given construct (Wainer & Braun, 1988). The content validity of the study was ensured by selecting the participants according to the selection criteria to ensure that sufficient relevant data were obtained. The interviews were all conducted by the same researcher; thus, ensuring consistency of all interviews. Furthermore, the interview schedule had been designed after reviewing relevant content areas in literature.
- Construct validity is a term used to assess the validity of the measurement procedure (e.g., a questionnaire) that is used to measure a given construct (Wainer & Braun, 1988). In this

sense, construct validity is a process that allows one to assess the validity of the research instrument. Construct validity was ensured in the research study through the pilot study and review of the pilot study. The pilot study was conducted to determine if the questions were clear and concise; thus, ensuring that the questionnaire measured what it intended to. All documents used for the collection of data had been translated to isiZulu and back-translated to English to ensure that translation was accurate. The study population selected for the research study presented with hearing impairment, and therefore, there was a likelihood of communication breakdown during the interview process. The researcher compensated for such by ensuring that there was no ambient noise in the environment and allowing her lips to be visible (for the purpose of lip reading) during the interview process. The data obtained from the interviews are only accessible to the supervisor of the research project and the researcher.

- To further ensure validity, the researcher also took down field notes during each interview. These assisted the researcher to note any gestures, expressions, or body language displayed by participants during the interview process. To maximise reliability in the study, the researcher then compared the notes taken during the interview to the audio recordings.
- The qualitative approach is spontaneous in that “the researcher is part of the research, not separate from it” (Aamodt, 1982, as cited in Krefting, 1991). The researcher must be aware of him or herself within the research and must continuously reflect on his or her own actions and thoughts with regards to how they may influence data collection and analysis (Krefting, 1991). The researcher made use of field notes to reflect on the researcher’s feelings and thoughts during the data collection process. By writing the field notes, the researcher became aware of her reactions and emotions about the research process.
- **Triangulation of results:** Field notes were taken during each interview. The notes were compared to the audio recordings of each interview. No errors were noted between the transcription and translation of the interview data. A professional qualitative research service, Recomart Consulting, assisted with reviewing data obtained and further analysis of data to improve the reliability and validity of the research data.
- **Sensitivity to context:** The researcher drew on literature relevant to the research topic to ensure that the data obtained would not be a repetition of any previous research. The present study showed sensitivity to participants in that they were permitted to answer open-ended questions; thus, allowing them to respond freely. Sensitivity was also shown during data analysis as the researcher allowed for different interpretations and reasons for participant’s views.
- **Coherence and transparency:** Transparency involves being explicit and clear about the methods and procedures used in the research. A pilot study was conducted before the main

study to ensure that the questions in the data collection instrument were suitable for all participants. Furthermore, the present study provides a clear explanation of how interview questions were developed and translated into isiZulu.

- **Commitment and rigour:** The researcher achieved commitment and rigour through a thorough data collection process. The researcher considered many factors as participants were selected through a purposive sampling technique. Furthermore, the researcher demonstrated rigour by being involved in all aspects of the research data collection and engaging with all participants.
- **Impact and importance:** The researcher identified a gap within the South African context regarding the psychosocial aspect of MDR-TB. This would give participants a voice to better position treatment and policy outcomes that will improve Quality of life.

3.14 Ethical and Legal Considerations

When conducting a study involving human participants, ethical factors must be considered (Leedy & Ormrod, 2005). The ethical principles that govern research were maintained throughout the study and involve informed consent, rights to protection from harm, anonymity, and honesty between the researcher and participants (Leedy & Ormrod, 2005). There were no hidden agendas or misunderstandings when obtaining information.

This study has taken into account the following ethical and legal considerations:

- **Gaining permission to proceed:** Permission to conduct this research study was obtained from the University of KwaZulu-Natal Biomedical Research Ethics Committee (see Appendix B), as well as the Gauteng Department of Health (see Appendix C), and the Chief Executive officer of Sizwe Tropical Hospital (see Appendix D).
- **Beneficence and non-maleficence** refer to ethical principles, which encompass doing no harm to participants as well as ensuring that the benefits of the research study outweigh the risks (Eddie, 1994). In assessing the potential risks or hazards for research participants, it was acknowledged that participation in the research study would cause no harm to participants. The information sheet (see Appendix E1 and E2) stated that participation in the study would not have any negative consequences on the participant's current or future medical management.

The psychosocial impact of hearing loss in the context of MDR-TB can be a sensitive and difficult topic for many individuals. Therefore, while preparing and researching the subject and data, the researcher was sensitive to the questions being asked. It is important to note that participants have different experiences and, therefore, the researcher was aware and acknowledged that for some participants, it could be upsetting to talk about their experiences and the impact on their Quality of life.

- **Debriefing:** Participants were debriefed at the beginning and end of their interviews. The process of debriefing requires researchers to provide participants with information about the present study, expected outcomes, and what the study findings indicate (Allen, 2017). If the participant is unsure about the study, it is the responsibility of the researcher to take reasonable steps in ensuring that any misconceptions are corrected during a debriefing process (Allen, 2017). Debriefing at the end of their interview included a health and wellness check. The researcher took reasonable steps to minimize any harm to participants. At the beginning of the interviews, participants showed no signs of sadness. However, the researcher identified that participants became very sad during the interview process. The researcher asked participants to think of something that makes them happy during the debriefing process to make them happy as well as engage in small talk. Participants were provided with referrals for counselling if there was a need indicated during the debriefing process. Furthermore, they were given information about whom to contact should they have any questions or comments about the research.
- **Confidentiality and anonymity:** A further ethical consideration is the researcher's responsibility towards ensuring confidentiality and anonymity. As anonymity was not possible due to the data collection involving a face-to-face interview, every effort was made to ensure that the principle of confidentiality was upheld and that the results obtained are presented in a manner that the source is not identified (McHaffie, 2000). To ensure the confidentiality and anonymity of participants, interviews were conducted in an area where no other patients were present. All participants in the study were assigned pseudonyms, and no personal information or names were used. There was no identifying information present.
- **Informed consent:** According to Polit and Beck (2014), informed consent means that participants are given enough information about the research, that they understand the information given, and have the power to either consent to or decline participation in the research. The process included providing participants with information about the benefits and risks of the research. A consent form (see Appendix F1 and F2) was given to all participants that included the essence of the research study, together with an information document regarding the study (see Appendix E1 and E2). Participants were required to sign a consent form, a copy of which was retained by the individual.
- **Autonomy:** The principle of autonomy means the freedom to decide what to do (McHaffie, 2000). Even when a participant has signed a consent form, they must be made aware that they are free to withdraw from the study at any time without giving a reason (McHaffie, 2000). They must also be able to request that the data they have given be removed from the study (McHaffie, 2000). An explanation was provided in the consent form that all participants could withdraw from the research study at any given time as their participation was voluntary and

also that withdrawal would not have any negative consequences for them. They were also advised that they were under no obligation to answer any questions, which made them feel uncomfortable. Prior to the commencement of each interview, each participant was made aware of the duration of the interview, and sufficient time was allowed before and after the interview for the participant to ask any questions relating to the research topic.

- **Justice:** All participants were selected based on the inclusion criteria for the study. Participants were not selected or excluded based on race, ethnicity, or socio-economic status.
- Hard copies of the data are stored in the Audiology department at the University of KwaZulu-Natal.
- Hard copies are to be shredded and digital copies to be deleted permanently should the study not be published within 5 years.
- The researcher has completed two online ethics course (see Appendix H).

3.15 Summary

This chapter provided the methodological framework for the study. The study aimed to describe the psychosocial impact of hearing loss on the Quality of life of adults with MDR-TB. A Phenomenological research design was used in the study with qualitative methods of analysis. This approach allowed the researcher to obtain in-depth data about the lived experiences of study participants. Thematic analysis was employed to analyse the attained data. Taking into account all the ethical and legal considerations of research, a semi-structured questionnaire was used during the interview process to realise the aims and objectives of this study. The next chapter provides the results of this study.

CHAPTER 4: RESULTS AND DISCUSSION

4.1 Introduction

This chapter presents and discusses the findings of the study, which aimed to describe the psychosocial impact of hearing loss on the quality of life of adults with MDR-TB. Additionally, it highlights the main themes, which arose from the analysis of the transcribed interviews. While the results are displayed in separate sections i.e. objectives, for clarity, it is evident that all these areas are interconnected. These results are presented according to the themes extracted following data analysis. These research findings are critically analysed and discussed by drawing on relevant literature.

4.2 Description of participants

Participants had provided details about their personal and employment life both before and after MDR-TB diagnosis and hearing loss. They had also provided reasons for their visit/stay at Sizwe Tropical Disease Hospital. All ten participants belonged to the black African community. All participants currently had a positive diagnosis of MDR-TB; four were still in hospital receiving treatment. All participants were unemployed. Seven of the participants had children, while nine were single. In-depth information of all participants is presented below.

****Participants have each been given pseudonyms to maintain confidentiality.***

The first participant was Sarah*, a 40-year-old single, unemployed mother of one, who had been hospitalised for six months, resulting in her not seeing her family for more than five months. She presented with physical weakness as she struggled to walk into the interview but indicated that she was well enough to participate. Sarah previously had pulmonary TB. She had completed Grade 10 in her schooling.

John*, a 39-year-old single and unemployed male, was the second participant. He had been an inpatient at the hospital for the second time due to defaulting on previous MDR-TB treatment and has a positive diagnosis of MDR-TB for the past two years. John has completed a grade 8 education and was a mine worker before his MDR-TB diagnosis; however, he has not been able to return to work. He had been unable to attend his son's funeral due to his hospitalisation.

The third participant was 34-year-old Andile*, who was accompanied by his parents, whom he lives with, as they attend all appointments with him. He has a diploma in engineering and was single. He presented with communication challenges and required much repetition during the interview due to the severity of his hearing loss.

Vusi*, a 29-year-old single, unemployed male, was the fourth participant in the study. He was an outpatient attending his annual audiology follow-up as he presented with challenges regarding his hearing aids. He was unable to attend appointments without the assistance of his local clinic transport due to finances and distance to the hospital. He has completed grade 12 in his schooling.

The fifth participant was Mandla*, a 40-year-old recently-divorced father of two. He has a grade 9 education and was unemployed. Mandla* had pulmonary TB before MDR-TB.

Bongi, a 29-year-old male, was the sixth participant and was still hospitalised at Sizwe Tropical Disease Hospital. Bongi* did not have any children. He requested to have his interview conducted outdoors in the sun, where he preferred to sit. He had Drug sensitive TB before his MDR-TB diagnosis. He has no formal education and reported challenges with literacy. He was unemployed and receiving a social grant.

The next participant was Sifiso*, a 33-year-old unemployed male, who has a diploma in business management. He had quit his previous job as a school clerk when he was diagnosed with MDR-TB. He had monthly audiological and medical follow-ups at the hospital. He had previously defaulted on Drug sensitive TB treatment and has also missed his audiology appointments several times. He did not have any children.

Sandile*, a 38-year-old single father of one, was the eighth participant. He is currently an outpatient, who had defaulted on his medication for Drug sensitive TB. He has a grade 11 education and is currently unemployed. He wore one hearing aid as he reported no hearing aid benefit on the other ear.

The ninth participant was 26-year-old Zinhle*, a single mother of one who has a diploma in administration and was employed in the retail industry before her diagnosis of MDR-TB. She acquired bilateral severe hearing loss in 2015 while on injectable aminoglycoside treatment for MDR-TB, and has not been able to find employment despite being an outpatient.

The last participant was Mary*, a 31-year-old single female with no children. Mary lived in Gauteng due to employment; however, she was initially from the Free State, where her family resides. She had been an inpatient for the past seven months with no family visits and has not been able to make friendships in the hospital due to the severity of illness and hearing loss. Mary* has a grade 12 education.

Information on the type and degree of hearing loss, duration of hearing loss, type of assistive hearing devices used, as well as diagnosis of MDR-TB, determined through a review of each participant's hospital file by the researcher and the resident Audiologist, is presented in Table 4.1, below.

Table 4.1

Participant's Audiological and Medical History

Participant	Diagnosis of MDR-TB	Degree of Hearing loss bilaterally	Duration of hearing loss	Assistive listening device/s
Sarah*	2016	Severe to profound	Three years	Bilateral hearing aids
John*	2015	Severe	Four years	None
Andile*	2015	Severe to profound	Three years	Bilateral hearing aids, awaiting Cochlear implant
Vusi*	2015	Moderate to profound	Four years	Bilateral hearing aids
Mandla*	2016	Severe	Three years	Bilateral hearing aids
*Bongi	2016	Moderately severe to severe	Two years	Bilateral hearing aids
Sifiso*	2016	Profound	Three years	Bilateral hearing aid
Sandile*	2017	Severe to profound	Three years	Unilateral hearing aid
Zinhle*	2015	Severe	Four years	Bilateral hearing aids
Mary*	2017	Moderately severe to severe	One year	None

4.3 Key Themes

The results presented under each theme are verbatim quotes from participants. The quotes were provided verbatim in isiZulu by participants; however, the English translation is provided. Five distinct themes emerged from the research data. A hierarchy of the themes identified from the results is indicated in Figure 4.1, below.

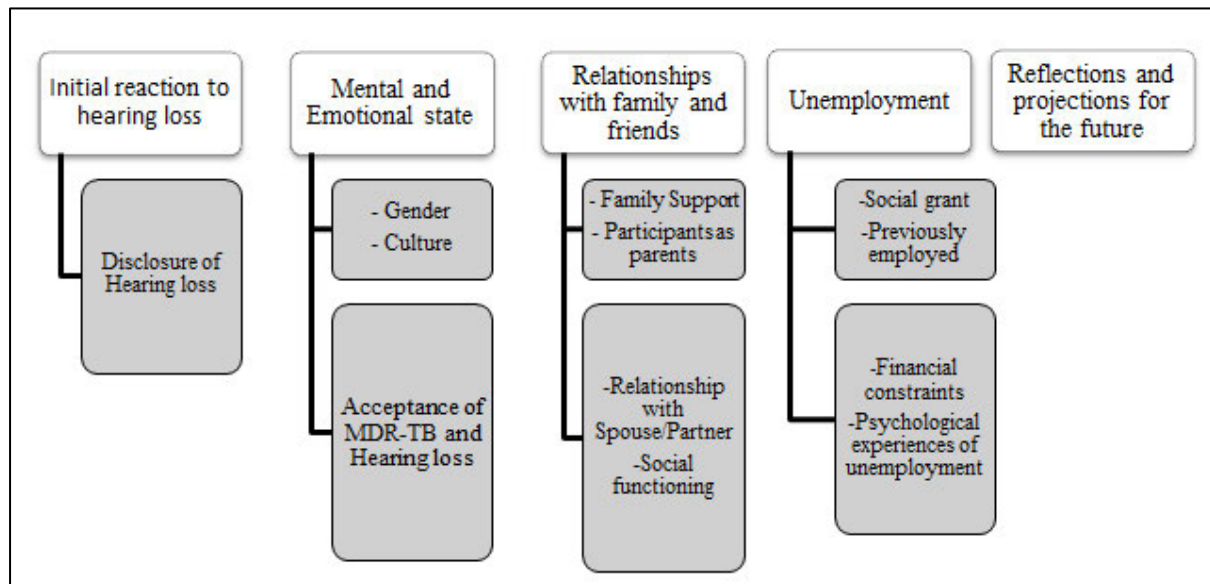


Figure 4.1: Hierarchy of themes

Each theme is discussed in further detail under each of the study objectives below.

