# PERCEPTIONS OF ADULT AURAL REHABILITATION SERVICES FOR A PATIENT WITH AN ACQUIRED HEARING LOSS POST MULTIDRUG-RESISTANT

### **TUBERCULOSIS (MDR-TB) TREATMENT:**

### **A CASE STUDY**

BY

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# SUBMITTED IN PARTIAL FULFILMENT OF THE REQUIREMENTS FOR THE DEGREE OF

## MASTER OF COMMUNICATION PATHOLOGY (AUDIOLOGY)

### THE DISCIPLINE OF AUDIOLOGY