4.3.1 Objective 1: To explore the psychological and emotional impact of hearing loss in adults with MDR-TB

The themes relating to the participants' initial reactions to hearing loss, their mental and emotional state, and their reflections and projections for the future address Objective 1. Furthermore, the sub-themes, namely disclosure of hearing loss, gender, culture, and acceptance of hearing loss, are discussed in detail.

4.3.1.1 Initial reaction to hearing loss

Hearing loss due to ototoxic drugs may ensue from a few minutes to several days after drug administration (Khoza-Shangase et al., 2009). However, late, and slowly progressive hearing loss for several years after completion of treatment is also possible (Khoza-Shangase et al., 2009). In the

current study, all participants acquired hearing loss while on aminoglycoside treatment for MDR-TB. These findings are consistent with Reuter et al. (2017), who reported that patients had documented hearing loss after the administration of aminoglycoside drugs, thus suggesting that this is an alarmingly frequent occurrence.

In the current study, hearing loss was reported to have been sudden, although signs and symptoms varied from individual to individual. All participants expressed similar experiences of reduced hearing sensitivity bilaterally following the administration of aminoglycoside drugs for the treatment of MDR-TB. The following signs and symptoms were noted:

- Unilateral or bilateral tinnitus described as high pitched or roaring,
- Blocked sensation,
- No signs or symptoms (sudden complete loss of hearing),
- Pain,
- Episodic vertigo,
- Decreased vision and
- Insomnia.

Most participants' initial reaction to hearing loss was fear. Additionally, participants reported experiencing shock, panic, and confusion, and expressed uncertainty about the cause as well as the future of their hearing loss, as illustrated in Figure 4.2 below.

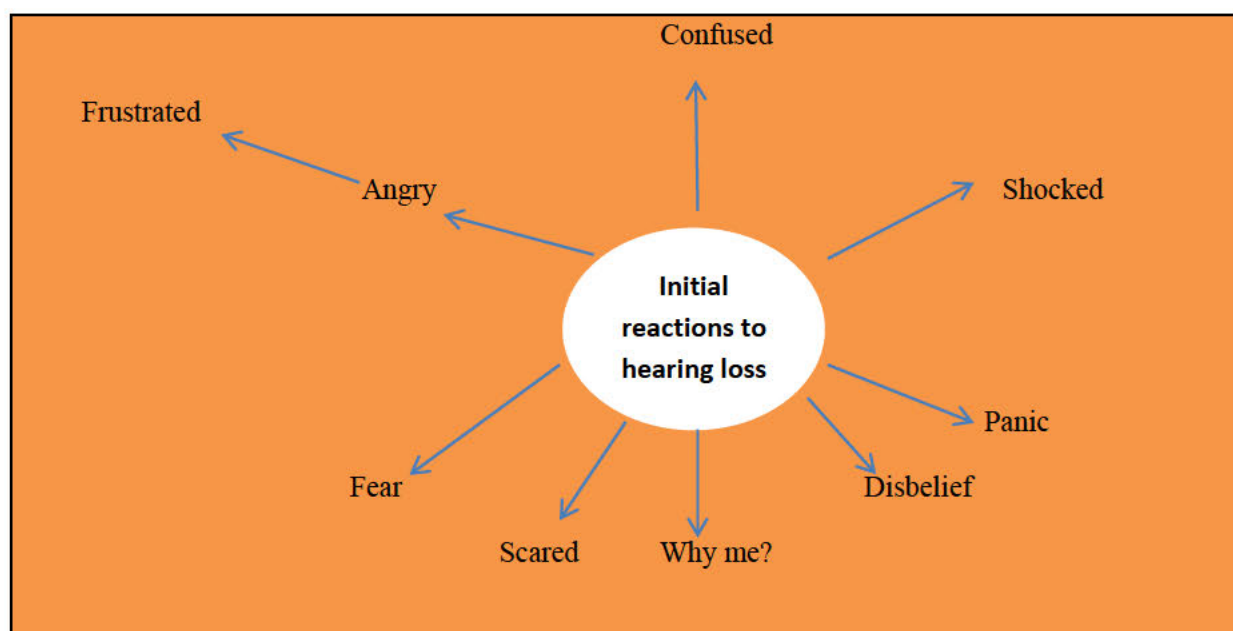


Figure 4.2: Participants' initial reactions to hearing loss

From Figure 4.2 above, it is evident that participants found the hearing loss to be a challenging experience. None of the participants had experienced hearing loss before, and neither were they aware that hearing loss was a side effect of their MDR-TB treatment. Additionally, none of them had previously encountered or lived with an individual with a hearing impairment, resulting in panic and anger, which led to further frustration, as reported by Andile:

“In the year 2015, I was diagnosed with MDR-TB. Three months after taking injections, I was sleeping at home and woke up in the morning. I put on the radio to listen to the news, and I could not hear anything. I put the volume high, but I could not hear anything (He shakes his head to emphasise his inability to hear). I asked my mother to come and check the radio because I thought it was not working and she told me, ‘No, the radio is fine.’ She started to talk to me louder than normal, and I couldn’t hear what she was saying. That was when I started to panic” (Teary).

Vusi expressed:

“When I went to receive my medication at the clinic, they told me that if I start to hear any sound in my ear, I must let them know very fast as it might be a sign of hearing loss. One day I heard something ringing in my ears. I went and told the sister at the clinic that I am not feeling well in my ears. She then said they would take me to Sizwe Hospital. When I got here to Sizwe at first, I was not aware that my hearing had a problem. I started to realise that when my phone rang, the volume was very low”.

John expressed a similar experience with the loss of hearing while undergoing treatment. He expressed confusion over not understanding what was happening as well as not being sure of the cause. Apart from confusion, denial was reported whereby he thought that his hearing would return to normal with each successive day:

“I lost my hearing two months after starting medication for MDR-TB. I was taking the injection every day. I heard a very loud ringing noise in my ears, and they felt blocked. The next morning when I woke up, everything outside was quiet. I got up to speak to other patients in the ward and when I could not hear them, I realised there was a problem with my hearing (Silent Pause). At the time I did not understand what was happening. Each night when I went to sleep, I thought my hearing would return by the morning “. (Pauses again)

Bongi had a similar reaction of not understanding why he had lost his hearing during treatment and expressed with confusion:

“I had TB before, this was the second time, but the first time I did not lose my hearing. I did not understand what was happening this time”.

From the participant's responses above, it is evident that they had begun their cycle of grief upon diagnosis of hearing loss. John's expression of not knowing what was happening to him when he experienced the hearing difficulties reflects his confusion and is in keeping with the denial stage of grief as the sudden change in his hearing status meant a sudden change in his life. Kübler-Ross (2005) noted that these five stages are not linear, and some people may not experience any of them, while others may undergo any number of stages rather than all five.

In the case of the participants in the present study, they experienced a sudden loss of hearing, and they appear to be mostly in the denial stage, which can initially help an individual survive the loss. However, they can be described as being between the stages of denial and bargaining, as John's expression of "*I thought my hearing would return by the morning*" is an indication of denial but may also include the stage of 'bargaining' as he had struggled to find the meaning of what had happened to him. They believe that life makes no sense, has no meaning, and is too overwhelming (Kübler-Ross & Kessler, 2005). They start to deny the news and, in effect, go numb. It is common in this stage to wonder how life will go on in this different state; the individual is in a state of shock because the life they once knew had changed in an instant (Kübler-Ross & Kessler, 2005).

Apart from confusion and denial, other initial reactions such as self-blame, internal shame, anger towards self, and pity were reported by participants, as they had previously been diagnosed with TB and defaulted on their treatment. These participants felt as though they had brought the hearing loss upon themselves, as reflected in Table 4.2, below.

Table 4.2

Participants' responses on initial reaction to hearing loss

Participant	Responses on initial reactions
Mandla	<i>"I blamed myself. I said, maybe I did not take my medication properly. Maybe it was my fault that my hearing was gone"</i>
Bongi	<i>"I was ashamed because this was my second time with TB"</i>
Sifiso	<i>"I was sad and also angry at myself. I thought this is what happens when you get TB again"</i>
Sandile	<i>"I would still be able to hear if I didn't stop my TB medication the first time"</i>

The experiences of previous treatment failures on the standard TB regimens had substantially shaped the psychological state of those participants. These experiences, therefore, resulted in feelings of self-blame and shame when the hearing loss had occurred as well as feelings of doubt and emotional insecurity regarding the possibility of ever being cured of MDR-TB. Mandla reported, *“Maybe it was my fault that my hearing was gone.”* This type of response may likely be attributed to inadequate counselling on the risks and benefits of treatment adherence when participants had initially been diagnosed with drug-sensitive TB. Additionally, it also reflects inadequate counselling on the side effects of aminoglycosides.

4.3.1.1.1 Disclosure of Hearing loss

Participants expressed challenges disclosing the diagnosis of MDR-TB, and the hearing loss, to their family. Most of the participants expressed that they were afraid of how their families would respond to their hearing loss. They had struggled to disclose their MDR-TB status to their family members, as disclosure of MDR-TB itself was presumed as a sensitive issue.

“I did not know what my family was going to say about my hearing loss. Everyone can hear normal in my family. Sometimes families do not understand that these things happen. I was scared of rejection” (Shakes head) – Zinhle.

Fear of disclosure was also exacerbated by the participant’s confusion and lack of understanding regarding hearing loss.

“I was still unsure of why I had lost my hearing. I also did not know what I was going to say to explain it to my family”. - Mary

Another issue of disclosure was the negative impact it might generate in the neighbourhood. One of the participants, Andile, had expressed that his neighbours had labelled him a ‘chronic sick person’ due to the MDR-TB and he stated: *“I was afraid of what the reaction about my hearing loss would be from both my family and neighbourhood.”* This expression translates to an experience of stigma, which is in keeping with Thiruvalluvan (2017), who reported that patients diagnosed with MDR-TB experienced stigma from their family and community members. Literature indicates that stigma may worsen psychological issues related to the disclosure of diagnosis. Moreover, stigma also has a direct impact on patients, as it hinders adherence to treatment (Thiruvalluvan, 2017). This finding is also in keeping with Loveday et al. (2017), who reported that the effects of stigma included experiences of social seclusion or rejection from family members, friends, neighbours, and/or health providers;

internalized shame; financial instability; discrimination; and its repercussions. It may be useful to educate not only patients but also their families on MDR-TB and hearing loss to help them understand the diagnosis and consequently overcome stigma.

Hearing impairment was reported to have affected participants soon after the diagnosis of MDR-TB, at a time when they reported that they were still overwhelmed with the diagnosis of MDR-TB.

“It was hard because I still did not know how I got MDR-TB. I was still trying to understand the disease and what was happening to my body. The problem with the hearing made it very hard. There was no space between the two. Everything was too much at the same time. I did not know what was happening to my body, honestly. Yah, I had MDR-TB, and that is fine because it is a disease. We know diseases are real, but why did I lose my hearing?” (She shakes her head in confusion)-Mary

Due to the short duration between the diagnosis of MDR-TB and acquiring a hearing loss, the psychological impact was likely more significant as the participants would not have had sufficient time to deal with the diagnosis of MDR-TB before acquiring a hearing loss. There are different psychological symptoms experienced by adults with early-onset (childhood) hearing loss in comparison to those with late-onset hearing loss (Kaland & Salvatore, 2002). Although similar feelings of anger, isolation, and denial are seen in both groups, adults with early-onset hearing loss may have a better understanding and coping mechanism of their hearing loss as they have grown up with hearing loss and associated challenges (Kaland & Salvatore, 2002). Despite the challenges of hearing loss, adults with early-onset hearing loss often report that they have incorporated hearing loss into their personalities and identity. Adults with late-onset hearing loss, however, find it difficult to understand their identity due to hearing loss, and this often leads to an identity crisis (Kaland & Salvatore, 2002).

4.3.1.1.2 Mental and Emotional State

Participants felt that hearing loss and MDR-TB had negatively impacted their psychological and emotional well-being. The most common emotion expressed by participants was a feeling of hopelessness and fear. They shared that their initial concerns had changed to constant fear and uncertainty about their future, where they found it difficult to resonate with any positive emotions regarding their medical state as well as hearing loss. They expressed a lack of emotional support from all sources in their life.

John reported that more focus was placed on physical and medical support and less on emotional well-being:

“People here ask me how I am, like in the morning; the nurses will ask how you are feeling. They ask if you have any body pain or something, but they do not ask how you are feeling in your emotions”.

Vusi expressed a similar sentiment:

“I have seen that many people think when you have something permanent like a hearing problem, you must move on. Like when you lose a leg or something. They do not see that there are problems, you feel sad, you always ask why me?”

4.3.1.1.3. Gender roles

Gender roles can be described as behavioural expectations and may be based on factors such as culture, social structures, policies, or one's own individual, cultural or religious beliefs (Helman & Ratele, 2016). Traditionally for many racial and ethnic groups, the male is seen as the provider, expected to be masculine, and display attributes of strength and power (Helman & Ratele, 2016). Men are also expected to display less affection and emotion openly (Helman & Ratele, 2016).

Challenges of gender roles were reported regarding emotional support, where males are usually seen as emotionally stronger and requiring less emotional support. Mandla expressed how the challenge of gender roles was a barrier towards him obtaining any form of psychological support or understanding from his family:

“My wife struggled to support my emotions. Maybe it was something she was not used to or did not know. I was still the ‘strong’ one, even if I was having problems. My children must also see me as strong because I am the father, so you see; there is never space for me to say I am not okay. Emotionally it is difficult because you want to provide, but you cannot for those who depend on you (Stares blankly at interviewer). It is very difficult to be honest with them because it just undermines you as a man”.

“I was previously able to support my family with money as we [are] a large family in one home. As a man, I brought in the most money”. - Bongi

“I do not think anybody is going to ask a grown man how he is feeling.” John

John was unable to express his feelings and emotions, which are likely due to gender expectations within his family and community. Similarly, Bongi's expressions bring about similar views on the expectations to provide for his family based on his gender. These expectations for gender roles may leave John and Bongi in extended periods of poor mental health without any alternatives to seeking professional help as this may go against the gender 'norm.'

Sarah reported that before being diagnosed with MDR-TB and acquiring a hearing loss, she had the responsibility of running the home as well as taking care of those within the home. The diagnosis of MDR-TB and a hearing loss had brought a sense of loss and worry for her as she was no longer able to carry out her role. She was worried about whether her family was coping without her. She had also felt like she had let them down.

"I worry who is taking care of my family at home. I wonder if they are fine. I did a lot at home every day I was cooking and cleaning and making sure there is always food. I wonder if maybe they will feel that I left them on purpose". -Sarah

Sarah's statement above clearly demonstrates her worry for the well-being of her household and family as she was no longer able to perform her duties within the household. This loss of household activity may also impact individuals within the home as they may not have the abilities of the individual who routinely performed household activities. Furthermore, this has had an impact on Sarah's psychological well-being, where she expressed concern that her family may think that she has left them intentionally. These emotions are substantiated by the findings of Ananthakrishnan et al. (2007), who reported that when a woman becomes sick from MDR-TB, the household may not only suffer from the loss of finances outside the household but may also suffer additional losses due to the reduction of activities that the woman performs in the household. It is crucial to consider the value of activities such as cooking, cleaning, and childcare that are commonly performed by women in the household in order to determine the impacts of disease on the household (Ananthakrishnan et al., 2007). Ignoring the contribution of women to the household leads to an underestimation of the costs associated with MDR-TB with regards to household activities and care (Ananthakrishnan et al., 2007). Relatively little attention has been given to the impact of MDR-TB on patients and their households. Most studies have focussed on finances lost due to illness or death; thus, underestimating the cost of MDR-TB, particularly for women.

4.3.1.1.4. Culture

Within the black community, there is a negative stigma surrounding mental health. Ward et al. (2013) reported that participants were not willing to openly acknowledge psychological challenges as they were concerned about the stigma within their communities surrounding mental health issues. Most participants had preferred religious coping methods for mental illness (Ward et al., 2013). Rather than seeking professional help for conditions such as depression and anxiety, many in the community resort to self-medication or isolation to solve their problems on their own (Ward et al., 2013), as is reflected in participants' expressions below:

"In our community, I mean, we know we do not talk about these things (expresses a deep sigh); being sad for a long time is like white people things, so it is what it is. Even at home, they will tell you something like 'I do not understand depression,' so you see". -Vusi

"I am the oldest son in my family, and I was the one who provided safety to my family. As an African man, you know, you must always be strong. I have some days where I am very sad. But you see, still, nobody will understand". -Sandile

Sandile's statement above indicates that he was having difficulty with his mental health but was unable to express his feelings and emotions openly to his family. Sandile preferred to isolate himself rather than admit to having emotional difficulties. Further to that, he did not believe that there was any platform for him to express these emotions within his family. Vusi's expression highlights the stigma around mental health within black African communities where mental health issues may be shunned. These challenges within the community may contribute towards participants not being willing to seek professional assistance for emotional and psychological challenges.

4.3.1.1.5 Acceptance of MDR-TB diagnosis and Hearing loss

Respondents in the present study reported that they struggled with acceptance of their hearing status. Their responses are expressed as follows:

"It was hard emotionally when I lost my hearing. I did not cope with my MDR-TB diagnosis, and now I had a hearing problem (Silently pauses). I continued taking my medication and got better with the TB, but my ears never got better. That made me very sad, and I did not understand why my hearing was not getting better as my health improved. It still hurts my feelings so much. I cannot accept that I will never have normal hearing again." -Sifiso

"I think it can be easy to accept something you did to yourself, you see; I did not do the hearing loss to myself." -Mary

“You move on with life (Shrugs shoulders) because you cannot tell anyone you are having problems with accepting that you cannot hear. Everybody will say you must move on, so you keep it to yourself”. –Sifiso

Challenges with acceptance brought about a negative shift, whereby participants felt as though their lives were different, that the impact of hearing loss and MDR-TB had brought on negative feelings about their physical and emotional state. Mary expressed her challenge with acceptance as:

“I was fine a few months ago. Suddenly I was weak and sick, worse I could not hear anymore. I moved on with life, but I did not tell anyone that I was struggling with acceptance”.

Andile expressed that a hearing loss added to the emotional distress of being diagnosed with MDR-TB. Feelings of anxiety and hopelessness were exacerbated by the knowledge that the hearing loss is permanent and will remain even after MDR-TB has been treated:

“It is hard to cope with any disease and try to recover from it. But, when you have something like a hearing problem, it is even harder. My TB is being cured, but my hearing will never be cured. I continue my hearing management, and I was told I am on a waiting list for a cochlea implant, which will improve my hearing, but I do not know when that will be. I feel very much panicked sometimes and hopeless” (Shakes head emphasizing hopelessness). -Andile

Feelings of anxiety were further expressed in relation to privacy, as hearing loss had taken away the ability to share communication within one’s personal space. Zinhle expressed that she was having difficulty maintaining privacy during calls, as she used her phone religiously to communicate with friends and family. She had become dependent on texting as an alternative form of telephone communication. She expressed:

“I struggle with phone calls. I feel nervous when I receive a phone call. Even with hearing aids, I still cannot hear over the phone unless it is on the loudspeaker. Everyone around me hears what my conversation is about. They hear everything I am saying because it is loud. I feel bad.”

In psychology, acceptance occurs when a situation or scenario is acknowledged and accepted by an individual. It is typically used in reference to the acknowledgement and assent to a negative situation (Walker et al., 2019). The participant’s statements above are in keeping with findings of

Sharma et al. (2012), who reported that most patients were worried, frustrated, or disappointed by the diagnosis of MDR-TB, and did not initially accept their diagnosis. Difficulties with acceptance may have been worse with participants in the present study as they not only had to accept the diagnosis of MDR-TB but were faced with a hearing loss as well. From the statements above, participants appear to have accepted their MDR-TB diagnosis but not their hearing loss, which may be attributed to the permanency of this impairment. The challenge of accepting a dual diagnosis can be assumed to be a very difficult one. The difficulties with the acceptance that participants experienced may have been lessened had they received some form of psychological support.

Psychological support, in the form of counselling from health care providers, was perceived as extremely important. Mandla expressed how the psychological support he received from health care workers while hospitalised helped him remain optimistic about his diagnosis and hearing loss. He had appreciated the patience displayed during communication breakdowns with him. He expressed that this had *‘made the process of being in the hospital with no hearing more bearable.’* He continued to express:

“One of the doctors was very kind, she kept telling me to remain positive, and she told me what was happening to me’. And like I said, some staff really helped. I know we always say nurses are mean, and they do not treat us right, but the nurses I saw at Sizwe were good people and helped me too. They had time, they were patient, and they wanted to see everyone get better.”

Individuals who are diagnosed with any disease often undergo psychological disturbances, and their medical outcome is influenced by the psychological interventions they receive (Peddireddy, 2016). Psychological support from health care providers in the form of informational counselling was noted to have brought about emotional relief; however, this support was only reported by one participant. Most participants reported feeling overwhelmed as they had not received an explanation of their diagnosis and treatment, cause of their hearing loss, as well as assessment and possible rehabilitation outcomes of hearing loss. There are different forms of counselling which may have aided participants to reduce the feelings of being overwhelmed as well as negative emotions and challenges they experienced. Barry and Murray (2005) describe these as:

“Educational counselling which is the provision of accurate and truthful information; rehabilitation counselling which is focused on assisting persons with physical, mental, developmental, cognitive, and emotional disabilities to achieve their personal, career, and independent living goals; and mental health counselling which involves talking about your problems with a trained medical professional such as a counsellor or psychotherapist” (Barry and Murray, 2005, p.8).

With the provision of appropriate counselling, participants may have had a clearer or better understanding of their medical conditions as well as reasons for the physical changes they had been experiencing. Participants reported shock and confusion as reactions to hearing loss, suggesting that they may not have been adequately counselled about the side effects of MDR-TB, as is also evident in the findings of Khoza-Shangase, Mupawose, and Mlangeni (2009). Khoza-Shangase et al. (2009) reported that while all participants were instructed to take their medications and complete the treatment, they were unaware of the possible side effects of the medication. No reports of recommendations relating to the auditory function and reporting of potential ototoxicity related side-effects from the nurse or doctor were obtained (Khoza-Shangase et al., 2009). Educational counselling may have provided participants with the knowledge of aminoglycoside-induced hearing loss as well as its progression and rehabilitation. Talking therapies such as rehabilitative and mental health counselling may have provided participants with the ability to talk freely, without fear of criticism or judgment, and understand what may have caused their problems and how to cope with the emotional concerns they had been experiencing (Barry & Murray, 2005).

Unfortunately, emotional concerns expressed by patients are often overlooked by the audiologist (Hefferman et al., 2016), as also indicated by the lack of any reports of any form of and attempt to initiate emotional counselling from the audiologist. This may be due to a lack of open conversation between the audiologist and the patient. Aural rehabilitation may be used as a platform by the Audiologist to initiate and engage in such conversation. However, the provision of aural rehabilitation services in South Africa is lacking and this has negative implications for the holistic audiological management of patients (Makhoba & Joseph, 2016). Audiologists within the South African context have a high interest in aural rehabilitation; however, service provision is limited which indicates a need for the revision of services provided (Makhoba & Joseph, 2016). Therefore, there is a need for Audiologists to be involved in further training in aural rehabilitation in order to provide improved service provision that may fully benefit patients with hearing loss (Makhoba & Joseph, 2016). The Audiologist may provide informational, and acceptance counselling and they need to attend to these emotional concerns to increase the likelihood of the patient adhering to rehabilitation. The audiologist may also serve as a referral source for the necessary pathways to relevant counselling interventions, which may lead to improved psychological outcomes and improved experiences of hearing loss.

The emotional well-being of participants was further impacted upon by their experiences of hearing loss in the wider society. Communication challenges had been found to have made it more difficult for participants to overcome these negative experiences. Hearing loss can result in individuals with hearing loss responding inappropriately to questions, missing valuable information,

and consequently feeling isolated (Jennie et al., 2014). However, personal space and privacy were also negatively impacted by hearing loss. Poor or ineffective communication strategies are likely associated with poorer psychosocial adjustments in persons with acquired hearing loss (Jennie et al., 2014). Hearing loss hampered the ability to have personal conversations without being heard by others around them, due to an inability to hear the conversation through the telephone unless it had been placed on a loudspeaker and having to speak much louder. Zinhle reported having to resolve to only using texting as a form of telephone communication not because she had enjoyed texting before hearing loss, but because it was the only alternative she had. Despite being fitted with hearing aids, Zinhle was still unable to hear a telephonic conversation, as hearing aids have difficulty blocking out background noise, and they do not separate speech and noise in noisy environments (Jennie et al., 2014). Similarly, Adoga et al. (2019) reported that 20 of their forty-two participants provided with behind-the-ear hearing aids, did not benefit from the hearing aids, due to the severity of their hearing loss as they presented with a profound hearing loss. Most hearing aids restore audibility but not intelligibility, as is evident in the present study whereby most of the participants wore hearing aids and reported that hearing aids had their limitations as some participants gained little benefit from them. Individuals with hearing loss can find it challenging to participate in family gatherings and to converse with family members (Jennie et al., 2014) even after being fitted with hearing aids; thus, further emphasizing the increased need for aural rehabilitation. Aural rehabilitation may provide individuals with hearing loss with the necessary skills to reduce or alleviate communication difficulties during conversations.

4.3.1.2 Reflections and projections for the future

Hopes for self were abandoned, to be replaced by the hope that life would not get worse. Spirituality and belief in God gave strength for a better future. Most participants reported that they felt close to a spiritual power that motivated them during this challenging phase of their lives:

“I am cautious now with my health; I try my best to be healthy. My hearing loss will always be a problem. But, I am a praying man and always say that God will find a way for me all the time. I will always try to be positive (smiles).” - Mandla

“I cannot change what has happened to me, but I have to make the most of what I have. I am trying to be a positive person; I try to see the good in life and pray. That is how I survive”.- Sandile

Andile spoke about looking back on his academic achievements and the significance of them for him:

“I am happy and proud of my education. It makes me feel that at least I achieved something good, and that means that I can achieve again someday”.

Not all participants shared the same hopes for their future. Feelings of uncertainty and hopelessness were maintained as some felt that their situation would not change regardless of how they may feel or function at present. Sifiso expressed that it was hard to stay positive and motivated:

“You find that you have much time, but you are not motivated to do anything, One day runs into the next, and you do not even know what day it is, it does not matter.”

Other participants also expressed:

“I am in a position that I cannot change. I do not know how my life changed so much so fast. I do not know. It feels very hopeless. I am just getting through the days (Teary, shrugs shoulders)”. -Zinhle

“There is very little hope. When you are very sick and then lose your hearing, it is hard to have any hope for a better life. We are human at the end of the day (she expresses a sarcastic laugh). I see people get discharged and come back again and wonder if it is possible to be free of MDR-TB. I have never had a hearing problem before.” - Mary

All participants expressed a decline in their overall quality of life due to the acquired hearing loss and MDR-TB diagnosis. Participants had ‘lost’ the lives they had worked for and known. They had difficulty adjusting and coping with their new reality. The difficulty that all participants faced was the sudden change in overall well-being. Not only were they dealing with a disease, but they were faced with the sudden reality of permanent hearing loss, which brought about considerable uncertainty for their future.

Reflections and projections for the future included abandonment of hopes for self, as expressed by Zinhle and Mary. Similar emotions were reported by Morris et al. (2014), who indicated that participants expressed concern for what their future held for them. They did not feel that they had a clear sense of their long-term health and expressed anxiety over these thoughts (Morris et al., 2014). For some participants in the present study, abandoned hopes were replaced by the hope that life would not get worse, and that their current circumstance was the worst any individual could encounter. Peddireddy (2016) stated that patients diagnosed with TB experience high levels of stress and

decreased quality of life. Patients undergo immense psychological stress. Psychological interventions renewed hope on life and adherence to treatment outcomes (Peddireddy, 2016). Due to the current emotional state of participants, it can be assumed that no psychosocial interventions were provided to help equip them with the challenges that arose from the diagnosis of MDR-TB and hearing loss. In the absence of such interventions, they continued to live with a reduced quality of life.

Research on the provision of community-based interventions for patients with MDR-TB has found these interventions to be effective and inexpensive for patients. These interventions highlight the need for patient-centred approaches to address the challenges and needs of patients MDR-TB, as this may help towards the control of MDR-TB. These interventions may also be helpful in the fight towards stigma as they include families and the broader community. Research has found that psychosocial interventions in the form of group therapies, home-based treatment, financial and psychological support are needed in this patient population. Group audiologic rehabilitation and therapy programs are a straightforward way to help individuals deal with the stigma of hearing loss and the loss of social identity which may have resulted from hearing loss (Preminger, 2007). Group therapy is also ideal for teaching communication strategies. Individuals are also able gain support when they share their experiences of hearing loss and their experiences of the stigma surrounding hearing loss. In so doing, this reinstates their feeling of belonging (Preminger, 2007). Based on the findings of the present study, psychosocial interventions for MDR-TB should also be inclusive of the broader challenges imposed by hearing loss. Patients with MDR-TB and hearing loss should have access to a good standard of patient-centred care and interventions for them to become knowledgeable and empowered about their disease and hearing loss, as well as improve family support. Furthermore, the provision of these services may help to improve patients' quality of life despite the challenges imposed upon them by MDR-TB, its treatment, and hearing loss.

4.3.2 Objective 2: To describe the experiences of the social impact of hearing loss in adults with MDR-TB

Objective 2 is addressed by the theme 'participants' relationships with family and friends'. The sub-themes of family support, participants as parents, and their relationships with spouse/partner as well as the participants' social functioning are discussed in detail.

4.3.2.1 Relationships with family and friends

Family and social relationships were reported to have been initially negatively affected by the diagnosis of MDR-TB and further impacted by the hearing loss. Participants used a variety of words to describe how they felt about their family and social relationships. These words retrieved during the coding process of data analysis are indicated in Figure 4.3, below:

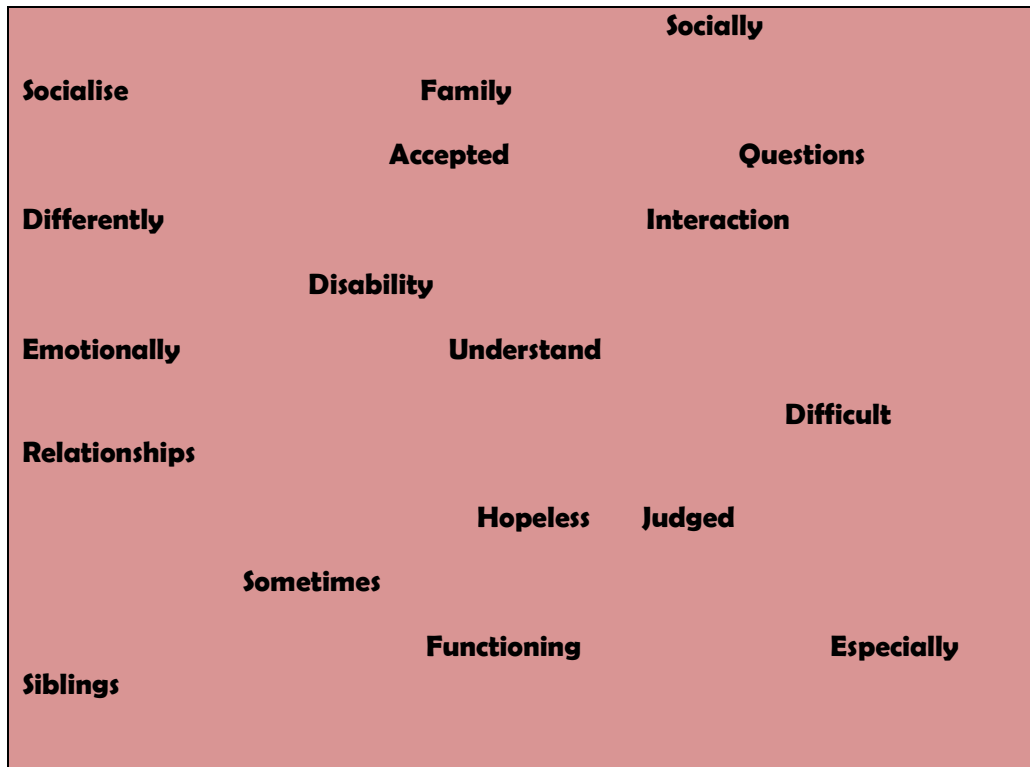


Figure 4.3: Word Cluster of participant's feelings towards relationships with family and friends

From Figure 4.3 above, the use of terms such as 'differently, disability, difficult, hopeless, judged' are clear indicators of the tenuous relationship participants now shared with their family and social relationships.

4.3.2.1.1 Family support

Family is a reliable shelter for any individual, upon which they can depend during challenges. Family members are often best suited to offer emotional support; however, for some participants, this was not the case. It had been reported that relationships did not remain the same following the diagnosis of MDR-TB. Sandile expressed how his relationship with his siblings and mother had changed and how he felt as though his mother felt pity for him and felt hopeless about his future.

“Sometimes, I feel like my mother feels pity for me like she feels hopeless about my future. I feel bad. I feel bad, to be honest. I am not saying she does not love me, my family loves me, but at the back of my mind, I feel like they will always see me as the one who got sick, the one who cannot hear. I do not know if they will ever see me in a normal way like before.” -Sandile

The long periods spent away from home during hospitalisation meant fewer stays at home and less time spent with family. Bonggi, who was still hospitalised, expressed how this time away made him feel forgotten and as though his value had decreased within the family:

“My relationship with my family is different than what it was. I have been in the hospital for almost a year and have not seen my family. If you can go for so long without seeing someone that means you can survive longer without them. I know things have happened in my family, events, ceremonies, decisions made without me. This means I am no longer important now that I have a hearing loss. I am side-lined.”

Furthermore, changes in family support were reported. Families were reported to have been initially supportive and understanding during the diagnosis of MDR-TB, but this had changed with time and when the hearing loss had developed.

“In the beginning, my family supported me a lot. They did not blame me for getting sick; they helped me with my medication. After seven months, the support decreased. It changed. I think they did not know that I was going to be sick for such a long time; they did not know that my hearing loss was permanent (Pauses as though deep in thought). So, I will say they got tired”. – Sifiso

“I think my mother thought I was going to be sick for a short time like with flu. Time went by, and I was sick for long. Not just sick, but I was weak when I was sick. When I got home after discharge, I felt the support was reducing. She seemed ‘fed up.’ I do not know if she was blaming me for what had happened or if she was just tired or maybe she was also tired of seeing me this way. She was tired of seeing me this way”. -Zinhle

Caregiver burnout, which is a state of physical, emotional, and mental exhaustion, may account for the change in attitude, from positive and caring to negative and unconcerned. Burnout can occur when caregivers or family do not get the help they need, or if they try to do more than they are able, physically, or financially (Peddireddy, 2016). The changes in family support in the current study may be attributed to possible emotional burnout of the family member, as well as lack of knowledge regarding the duration of the illness and the permanency of the side effect, i.e., hearing loss. Again,

this highlights the implications of the lack of adequate counselling for participants and their families. Caregivers may also lose confidence during treatment and not know how to communicate with a family member who is now hearing impaired; consequently, resulting in reduced support. Aural rehabilitation can improve the quality of life for both the individual with hearing loss as well as their significant others (Preminger, 2007). Individuals with hearing loss are more likely to benefit from aural rehabilitation when their significant others are involved in the process as the significant other gains an understanding of the needs and challenges of the individual with hearing loss (Preminger, 2007). Evidence has shown that the inclusion of the significant other in aural rehabilitation has favourable outcomes for both the hearing impaired individual and their significant other (Preminger, 2007). This, therefore, brings to the fore the need for family-centred intervention and the inclusion of significant others during aural rehabilitation.

Andile had been the only participant to report no changes in family support. His family had always reacted positively. He reported a great deal of support from his parents. They had accompanied him to all his appointments and had made provisions for visiting him routinely while he was hospitalised. His parents had shown interest in his audiological assessments and management and had tried to the best of their ability to assist him with communication breakdowns due to the hearing loss. He expressed the benefit of the support from his parents during his journey:

“My relationship with my family is the same. My parents have always been supportive. Since the day I was told I have MDR-TB up to the time I lost my hearing in both my ears. They understand and come to all my appointments with me, both of them. They did not blame me for anything that happened to me. I still feel that I am part of the family in the same way as before. My family has been my biggest support during this process.”

The current researcher postulates that the continuing support received from his family may be due to family dynamics before the diagnosis. It may be likely that the relationship between Andile and his parents has always been excellent and that they may have always been very supportive of him. Additionally, the parents’ attendance at Andile’s medical appointments may have also resulted in the parents being better informed and better prepared to deal with the consequences of MDR-TB as well as hearing loss.

4.3.2.1.2 Participants as parents

Participants who were parents expressed that their role as a parent had suffered as they had been absent from the lives of their children due to illness and hearing loss. They experienced significant loss as they felt that these changes were out of their control, as is evident in their responses in Table 4.3.

Table 4.3

Participant's responses on their relationships with their children

Parent	No. of children	Current relationship
Sarah	1	<i>"I have not seen my daughter in like six months. She is 12. I do not talk to her on the phone because I do not want her to know that I have these problems. She cannot visit me as well because children are not allowed to visit in the hospital. She lives with my mother and the rest of the family. She is fine, I think." (Shakes head and stares at the floor in deep thought)</i>
John	1	<i>"My son passed away while I was here at Sizwe. I could not go to the funeral because I was still sick and weak. I did not even talk to him before he died because of my problems with hearing on the phone. I did not get to speak to him or see him before he died (Starts coughing uncontrollably). It hurt me a lot. I got very sick after he died."</i>
Vusi	2	<i>"Both my children live with their mothers. They come to visit my family sometimes during the holidays. I had children when I was still young, so my family is always helping with them. I wish I could do more- like to see them more, but I will always need help with them because of my hearing."</i>
Mandla	2	<i>"My daughter dropped out of school in grade 10. She sits at home every day watching TV doing nothing. I do not understand because education is free. I blame myself because I was absent. I was away when I was in the hospital at Sizwe and did not play my role as a father. Sometimes I say maybe she is angry at me; maybe she does not understand that I was sick. She is very upset at me, and we do not talk well with each other. She lives with her mother because we are divorced."</i>
Sandile	1	<i>"My son lives with his mother because we are not together anymore. He is five years, and I last saw him when he was around three. I cannot help them with money, and they stay far from me. Sadly, I am missing out on this time when he is growing."</i>
Zinhle	1	<i>"I am still a mother to my daughter. She is six years old. She does not understand what happened, but she can see that now it is harder to talk to me. I am having a problem doing things for her that need money. I am scared of how things will be when she is growing up."</i>

Parents had reported substantial shifts in their parenting roles due to both MDR-TB and hearing loss, as they felt absent from their children's lives. They expressed great sadness on missing critical life events during hospitalisation for MDR-TB, which was aggravated by communication challenges imposed by the hearing loss even when participants returned home. Where a child had passed on or encountered a negative life experience, parents experienced blame for having been absent. They felt as though outcomes for their children would have been different if they had been able to communicate effectively with them. Others felt powerless where decisions were made regarding their children on their behalf. The presence of an adult with a disability alters the quality of family life, as it requires greater adaptation to the needs of that member (Rellano & Peralta, 2015). Families may not understand how an individual with hearing loss may parent effectively. Besides family, the individual with hearing loss may also not know how to parent with a hearing loss, possibly leading to parents feeling inadequate and guilty as though they are purposefully absent from the lives of their children, as is seen in the current study. Rellano and Peralta (2015) found that parents with disabilities often try to parent according to "sighted ways of functioning" when they do not have role models with similar disabilities. The parents in the study did not have any 'role model' to gain information and support from, in terms of parenting with a hearing loss. Having access to information or networks of parents with hearing loss may ease the challenges of parenting faced by participants. Regardless of whether they have a disability, all parents need support, both formal and informal, to help them in parenting. Research has found that parents with disabilities tend to be isolated and to have limited social networks (Reallano and Peralta, 2015). The use of group therapy sessions for these adults diagnosed with MDR-TB and the consequent side-effect of hearing loss would have been beneficial in providing participants with a platform to develop a social network to discuss similar issues.

Sarah had not seen her daughter in six months, Sandile has not seen his son for two years and Zinhle is unable to raise her daughter independently. They have likely been isolated from their children's lives, and have not been able to play their role as parents fully. It is unlikely that any formal or informal assistance has been made available to assist them with parenting as there was no mention of any. Zinhle expressed fear of the challenges she would encounter with parenting as her daughter matured, *'I am scared of how things will be when she is growing up.'* Her fear may be as a result of the minimal support she had received as a parent with a disability. Therefore, it is likely that aural rehabilitation incorporating group counselling may be beneficial to these parents with newly acquired hearing loss as they could learn from the experiences of other group members. In addition, group counselling also has the advantage of providing members with a sense of belonging. The group aural rehabilitation approach has advantages in that it enables the hearing impaired individual to share their feelings and emotions as well as possible solutions to alternative ways of dealing with communication failure (Hawkins, 2005).

4.3.2.1.3 Relationship with Spouse/ Partner

Similar to family and family support, marriage was also reported to have been impacted by the diagnosis of MDR-TB and worsened by hearing loss. Mandla went through a divorce as time away from home during treatment for MDR-TB put a strain on his marriage. He reported that his marital problems had worsened throughout the treatment duration, and these challenges were exacerbated by hearing loss. He expressed:

“My relationship with my wife has been a challenge with my sickness. She found it hard to be the provider for money because I am not working. I was sick for over a year, and my hearing loss made it worse and came between our talking almost all the time. We had both never seen or lived with someone who is not hearing. Marriage is hard, yes, but we had not been in this situation before. I would get furious at her because I couldn’t hear her well, and she would also get angry at me. We were fighting all the time. Our marriage ended. I do not blame her. It hurts my feelings, but it was hard for her. It was hard for me as well because I knew nothing was going to change. This is my life forever anyway” –Mandla.

In the current study, Mandla’s marriage had ended due to the hearing loss in the context of MDR-TB diagnosis. The marital impact of MDR-TB is well known as, in many instances; knowledge of diagnosis has resulted in divorces or second marriages (Loveday et al., 2017). This holds true for the present study but with a greater impact due to the added burden of a hearing loss. Mandla’s reports of frustrations and constant arguing between his spouse and himself due to both partners feeling as though they were not understood is in keeping with Govender, Maistry, Soomar, and Paken (2014). These authors reported that when one spouse acquires a hearing loss later in life, especially after relationship patterns have become established, the couple may experience anger, anxiety, depression, resentment, guilt, and withdrawal. These negative emotions may be attributed to communication difficulties between the couple being misinterpreted as a lack of concentration or unwillingness to communicate, rather than the hearing loss (Govender et al., 2014). Extensive repetitions during conversations with their hearing-impaired partner resulted in a significant change in typical communication, which affected both partners differently (Govender et al., 2014). Other areas that presented a challenge to spouses with normal hearing were the need to continually raise the volume of their voices and having to maintain face-to-face contact during communication (Govender et al., 2014). Speaking at a louder volume was considered more detrimental to the relationship than having to maintain face-to-face contact during communication (Govender et al., 2014). Mandla’s feelings mirror these findings as he expressed, *“I would get furious at her because I couldn’t hear her well, and she would also get angry at me,”* and further indicate that a breakdown in communication affected both partners significantly. Where marriage may have possibly survived in the diagnosis of MDR-TB, the impact of hearing loss on marriage cannot be understated as the communication

barriers brought on by hearing loss may have been too difficult to overcome. Similarly, participants, who were not married, also reported relationship challenges with their romantic partners. For one participant (Bongi), the hope of finding a partner or spouse had been lost. Their responses are recorded in Table 4.4, below.

Table 4.4

Participants' responses on challenges experienced with romantic relationships

Participant	Response
Sandile	<i>"My son lives with his mother full- time because we are not together anymore. It was hard when I was away in the hospital, so even when I went back home, we could not catch up. The hearing loss made it very hard to catch up".</i>
Bongi	<i>"I do not have any kids, and I am not married. I wanted to have a wife and have a family one day, but I do not have a partner at the moment. I doubt it will happen".</i>
Mary	<i>"When I came to Johannesburg from Free State, I came for work, to find a job. I did not think of finding love, but these things always happen. I had a partner I saw for a while, but the relationship ended when I got sick. Some people are not patient. I do not think about that kind of thing anymore. Dating. I think it will be hard to find someone who will understand that I have a hearing problem."</i>

As seen from the participants' responses in Table 4.5, above, they were unable to maintain their relationships with their significant others, which may potentially lead to diminished prospects of future marriage. Participants may be afraid to attempt a new relationship due to fear of not finding a suitable partner who will understand their hearing-related challenges, as indicated by Bongi, who has never been married before and has lost hope of a future marriage, and the possibility of having children and being a father.

4.3.2.1.4 Social Functioning

Participants reported reduced participation in their social life initially due to MDR-TB diagnosis, which then continued due to the hearing loss. The effect of treatment and hearing loss led beyond the physical to self-imposed social isolation. Role functioning was also hampered. Participants were unable to play their part in their family or society as they had hoped for or as they had done previously. One participant expressed how much more difficult it would be to try and do so with a hearing loss:

“I have been able to keep old friendships. I appreciate them, but I have stopped meeting new people. With new people, you must always explain that you have a hearing problem, and then they ask questions, and you must explain how you got the hearing loss. It is a problem and makes me tired, so I just stay with the people I already know because they understand.”- Andile

Time spent away from society, as a result of hospitalisation or staying indoors while home, was reported by participants to have resulted in reduced social interaction. Participants found it challenging to maintain their social lives as they previously were, as much had changed in the society around them during their absence.

“I used to be a very sociable person who loved people. I do not want to be with people anymore. When I got sick and lost my hearing, I was away from people, and they moved on with their lives. I think it does not mean they do not care about you, but life goes on. Nobody is going to stop living because you are sick.”-Vusi

Sandile shared similar feelings of how being away from society for an extended time impacted his ability to re-integrate himself once he had returned home:

“When I got better from the TB, my hearing was not good. Now you can imagine going back to people you haven’t seen in a long time, and you cannot hear properly. I rather just stay at home. Just imagine trying to do all that with a hearing problem.”-Sandile

Zinhle was confused about her social status and expressed how she often wondered if she was isolated or if her life was healthy. She felt that she had not adjusted well to her current social standing:

‘I do not have a clear memory of my previous social life. I constantly ask myself if anyone needs to socialise to survive or not.’-Zinhle

Participants reported reduced participation in their social life as a result of hearing loss. Coping representations suggest that individuals with hearing loss who attend many social events could appear, on the surface, to have a high degree of social functioning; yet, they could feel quite isolated and dissatisfied (Hefferman et al., 2016). This inability to participate in valuable and meaningful interaction meant that participants were still socially isolated even if they were present in a social situation, and this has negatively impacted role functioning and the individual’s quality of life.

Sandile had spoken about wanting to '*reintegrate into society*,' suggesting that he had enjoyed being a part of society and that it had been a significant part of his life that he hoped to return to once he had been cured of MDR-TB. However, the hearing loss made this process difficult and quite impossible for him to do. It can be understood that he has lost a significant aspect of his life due to the hearing loss. The burden of having to explain a hearing loss while an individual presents with communication difficulties can make it more challenging to be a part of a social network, as also reflected by Andile, who added that he had stopped meeting new people and preferred to be around those who already knew that he had a hearing loss. However, this may not mean that he was capable of being an effective communicator within the group, but it may have been easier than having to explain when and how he had acquired the hearing loss.

A good social network may be important in assisting a patient to overcome the influence of structural factors such as hospitalisation. Patients often find themselves locked in a negative cycle due to the social impact of MDR-TB on their families and themselves, resulting in significant changes in relationships with family and friends. Findings in the present study were in keeping with that of Seedat et al. (2009), who stated that the long periods spent away from home and society during hospitalisation meant fewer stays at home and less time spent with family and friends. In the current study, participants reported living a solitary life as well as lack of participation in their routine; resulting in them feeling less valuable and sometimes leading to a perceived loss of self-identity, low self-esteem as well as feelings of guilt, and isolation. Isolation was reported to have resulted from being excluded by family during crucial discussions and gatherings, further indicating a lack of family support.

The findings of the current study revealed how role functioning was hampered due to participants being unable to play their part in their family or society as they had hoped or as they had done in the past. These findings, therefore, reiterate those of Sharma et al. (2012), who reported that patients admitted to isolation facilities felt lonely, bored, confined, or abandoned. After discharge from the health care facility, many patients were not received back into their homes. Participants acknowledged that it was not easy to maintain a social life and that it was difficult to integrate back into society after being hospitalised for a lengthy period. This attempt at societal re-integration may have been made more difficult by hearing loss. The difficulty of having to re-integrate into homes and societies after illness and after a patient has acquired a hearing loss can be devastating, thus emphasizing the importance of family support, which can be facilitated by including family and significant others during counselling sessions and aural rehabilitation. This is evident in the case of

Andile, who still maintains a good relationship with family, as his parents had attended all medical appointments with him.

Participants expressed how a person could be very vulnerable to depression depending upon a lot of different factors, i.e., if there is a good network of family and friends around or not. The interviews, therefore, also highlighted the importance of maintaining relationships with family and friends, as they provide invaluable moral support and encouragement. Guo et al. (2009) reported that even after the MDR-TB patients had completed their treatment and were considered microbiologically ‘cured,’ their quality of life remained poor in comparison to the general population. Furthermore, the inability to participate in valuable and meaningful interactions due to hearing loss had a further negative impact on the individual’s quality of life. Therefore, it is essential that there are intervention practices such as aural rehabilitation and psychological counselling to help these individuals cope better with hearing loss in the midst of an MDR-TB diagnosis.

4.3.3 Objective 3: To describe the experiences of the economic and vocational impact of hearing loss in adults with MDR-TB

The theme of unemployment addresses Objective 3, with discussions of the sub-themes of social grant, previously employed participants, financial constraints and psychological experiences of unemployment being elaborated on.

4.3.3.1 Unemployment

All participants reported a significant decline in their financial situation as a result of their MDR-TB diagnosis and hearing loss. None of the participants were able to find stable work after completing their treatment. Nine participants experienced unemployment and loss of finances during and after treatment, with a high level of unemployment amongst participants being mostly attributed to the hearing loss.

4.3.3.1.1 Social grant

Social disability grants were the only source of income for Sandile, Mary, Vusi, and Andile. This social grant was received temporarily during MDR-TB treatment and lapsed either after six months or after they had completed their treatment. They then received a permanent disability grant due to the hearing loss. Andile was a transport driver for school-going children, and this was a form of assistance for his parents with their transport business. He reported that a massive part of doing the work was to avoid sitting at home for the entire day, as he had been unemployed for four years since

completing his MDR-TB treatment in 2015. The lack of employment was attributed to the communication difficulties resulting from the hearing impairment. He stated:

“I am unemployed. I survive on a disability social grant. It is hard to find a job when you cannot hear (silent sigh). Coping in an interview is hard, and you are already judged. People see you as dumb (he shakes his head); they think that you cannot do the job; they do not look beyond the hearing loss. It is hard. If I were to get a job, it would have to be one that does not need hearing, talking, and listening because I will not be able to do that properly. I am not ready to put myself there as yet”.

Sandile, who had been unemployed for a long time due to hearing loss expressed:

“My grant expires every time after six months, and I have to re-apply. The grant is not enough money. The only thing I can do is piece jobs because I do not need to talk to anyone for it. I get R200 or R300 and can buy food and have a meal at home. I have been looking for a job now for almost three years. I know I will not get it because of my hearing. You can just imagine”.

The social grant was not only used for the individual but was also extended to support his/her family financially. For some families, the social grant had been the only source of income received and financial instability, therefore, extended towards the entire family:

“A grant is not enough to take care of yourself or your family. I receive R1400 a month from the grant. We are just surviving. My family does not have any other money because nobody works. Not having enough money is a very painful experience, and I am still young (Stares into space, deep in thought). I do not wish it upon anyone”. -Vusi

“I get a social grant for disability, but I am in and out of the hospital. Even if I get a full discharge, it will be difficult to find a job because of my hearing problem. The only thing I will be able to do is easy work where I do not need to hear well”. –Mary

4.3.3.1.2 Previously employed

Loss of self-esteem and confidence, resulting from hearing loss, were reported to have been barriers to re-employment. Zinhle and Sifiso were employed before the diagnosis of MDR-TB and hearing loss. Work had been significant in providing a purpose and structure to their day. They expressed how they had to leave the workforce unwillingly due to their diagnosis of MDR-TB. Following treatment, hopes of re-integrating into the working environment were minimal due to the hearing loss.

Zinhle expressed with deep sadness: *“I worked at a jewellery store under sales. I cannot go back there now because in that job we talked a lot with customers. I will not even try because I know I will struggle and lose the job again. I do piece jobs like cleaning when I can get them. It is very difficult to get a good job when you have a hearing loss. I also cannot borrow money as I will not afford to pay it back”* (teary-eyed).

Sifiso further reflected:

“I was employed as a clerk in a school. After getting MDR-TB, I resigned because I was afraid of infecting others, especially school children. Also, I knew I was going to lose my job. There was no hope for me to keep my job, so I left on my own. I thought maybe when I am well again, I will get my job back or another job, but when I lost my hearing that was not possible anymore”.

Unemployment had a further impact as they had significant on-going financial commitments such as rent and school fees.

“I have a daughter who is still in school, and it is a problem to get her all the things she needs as I do not have money.” –Zinhle

“I cannot afford the things I used to afford; life has changed. You know, paying for your own things, getting what you want, doing things you enjoy. I also live at home now because it is cheaper than being on my own. I do not have to pay for where I stay because you know it needs money”. –Sifiso

Both Sifiso and Zinhle acknowledged that work was essential in the creation and maintenance of a person’s identity. They described how one’s identity revolves around work. For these individuals, one’s work defined them as individuals:

“I survived on my savings for a while until they were depleted. My finances have gotten worse because I do not have any monthly payments. I have lost my identity.”-Sifiso

“When I was still working, I had something to wake up and do every day. That was who I was.” –Zinhle

Furthermore, much of the stress placed on relationships due to unemployment was attributed to the changing of the breadwinner role in families, which is traditionally held by males. Changing relationships within the family and the fact that one member of the family now spends more time at home with no clearly defined role can lead to frustration and resentment (Powell et al., 2011). Bongi's statements reiterate this point as he highlights the massive reduction in his income and struggles to assist his family financially. In addition, he described feelings of guilt as he is not contributing to the family financially and believes that the breadwinner's role should be his task. He expressed:

"I was previously able to support my family with money as we [are] a large family in one home. Now, I do not have money. Even if they did need money, they would not ask me because they know that I do not have it. They will expect me to work once I get discharged, but it will be difficult to find work with my hearing loss. You see, hearing aids do not help me much. I feel a lot of stress and guilt." - Bongi

4.3.3.1.3 Financial constraints

Travel costs brought on much stress as participants often did not have the finances to travel to the hospital or clinic for their appointments. Participants often had to travel long distances, which equated to higher travelling costs. The stress was reported to have worsened over time as participants were booked for regular monthly appointments both for the MDR-TB treatment as well as their hearing-related treatments.

Vusi expressed:

"I live in Orange Farm, but I do my follow up at Sizwe. To travel to Sizwe from home, I must take four taxis to return, and I am not working. So it means I must have like R100 for one day, it is a lot of money. I go to the clinic and take the transport from there to Sizwe. We wait for long, but at least it is free".

"I do not have the money to go to the clinic every month, but I must go. It is a lot of money for me because the taxi fare is double. They said at Sizwe that I must go to the clinic for follow up, but it was better to go to Sizwe because the transport was free. I care about my health, so I go, but it costs me money". –Sandile

For those participants who were hospitalised, their families were impacted by the travel costs:

"I have not seen my family in over five months. They stay far, and we do not have money for them to come and see me." –Sarah

“My family is in the Free State, where I am from. There is not enough money to travel to Johannesburg to visit for one day or two days. It costs much money to come here from there. I have been here for seven months now and have not seen anyone from home.” - Mary

“My family cannot come and visit me at the hospital because they live far and cannot afford the transport money to the hospital. I cannot help them because I do not have money.” – Bongi

The financial constraints that participants were experiencing affected their ability to access their medical treatment. Those who had been hospitalised were able to access their medical treatment but unable to see their families for extended periods. Considering the challenges brought on by the dual diagnosis of MDR-TB and hearing loss, it is likely that family support and visits would have been beneficial for participants, but was not always possible due to the financial cost of travel.

4.3.3.1.4 Psychological experiences of unemployment

Participants in the current study expressed profound emotional challenges resulting from unemployment due to their hearing loss, as reflected in Table 4.5, below.

Table 4.5

Participants’ responses on the psychological impact of unemployment

Participant	Response
Vusi	<i>“When I finished my treatment, my grant was closed. I struggled to find a job because of my hearing loss. I went back to my old boss and explained my situation. I then asked for any type of work but could not get a job. I feel sad. I feel bad. I do nothing. Every day is the same. I do not believe in these depression things and stories you know, but I am very sad”.</i>
Mandla	<i>“Emotionally, it is difficult because you want to provide, but you cannot for those who depend on you. That can be difficult. Say when one of the kids comes home from school, and they are looking for money for a school trip, and you must be honest with them, and it is very hard, to be honest with them” (Trying to hold back tears).</i>
Zinhle	<i>“You feel worthless, the longer you are unemployed. You just feel like you are never going to work again. You think: “is this going to be my life?” you can see why people become suicidal. Yeah, the longer that I am unemployed I thought there is something wrong with me, okay yes; my hearing is something wrong with me. But I am still a</i>

person. I cannot seem to get a job, my belief in myself is going, I am always thinking there is something wrong with me, and they do not want to employ me. I was starting to get depressed. I think someone can think about suicide and people who have big debts, they have no way out, and when you have no way out, you cannot see any light”.

Unemployment can have a devastating impact on people's lives, as it affects not just the unemployed person but also family members and the wider community (Wurie, Cooper, Horne, & Hayward, 2017). The impact of unemployment can be long-lasting. As unemployment becomes long-term, its impact becomes more far-reaching, often affecting living standards substantially (Wurie, Cooper, Horne, & Hayward, 2017). If living standards are poor, the likelihood of the spread of infectious diseases is higher, and the individual's recovery from the disease may be longer. Ankale, Nair, Uppe, Mathew and Shah (2017) reported that DR-TB is most prevalent in low-income households, where the quality of housing and the living conditions are typically poor, i.e. poverty, malnutrition, poor hygiene, sanitation as well as overcrowding; thus creating a favourable habitat for the spread of the TB bacteria. Low income is also known to be a determinant for poor adherence to TB treatment (Wurie et al., 2017), and these patients may be trapped in a cycle of infection and reinfection fuelled by unemployment. It can be said that participants' quality of life is largely decreased by their living standards and socio-economic status. It may be more difficult for them to improve their health status and prevent re-infection of MDR-TB if their standard of living does not improve. Therefore, participants may find themselves in a permanent state of unimproved quality of life as they are continuously unable to find employment and improve their financial situation.

Participants experienced a significant decline in their financial situation resulting from their MDR-TB diagnosis and hearing loss. Overall, the high level of unemployment amongst participants was mostly attributed to the hearing loss. Participants in the present study had lost hope of finding work again, not because they were incapable or did not want to work but because they felt that their chances of employment were reduced due to the hearing loss. These feelings were due to the communication challenges they experienced combined with the knowledge that for them, most of the 'stable' employment required excellent communication abilities which they did not possess.

One of the significant effects of hearing loss is the deterioration in loudness perception, frequency discrimination, and temporal resolution (Hawkins, 2005). Therefore, an individual with impaired hearing will have significant communication difficulties, many of which are situation-specific. Due to these communication challenges, hearing aids alone, while helpful, may not provide

optimal rehabilitation for the hearing-impaired individual (Hawkins, 2005), as expressed by Bongi 'hearing aids do not help me much', which indicates that even after being fitted with assistive listening devices such as a hearing aid, communication challenges persisted. Even if participants were to gain employment, they may not have been able to stay employed as their communication challenges would continue. Therefore, the inclusion of aural rehabilitation encompassing counselling and communication strategies training becomes more critical in the holistic management of these patients. Aural rehabilitation is a process or therapy aimed at optimising a hearing-impaired person's ability to participate in activities that have been limited or restricted owing to hearing loss (Hawkins, 2005). The benefits of aural rehabilitation appear to be 'a reduction of the perception of hearing handicap, improvement in perceived quality of life, better use of hearing aids and communication strategies' (Hawkins, 2005, p.6). There may also be some improvement in personal adjustment to the hearing loss and the hearing assistive device such as a hearing aid (Hawkins, 2005). The provision of aural rehabilitation by an Audiologist may have assisted participants like Bongi, who is fitted with hearing aids but receives minimal communication benefit to acquire the necessary communication abilities and adaptation skills. These could have assisted him in being able to utilise his hearing aids optimally in conjunction with compensatory communication strategies (Hawkins, 2005).

Once diagnosed with MDR-TB, those who had been employed were forced to leave their work due to fear of infecting those around them as well as the inability to perform their job adequately as the hearing loss had posed severe communication challenges. These findings are in keeping with Thomas and Shunmugan (2016), who reported that patients were no longer able to work after the diagnosis of MDR-TB, and those who continued to work received less income due to absence at work. In South Africa, 4.3% of the South African population is disabled (South African Board for People Practises, 2019). With an acknowledgement of the current unemployment rate of 27.7%, people with disabilities find it more challenging to find or secure employment as well as be accepted within society as individuals who can perform work tasks efficiently (SABPP, 2019). This assumption requires a change in perspective, as people with hearing loss should be granted equal opportunity to jobs. Being unfamiliar with a disability as well as the legislations of disability can lead to stereotypes that individuals who present with disabilities are unable to perform optimally in jobs and work independently (Doolabh & Khan, 2019). Therefore, the role of aural rehabilitation for an adult with a recently acquired hearing loss is emphasised, as it would also provide them with the necessary compensatory communication strategies to improve their chances of being employable.

Most participants in the current study relied on social disability grants as a source of financial income. The grant was obtained due to either the diagnosis of MDR-TB or hearing loss. The social

grant was a permanent monthly income when obtained due to the hearing loss and was often used to support the finances of the entire family. Even though social disability grants are received monthly, the amount received is not sufficient to provide financial security and is therefore likely to result in chronic financial instability within families. The estimated costs of MDR-TB patient diagnosis and treatment are higher than those for other TB patients, mainly due to the more extended period for treatment (van den Hof et al., 2016). If the patient is the breadwinner of the family, the combination of lost income and extra costs, generally, is catastrophic (van den Hof et al., 2016). This is in keeping with present findings where financial instability was often a result of the loss of finances from the breadwinner within the household. Participants who were the primary financial provider for their family felt guilty that they were no longer able to contribute to the family financially. When participants had lost their jobs, they also struggled with changes in financial/breadwinner roles in cases where another family member had to take on that role.

Participants who had been employed prior to their diagnosis of MDR-TB and hearing loss expressed how they had felt a loss of identity, and hopes of re-integrating into the working environment were minimal due to the hearing loss. It is evident from the findings that the impact of unemployment on an individual's sense of identity can be quite significant. (Platt, 1984, as cited in Brannen, 2015) argues that when an individual loses their job, they inevitably lose some aspect of their identity as they associate work with feeling good about themselves and with contributing to society. The attributes which work provides for an individual such as the latent functions, (time structure, status, and identity, goals anchored in collective participation, social experiences and enforced activity) proposed by (Jahoda, 1982, as cited in Drydakis, 2015) (1982), were seen as significant by the participants because they provide meaning and purpose to a person's life and were therefore seen as a prerequisite to overall well-being. Powell et al. (2011) reported that the psychological costs of retrenchment and prolonged unemployment during the productive years of life impact harshly on the quality of life of affected individuals and families. Experiences of low self-esteem and loss of self-identity impact on the physical and mental health and can extend to broader consequences of social isolation and the loss of social networks and support (Powell et al., 2011). At the very least, it reduces an individual's sense of membership and contribution to the life of the community (Powell et al., 2011); highlighting that the insidious impact of unemployment extends to the individual's mental health.

Thomas and Shunmugan (2016) stated that MDR-TB was found to contribute significantly towards stress and anxiety as most patients were no longer able to work after diagnosis, and the economic barriers included inaccessibility of treatment, the distance away from the hospital, transport

costs and costs incurred during hospitalization. Transport costs may appear to be a small part of the total cost of treatment, but this is not necessarily so as such expenditures could lead to defaulting from treatment, particularly among the poor, as is seen in the current study. Participants had to travel long distances to attend their appointments either for the collection of medication or for hearing-related assessments, with them often struggling to finance their travels and consequently borrowing money, as not attending an appointment was not an option. These findings are congruent with that of Loveday et al. (2017), who revealed the difficulties experienced by patients to include the chronic economic vulnerability of households, commuting time as well as costs of hospital visits. Patients reported that they struggled to finance their hospital visits, as they were unemployed or unable to find employment. This further emphasises the extent to which participants were impacted by unemployment. Being unemployed also meant that the process of accessing their medical management was made more difficult due to their financial status.

For those participants who were hospitalised during treatment, travel costs were incurred by family members who had to travel long distances to visit the individual, as some MDR-TB central sites were not in close proximity. Participants were unable to assist their families with travel costs as they did not have any income, which meant going for long periods without any family interaction, causing considerable strain on relationships and increased feelings of isolation for the participant. Those participants who were not hospitalised, however, had to spend long hours travelling while using free transport methods. This may also similarly lead to stress whenever participants had to attend their appointments as they had no regular income to finance their hospital appointments.

One of the main adverse effects of unemployment is that there is a loss of regular income, resulting in much stress regarding how the lack of income was to be compensated. When a person loses their income, it means that they do not have the ability or means to plan for their future, which is a further worry (Strandh, 2000). Zinhle had expressed that *"I cannot borrow money as I will not afford to pay it back."* This meant that even if the potential of borrowing money to ease her financial strain was possible, it was not an option for her; thus, suggesting that she had no means of accessing finances even when she needed it the most. South Africa is a country with much of the population living in low socioeconomic status and rural areas (Helmen & Ratele, 2016). Therefore, there is a higher risk of MDR-TB due to poor treatment compliance, resulting in treatment with aminoglycosides and thereby increasing the risk of ototoxic hearing loss.

4.4 Alignment of themes with quality of life model

In the current study, each theme should not be viewed in isolation, as the content of one theme was sometimes reflective of aspects of another theme, or the result or cause of another theme. The participant's diagnosis of MDR-TB and loss of hearing resulted in feelings of anger, disbelief, fear, and frustration, which in turn affected their mental and emotional state. The mental and emotional state was further impacted by unemployment. Research findings have shown that unemployment can affect an individual's psychological well-being. Individuals *"have deep-seated needs for structuring their time use and perspective, for enlarging their social horizon, for participating in collective enterprises where they can feel useful, for knowing they have a recognized place in society, and for being active"* (Jahoda, 1982, as cited in Drydakis, 2015, p. 298). At the same time, their relationships with family and friends were negatively affected. These changes were further expounded on by what seemed to be a permanent state of unemployment. With a decline in their quality of life due to these changes, participants had very little hope for their future. The themes in the present study can be said to be similar to the quality of life scale proposed by WHO (2010), which identifies the domains of quality of life as physical, social, environmental, and psychological. The themes in the present study narrated the challenges participants had experienced across these domains. The alignment of themes to the Quality of Life Model is indicated in Figure 4.4 below:

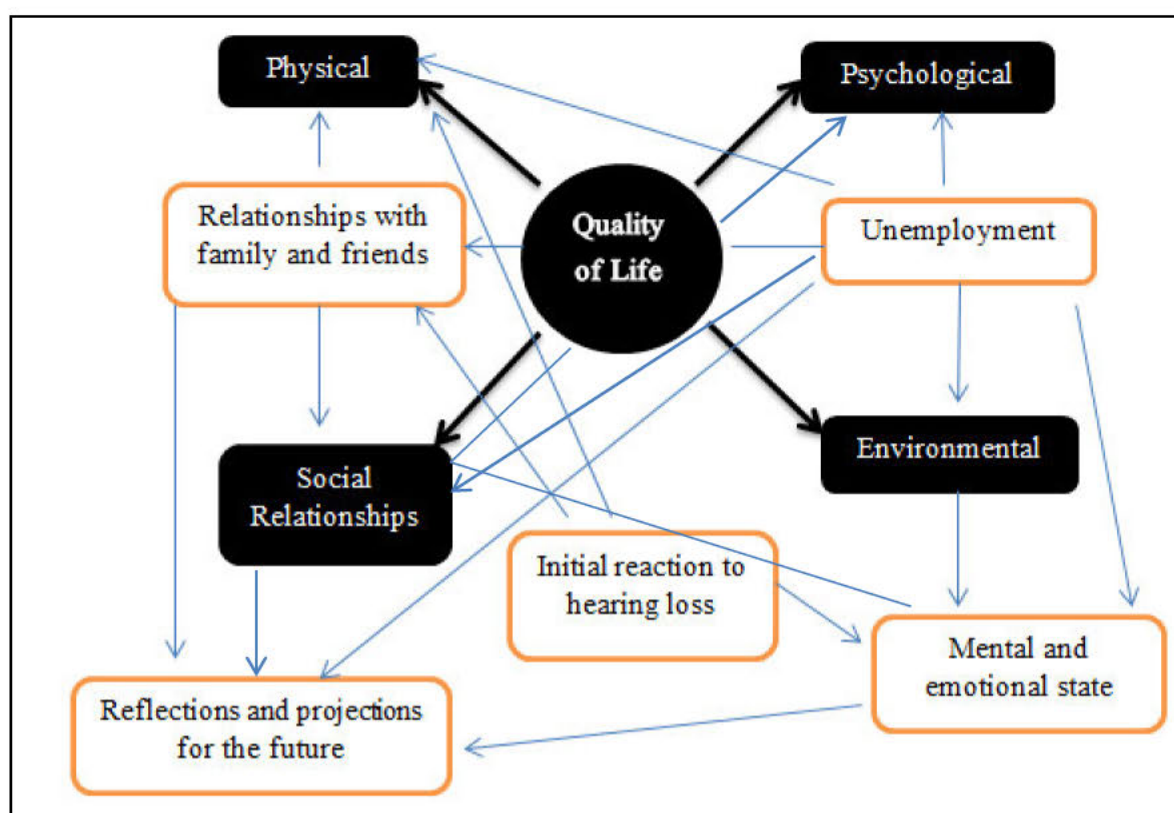


Figure 4.4: Alignment of themes with Quality of Life Model

Quality of life is influenced by an individual's physical and mental health, the degree of independence, and social relationships with the environment (WHO, 2014). An integrated evaluation of the quality of life must include all domains. The participants in the present study had significant challenges in all domains of their life, which is an indication of the decline in their overall quality of life. Seemingly, clinical assessments remain stable over time, and yet patients report a worsening of their quality of life. The main purpose of the health care system is to increase the well-being of those it treats, but this can only be achieved if patient views are incorporated into treatment evaluations and rehabilitation, thereby ensuring that health and medical care are entirely evidence-based. The use of evidence based measurement scales may aid towards the evaluation of quality of life. Measurement scales may be useful in allowing patients to identify the aspects of their Quality of life that may have been affected; therefore, allowing for improved intervention. This, consequently, may aid in improving the patient's quality of life.

4.5 Summary of Chapter

In the current study, the economic burden and loss of income caused by the long duration of the illness and hearing loss is evident. The study findings have also highlighted the economic burden related to transport costs and the inability to support and provide for families financially. Furthermore, these economic and financial challenges have had a broader psychological impact not only on participants but on their families as well. The psychological disturbances due to MDR-TB and hearing loss are a matter of concern. Psychological issues were seen to have persisted over time and gotten more severe as social issues, and challenges with family relationships worsened. The provision of psychosocial interventions may have had a positive impact on the quality of life of participants, thus highlighting the importance and influence of counselling in the intervention.

The findings of this research study mirror the findings of previous research carried out to date on the impact of MDR-TB on quality of life. The results of the present study have shown that the impact is worse when there is an acquired hearing loss. There were limitations to this study, which are discussed in the following chapter. Reference to future clinical and research implications is also made.

CHAPTER 5: CONCLUSION, LIMITATIONS, AND RECOMMENDATIONS

5.1 Introduction

This chapter provides a summary of the main findings and also highlights the limitations of the study, as well as present the clinical implications drawn from the study. Lastly, recommendations for further research are provided.

5.2. Summary of main findings

The study aimed to explore the psychosocial impact of hearing loss on the quality of life of adults with MDR-TB. The study was conducted through a qualitative phenomenological approach, which enabled the researcher to explore the lived experiences of participants within their natural context. All information was obtained directly from participants through the process of interviews. A review of the literature provided the researcher with a greater understanding of the data obtained from participants who had acquired permanent hearing loss following the administration of aminoglycosides for the treatment of their MDR-TB diagnosis. The results of the study addressed the research objectives as follows:

5.2.1 Objective 1: To explore the psychological and emotional impact of hearing loss in adults with MDR-TB

As the narratives have shown, there are significant emotional and psychological implications experienced by this population, both due to the disease and its treatment complexities as well as outcomes of hearing loss. One of the main findings which arose from the themes obtained during data analysis was the lack of psychosocial support received by participants. Positive reception and support from families were limited. Gender roles influenced the willingness of male participants to seek emotional and psychological assistance. Participants experienced significant difficulty with acceptance of MDR-TB diagnosis and hearing loss. There was no mention of support outside the home or within the clinical setting. Study findings emphasized the minimal role of health care providers with regards to counselling during treatment and intervention for MDR-TB patients who present with hearing loss. Counselling was noted to have been insufficient throughout the patient's medical journey as they had limited knowledge about ototoxicity as a side effect of aminoglycoside use. Poor mental health without any psychological intervention may also deter people with MDR-TB from disclosing their psychological symptoms and challenges. Therefore, mental health disorders may be missed by health workers and, ultimately, by policymakers. In the current study, the 'dual

diagnosis' of hearing loss and MDR-TB left individuals with feelings of hopelessness, a lack of self-identity, feelings of anxiety, and increased stress levels.

5.2.2 Objective 2: To describe the experiences of the social impact of hearing loss in adults with MDR-TB.

Significant changes in family structure, loss of self-identity as well as the stigma around MDR-TB and hearing loss in present-day society had a significant impact on the participants' relationships with society as well as their families. Participants had not been able to reintegrate themselves into the community as a result of the amount of time spent away from society due to the long period of hospitalisation/treatment. Even after recovery from MDR-TB, it was difficult for participants to maintain or be a part of a social circle due to the hearing loss. This led to participants being isolated from their friends and families. Participants, as parents, were no longer able to fulfil their roles. They had been absent during treatment for MDR-TB. Additionally, unemployment and hearing loss created more barriers to their roles as parents. Participants felt uncertain about their future as their present quality of life had deteriorated significantly from what they had worked for and known. Therefore, an overall decline in quality of life was seen across all participants. They had lost their way of life as they had previously experienced it and had no means to improve their current state, leaving them with a permanent state of hopelessness. Any hopes of changing their current circumstances and improving their quality of life had been lost.

5.2.3 Objective 3: To describe the experiences of the economic and vocational impact of hearing loss in adults with MDR-TB

There was a high rate of unemployment amongst participants owing initially to MDR-TB diagnosis and then maintained and possibly worsened by hearing loss. Participants experienced considerable financial decline and difficulty. They were unable to provide any financial stability for themselves and their families. Some participants relied on a social grant as a monthly income, whereas some had no access to a social grant. Participants did not have confidence in their ability to perform optimally in a position of employment due to the communication challenges they experienced as a result of hearing loss. Therefore, unemployment was seen as a permanent state by participants. The stigma of hearing loss has also made it difficult for participants to gain employment. Participants felt as though they were being judged or labelled as incapable purely because of their hearing loss. This lack and loss of finances also impacted profoundly on their psychological well-being.

5.3 Strengths of the study

- The study sample was small and limited to ten participants, thus allowing for more in-depth information from participants.
- The researcher was a first language isiZulu speaker, which assisted the researcher to be able to probe further during interviews where necessary.
- The research data was analysed through audio recordings as well as field notes. This assisted with increasing the reliability and validity of the study.

5.4 Limitations of the study

The study set out to describe the psychosocial impact of hearing loss on the quality of life of adults with Multidrug-Resistant Tuberculosis. Therefore the findings of this study need to be considered in relation to the limitations of the research:

- While the recruitment of participants in the study followed several steps, as detailed in the methodology chapter, the role of the Audiologist in the identification of participants' may have influenced the process based on the participants' reliance on their relationship with the audiologist.
- While steps such as coding were taken to reduce researcher bias during the data analysis process, the researcher's involvement in designing the study and in data collection may have influenced the study findings, as the researcher is an Audiologist with frequent interaction and experience with MDR-TB patients who present with hearing loss.
- The study was conducted among patients with MDR-TB and hearing loss within a government health facility, with similar socioeconomic status and within one race group. The results obtained from the present study may be unique to the setting in which the study was conducted and may not be generalised to the entire population. However, the issues highlighted in the study are likely to be relevant to other countries with similar socioeconomic status and high MDR-TB burden similar to South Africa.

5.5 Implications of the study

5.5.1 Research Implications

MDR-TB remains an on-going challenge within the South African health system, and the risk of ototoxicity from aminoglycoside use remains high.

- Research is needed to identify clearly defined psychosocial support interventions for individuals with MDR-TB, who further acquire a hearing loss.

- Research should focus on how to identify and measure psychosocial challenges faced by patients diagnosed with MDR-TB and hearing loss. This may inform policy regarding interventions required to provide effective psychosocial support for this population.
- Based on the results obtained from the present study, it is believed that a more committed and sophisticated approach towards MDR-TB and hearing loss is required to develop patient support interventions that are evidence-based. Therefore, National TB programmes should adapt and integrate the principles of quality of life into treatment guidelines.

5.5.2 Clinical implications

- Greater importance should be placed on the provision of the necessary education and training for Audiologists regarding clinical interventions to assist patients with MDR-TB and hearing loss with a better understanding of their diagnosis.
- An integrated intervention model for patients should comprise of psychosocial care packages which include counselling, support groups (to provide treatment literacy on medication as well as health education for the patient's families and caregivers), and psychiatric interventions.
- Audiologists should ensure that counselling is provided to all patients, as this may aid in improved adherence to treatment for MDR-TB.
- Audiologists, with the provision of aural rehabilitation services, should play an integral role in assisting participants to communicate better in their everyday situations to become better equipped for employment prospects.

5.6 Conclusion

This chapter outlined the main findings of the present study, limitations of the research, and has made recommendations for future studies. The data collected from the study led to the development of themes, which allowed the researcher to explore the psychosocial impacts of hearing loss on the quality of life of patients who had been diagnosed with MDR-TB.

South Africa is a country with one of the highest numbers of MDR-TB infections. As these infections continue to rise, aminoglycoside drugs used for the treatment of MDR-TB pose a significant threat to patient's lives as it places them at risk of developing an aminoglycoside-induced hearing loss. Hearing loss acquired during treatment of MDR-TB has a significant impact on the quality of life of the affected individual and further extends to their families. Patients experience a variety of psychosocial challenges during and after treatment for MDR-TB. Their life is hampered by

these challenges, which have been consistent and stagnant for all participants. Quality of life is a global imperative, and all patients should be given the necessary support to assist them to overcome challenges and improve their daily and future life outcomes.

Despite the pharmacological profile of patients, which is a necessary determinant for treatment outcomes, psychosocial profiles and interventions are a crucial aspect in achieving better treatment outcomes in many diseases, including MDR-TB. Such non-medical interventions should be practiced mostly because of the adverse treatment outcomes on patient's quality of life. With the current move towards the introduction of shorter treatment regimens for MDR-TB, which may be potentially less toxic, the consideration of how patients can be best supported should be an integral component of TB programmes.

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Appendix A1- Interview Schedule English



COLLEGE OF HEALTH SCIENCES

Participant Code: _____ Date: _____ Venue: _____

DEMOGRAPHIC DATA

Race: _____ Age: _____ Gender: _____

Highest level of education: _____ Degree of hearing loss: _____

MEDICAL HISTORY

1. Describe your medical history including your MDR-TB and diagnosis.
2. Describe your hearing status including onset and progression.

PSYCHOLOGICAL AND EMOTIONAL IMPACT

3. How does your MDR-TB diagnosis and hearing loss make you feel?
4. Describe the support you are receiving from your family since your diagnosis
5. Describe how your diagnosis and hearing loss has affected your overall daily functioning?

SOCIAL IMPACT

6. How has your MDR-TB diagnosis and hearing loss affected you socially?
7. How has your MDR-TB diagnosis and hearing loss affected your interaction and relationship with your family members?
8. How do you feel about the state of your relationships currently?

EMPLOYMENT AND ECONOMIC STATUS

9. What impact has your MDR-TB diagnosis and hearing loss had on your employment and financial status?
10. What impact has it had on your family financial status?
11. If there has been a change/ loss of finances due to your MDR-TB diagnosis and hearing loss, how does it make you feel?

Thank you for participating

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Discipline of Audiology

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Founding Campuses:  Edgewood  Howard College  Medical School  Pietermaritzburg 
Westville

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Appendix A2- Interview Schedule IsiZulu



**COLLEGE OF
HEALTH SCIENCES**

Khodi Yomhlanganyeli: _____ Usuku: _____ Indawwo: _____

IMININGWANE YAKHO

Uhlobo: _____ Iminyaka: _____ Ubulili: _____

Izinga lokufunda: _____ Isimo sokuzwa: _____

UKULASHWA KWAKHO OKWEDLULE

1. Chaza ukulashwa kwakho okwedlule kanye nokugyla kwakho ngeMDR-TB.
2. Chaa indlela ozwa ngayo emadlebeni kusukela ekuqaleni kuze kube imanje.

UMTHELELA NGOKWENGQONDO NANGO KWEMIZWA

3. Ukugula kwakhe ngeMDR-TB kukwenza uzizwe kanjani emoyeni
4. Kunjani ukweseka okuthola kumndeni wakho ngendaba yokugula kwakhe nge MDR-TB
5. Chaza ukuthi ukugula kwakhe ngeMDR-TB nokungexwa emadlebeni kukuhlupha kanjani empilweni yakho ntsuku zonke.

UMTHELELA KWEZENHLALAKAHLE

6. Uyini umthelele wokugula kwakho ngeMDR-TB nenkinga yokuzwa ekutheni ukwazi ukuhlala nokuxhumana nabantu?
7. Uyini umthelela wokugula kwakhe ngeMDR-TB nenkinga yakho yokuzwa kumndeni wakho
8. Uzizwa kanjani ngobudlelwane obukhona empilweni yakho?

ISIMO SOKUSEBENZA NESIMO SOMNOTHO

9. Uyini umthelela wokugula kwakho nge MDR-TB nenkinga yokuzwa ekutheni ukwazi ukuthola umsebenzi?
10. Uyini umthelela kwisimo somnotho somndeni wakho?
11. Uma kukhona ushintsho ngezemali zakho, uzizwa kanjani?

Ngiyabonga ngokuthi uzinikele

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Founding Campuses:  Edgewood  Howard College  Medical School  Pietermaritzburg 

Westville

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Appendix B- Ethical Clearance Certificate



28 October 2019

Ms A Thusi (211501649)
School of Health Sciences
College of Health Sciences
thusi.amanda6@gmail.com

Dear Ms Thusi

Protocol: The psychosocial impact of hearing loss on the quality of life of adults with multi-drug resistant tuberculosis
Degree: Master of Audiology

BREC Ref No: BE274/19

EXPEDITED APPLICATION: APPROVAL LETTER

A sub-committee of the Biomedical Research Ethics Committee has considered and noted your application received on 02 April 2019.

The study was provisionally approved pending appropriate responses to queries raised. Your response received on 18 September 2019 to BREC letter dated 28 May 2019 has been noted by a sub-committee of the Biomedical Research Ethics Committee. The conditions have been met and the study is given full ethics approval and may begin as from 28 October 2019. Please ensure that outstanding site permissions are obtained and forwarded to BREC for approval before commencing research at a site.

This approval is valid for one year from 28 October 2019. To ensure uninterrupted approval of this study beyond the approval expiry date, an application for recertification must be submitted to BREC on the appropriate BREC form 2-3 months before the expiry date.

Any amendments to this study, unless urgently required to ensure safety of participants, must be approved by BREC prior to implementation.

Your acceptance of this approval denotes your compliance with South African National Research Ethics Guidelines (2015), South African National Good Clinical Practice Guidelines (2006) (if applicable) and with UKZN BREC ethics requirements as contained in the UKZN BREC Terms of Reference and Standard Operating Procedures, all available at <http://research.ukzn.ac.za/Research-Ethics/Biomedical-Research-Ethics.aspx>.

BREC is registered with the South African National Health Research Ethics Council (REC-290408-009). BREC has US Office for Human Research Protections (OHRP) Federal-wide Assurance (FWA 678).

The sub-committee's decision will be noted by a full Committee at its next meeting taking place on 10 December 2019.

Yours sincerely


Prof V Rambiritch
Chair: Biomedical Research Ethics Committee

cc: Postgrad administrator: shumaleet@ukzn.ac.za Supervisor: pakeni@ukzn.ac.za

Biomedical Research Ethics Committee
Professor V Rambiritch (Chair)
Westville Campus, Govan Mbeki Building
Postal Address: Private Bag X54001, Durban 4000
Telephone: +27 (0) 31 200 2485 Facsimile: +27 (0) 31 250 4809 Email: brec@ukzn.ac.za

Appendix C- Permission from Gauteng Department of Health



GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

Department of Health
37 Sauer Street, Marshalltown
Private Bag X085
Johannesburg
2107
Tel: 011 0356 3000/3513
Fax: 011 355 3811
Email: hr@gautenghealth.gov.za
www.gautenghealth.gov.za

Reference: GP 201907 039

Dear Ms A Thusi

Subject: Approval of a Research Proposal

1. The research proposal titled '**The psychosocial impact of hearing loss on the quality of life in adults with multi-drug resistant tuberculosis**' has been reviewed by the National Health Research Database under the Gauteng Department of Health Research Committee.

The proposal is hereby **APPROVED** for research to be undertaken at Sizwe Tropical Disease Hospital.

2. You are requested to take note of the following:
 - a) Make the necessary arrangement with the identified facility before commencing with your research project.
 - b) Provide an interim progress report and final report (electronic and hard copies) when your research is complete.
3. Your final report must be posted to **GAUTENG DEPARTMENT OF HEALTH RESEARCH MANAGEMENT, PRIVATE BAG X085, JOHANNESBURG, 2107** and an electronic copy to the NHRD website under your profile.

For any additional information please contact Ms Z Ndlovu on 011 355 3512

Yours Sincerely



PROF. M. LUXHELE
HEAD OF DEPARTMENT: HEALTH
DATE: 2019/08/29



Appendix D- Permission from the Chief Executive Officer of Sizwe Tropical Disease Hospital



GAUTENG PROVINCE

HEALTH
REPUBLIC OF SOUTH AFRICA

Enquiries: Dr. M.C. Louw
Tel: 011 531- 4305
Fax: 011 531-4377
Date: 15 July 2019

Miss A. Thusi

RE: THE PSYCHOSOCIAL IMPACT OF HEARING LOSS ON THE QUALITY OF LIFE OF ADULTS WITH MULTI-DRUG RESISTANT TUBERCULOSIS

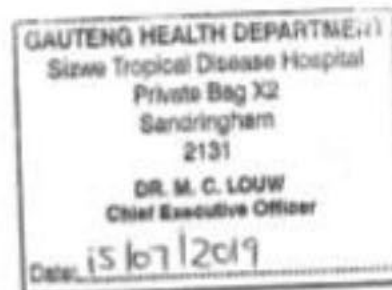
The study "The psychosocial impact of hearing loss on the quality of life of adults with Multi-Drug Resistant Tuberculosis" has reference.

The psychosocial impact of hearing loss on the quality of life of adults with Multi-Drug Resistant Tuberculosis is supported and permission is granted for the study (ethics: BE274/19) to be conducted in Sizwe Tropical Disease Hospital.

Kind regards



Dr. M.C. Louw
CEO: Sizwe Tropical Disease Hospital



Appendix E1- Information document in English



**COLLEGE OF
HEALTH SCIENCES**

TITLE OF RESEARCH PROJECT: THE PSYCHOSOCIAL IMPACT OF HEARING LOSS ON THE QUALITY OF LIFE OF ADULTS WITH MULTIDRUG RESISTANT TUBERCULOSIS.

Good day, I, Miss A. Thusi, Audiologist at Chris Hani Baragwanath Academic Hospital would like to invite you to take part in my research study. This research study aims to explore the difficulties and daily challenges of hearing loss in patients diagnosed with Multidrug-resistant Tuberculosis. This information will help us to understand how MDR-TB and a hearing loss have affected your life to assist us to improve the quality of care for patients with MDR-TB who further develop a hearing loss. I am kindly inviting you to participate in this study and to answer the questions in an interview to the best of your ability. You will be audio-recorded during the interview. The interview should take between 20-35 minutes to complete.

Please note that your participation is voluntary and all information will be kept confidential and anonymous i.e. your name will not be used in the study or disclosed to anyone other than the researcher and the research supervisor. You are free to decline, withdraw or stop the questionnaire at any time, and your decision will not have any negative consequences on your treatment. There will be no costs incurred by you as a result of participation and there are no incentives or reimbursements for participation in the study. You may ask questions about the study at any point during your participation.

Please contact me at 0794842840/011933 9265 or Email: thusi.amanda6@gmail.com if you have any queries or the Biomedical Research Ethics Administration, Westville Campus, Govan Mbeki Building, Private Bag X54001, Durban 4000, KwaZulu-Natal, South Africa, Tel: 27 31 2604769- Fax: 27 31 2604609, Email: BREC@ukzn.ac.za

Thank You



Miss A. Thusi



Ms Jessica Paken (Research Supervisor)

Tel: 031 260 7548, Email: pakenj@ukzn.ac.za

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Discipline of Audiology

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Founding Campuses:  Edgewood  Howard College  Medical School  Pietermaritzburg  Westville

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Appendix E2- Information document in IsiZulu



**COLLEGE OF
HEALTH SCIENCES**

ISIHLOKO SOCWANINGO: IZINKINGA NEZIKHALAZO ZESIMO YEMPILO EZIDALWA INKINGA YOKUZWA KUBANTU ABADALA ABANESIFO iMDR-TB

Mina, uAmanda Thusi, ngiyiAudilogist esbhedlela iChris Hani Baragwanath ngizocela ukukumema ukuthi ube ingxenywa locwaningo lami. Lolucwaningo lizozama ukubheka zonke izinkinga nezikhalazo ezibhekene nomuntu onenkinga yokuzwa kanye neMDR-TB.

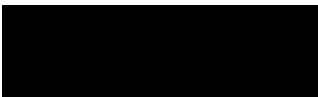
Lolulwazi luzosiza isifundazwe sezempilo njengoba luzoveza zonke lezinkinga kanye nokuthi impilo yomuntu itintheke kanjani uma esenenkinga yokuzwa kanye nesifo seMDR-TB. Ngiyethemba ukuthi lolulwazi luzosiza ekutheni kwenziwe kangcono ukwelashwa kwesifo seMDR-TB kuhambiselane nezidingo zeziguli. Ngiyacela ukukumema ukuthi ube ingxenywa yalolu cwaningo uphendule yonke imibuzo ngokwamandla akho. Izimpendulo zakho zizo qophwa.Imibuzo izothatha isikhathi esingangemizuzu engu 20-30 ukuqeda.

Ngicela ukukwazisa ukuthi imvumo yakho ayiphothiwe futhi imininingwane yakho izoba imfihle ayizokwaziswa kumphakathi, izokwaziwa ngami nomphathi wami kuphela. Unalo ilungelo lokunqaba,ilungelo lokuyeka noma usuqalile. Isinqumo sakho angeke sibe nesithelelo kukwelashwa kwakho. Azikho izimali ezidingeka ukuthi ube ingxenywa futhi azikho izimali ozozithola ngoba ingxenywa. Khululeka ukuba imibuzi ngocwaningo nganoma isiphi isikhathi.

Ngicela ungithinte kulenombolo 0794842840/0119339265 noma uthumele imeyili ku: thusi.amanda6@gmail.com. Uma unezikhalazo thumela imeyili kwa Biomedical Research Ethics Administration, Westville Campus, Govan Mbeki Building, Private Bag X54001, Durban 4000, KwaZulu-Natal, South Africa, Inombolo: 27 31 2604769- iFax: 27 31 2604609

Imeyili: BREC@ukzn.ac.za

Ngiyabonga



Ms A. Thusi

Ms Jessica Paken

Umpathi wocwaningo

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Founding Campuses: Edgewood Howard College Medical School Pietermaritzburg Westville

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TITLE OF RESEARCH PROJECT: THE PSYCHOSOCIAL IMPACT OF HEARING LOSS ON THE QUALITY OF LIFE OF ADULTS WITH MULTIDRUG RESISTANT TUBERCULOSIS.

I _____ (print name) voluntarily consent to participate in the research study. I acknowledge and have read all the information provided. I have had the opportunity to ask questions about the research and all my questions have been answered to my satisfaction.

I understand that I can withdraw from the study at any time. I have been assured that any information revealed to the researcher will be kept strictly confidential and anonymous. I understand that in the event of refusal/withdrawal of participation, I will not incur any penalty or loss of treatment. I understand that no costs will be incurred by me as a result of participation. I understand that there are no incentives or reimbursements for participation in the study.

I understand the purpose and procedures of the study.

I am aware that the results of this research may be used for educational purposes.

I am aware that I will be audio recorded.

I hereby agree to participate in this Research Project and give permission to be audio recorded.

Signature of participant _____ Witness: _____

Place _____

Date _____

If you have questions or concerns about my rights as a study participant, or if you are concerned about an aspect of the study or the researchers, then please contact me at 0794842840/011933 9265 or Email: thusi.amanda6@gmail.com if you have any queries or the Biomedical Research Ethics Administration, Westville Campus, Govan Mbeki Building, Private Bag X54001, Durban 4000, KwaZulu-Natal, South Africa, Tel: 27 31 2604769- Fax: 27 31 2604609, Email: BREC@ukzn.ac.za

Thank You



Miss A. Thusi

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Founding Campuses: Edgewood Howard College Medical School Pietermaritzburg Westville

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Appendix F2- Consent Form in isiZulu



**COLLEGE OF
HEALTH SCIENCES**

ISIHLOKO SOCWANINGO: IZINKINGA NEZIKHALAZO ZESIMO YEMPILO

EZIDALWA INKINGA YOKUZWA KUBANTU ABADALA ABANESIFO iMDR-TB

Mina _____ (bhala igama) Ngiyavuma ukuba ingxenya yocwaningo. Sengifundile yonke imininingwane nolwazi enginikezwe lona. Ngiyavuma ukuba umhlanganyeli. Benginikeziwe ithuba lokubuza imibuzo futhi imibuzo yami iphenduliwe ngokwaneliseka.

Ngiyaqonda ukuthi ngingayeka ukuba umhlanganyeli nganoma isiphi isikhathi uma ngifisa kube njalo. Ngiqinisekile ukuthi yonke imininingwane ezonikezwa umethuli wocwaningi ayizokwaziswa kumphakathi. Ngiyaqonda ukuthi uma ngikhethe ukuyeka ukuba umhlanganyeli, angeke kube nomthelelo omubi kumina nokulashwa kwami. Ngiyaqonda ukuthi azikho izindleko zemali engizobhekana nazo ngokuba umhlanganyeli. Ngiyaqonda ukuthi azikho izipho noma isibuyelwano semali engizokuthola ngokuba umhlanganyeli.

Ngiyazi ukuthi lolucwaningo lwenziwelani nokuthi lumayelana nanim.

Ngiyazi ukuthi imiphumela yalolucwaningo ingasebenziswa mayelana nokwezifundo.

Ngiyazi ukuthi izimpendulo zami zizoqophwa

Ngiyavuma ukuba ingxenya yalolucwaningo futhi ngiyavuma ukuthi ngiqophwe

Isignesha yakho _____ Ufakazi: _____

Indawo _____

Usuku _____

Uma unemibuzo noma isikhalazo ngamalungelo akho kulolucwaningo noma nezikhalazo ngalo ucwaningo ngicela ungishayeke kulombolo 0794842840 noma uthumele imeyili ku: thusi.amanda6@gmail.com noma Biomedical Research Ethics Administration, Westville Campus, Govan Mbeki Building, Private Bag X54001, Durban 4000, KwaZulu-Natal, South Africa, Inombolo: 27 31 2604769- Fax: 27 31 2604609, Imeyili: BREC@ukzn.ac.za

Ngiyabonga



Ms A. Thusi

Ms Jessica Paken

Umpthathi wocwaningo

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Appendix G1- Pilot Study Survey English



**COLLEGE OF
HEALTH SCIENCES**

TITLE OF RESEARCH PROJECT: THE PSYCHOSOCIAL IMPACT OF HEARING LOSS ON THE QUALITY OF LIFE OF ADULTS WITH MULTIDRUG RESISTANT TUBERCULOSIS.

Pilot Study Survey

Thank you for participating in the research pilot study. The pilot study is not the main study and was conducted to identify any possible problems of the study, to develop and test the research instrument, and to assess whether the research protocol is realistic and workable. This information will allow the researcher to make changes to the main study as appropriate.

Kindly answer the following questions to the best of your ability:

1. How long did the interview take?

2. Did you find the length of the interview to be a reasonable time?

3. Were the questions clear?

4. Which questions were unclear?

5. Did you understand all the questions?

6. Which questions did you not understand?

7. Are there any questions you think should be added to the interview?

Please contact me at 0794842840/011933 9265 or Email: thusi.amanda6@gmail.com if you have any queries or the Biomedical Research Ethics Administration, Westville Campus, Govan Mbeki Building, Private Bag X54001, Durban 4000, KwaZulu-Natal, South Africa

Tel: 27 31 2604769- Fax: 27 31 2604609

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Thank You



Miss A. Thusi



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Appendix G2- Pilot Study Survey IsiZulu



**COLLEGE OF
HEALTH SCIENCES**

ISIHLOKO SOCWANINGO: IZINKINGA NEZIKHALAZO ZESIMO YEMPILO EZIDALWA INKINGA YOKUZWA KUBANTU ABADALA ABANESIFO iMDR-TB

Imibuzo ngokuhlolwa kwocwaningo

Ngiyabonga ukuthi ube umhlanganyeli wokuhlola ucwaningo oluzokwenzeka. Lokhu sikwenza ukubona izinkinga okungenzeka sibhekane nazo uma sekwenziwa ucwaningo nokubona ukuthi luhleleke ngendlela efanele na. Lolu lwazi luzosiza ekutheni umhloli abone ukuthi ucwaningo luhlelwe kahle na ukuze kwenziwe ushintsho uma ludingeka.

Ngicela uphendule ngokuzama nokuzimisela

1. Inkulumoluhlolo ithathe isikhathi esingakanani?

2. Ubone sengathi isikhathe besanele noma besisinde kakhulu?

3. Imibuzo ibicacile?

4. Iyiphi imibuzo ebingacacile?

5. Ubuyiqonda yonke imibuzo?

6. Iyiphi imibuzo obungayiqondi?

7. Ikhona imibuzo ocabanga ukuthi bekumele engabe ibuziwe?

Ngicela ungithinte kule nombolo 0794842840/011933 9265 noma thumela imeyli:
thusi.amanda6@gmail.com uma unezikhalazo noma imibuzo noma thinta Biomedical Research Ethics
Administration, Westville Campus, Govan Mbeki Building, Private Bag X54001, Durban 4000,
KwaZulu-Natal, South Africa

Inombolo: 27 31 2604769- Fax: 27 31 2604609

Imeyili: BREC@ukzn.ac.za

Ngyabonga



Miss A. Thusi

Ms Jessica Paken

Umphathi wocwaningo

Inombolo: 031 260 7548

Imeyili: pakenj@ukzn.ac.za

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INSPIRING GREATNESS

Appendix H- Online research ethics course certificates



Zertifikat Certificat

Certificado Certificate

Promouvoir les plus hauts standards éthiques dans la protection des participants à la recherche biomédicale
Promoting the highest ethical standards in the protection of biomedical research participants



Certificat de formation - Training Certificate

Ce document atteste que - this document certifies that

Amanda Thusi

a complété avec succès - has successfully completed

Introduction to Research Ethics

du programme de formation TRREE en évaluation éthique de la recherche
of the TRREE training programme in research ethics evaluation

July 24, 2018
CID : NSUJHKA3



Professeur Dominique Sprumont
Coordonnateur TRREE Coordinator



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Programme de Formation Continue (5 Crédits)



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Zertifikat Certificat

Certificado Certificate

Promouvoir les plus hauts standards éthiques dans la protection des participants à la recherche biomédicale
Promoting the highest ethical standards in the protection of biomedical research participants



Certificat de formation - Training Certificate

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South Africa

du programme de formation TRREE en évaluation éthique de la recherche
of the TRREE training programme in research ethics evaluation

October 23, 2018
CID : NSUJHKA3



Professeur Dominique Sprumont
Coordonnateur TRREE Coordinator



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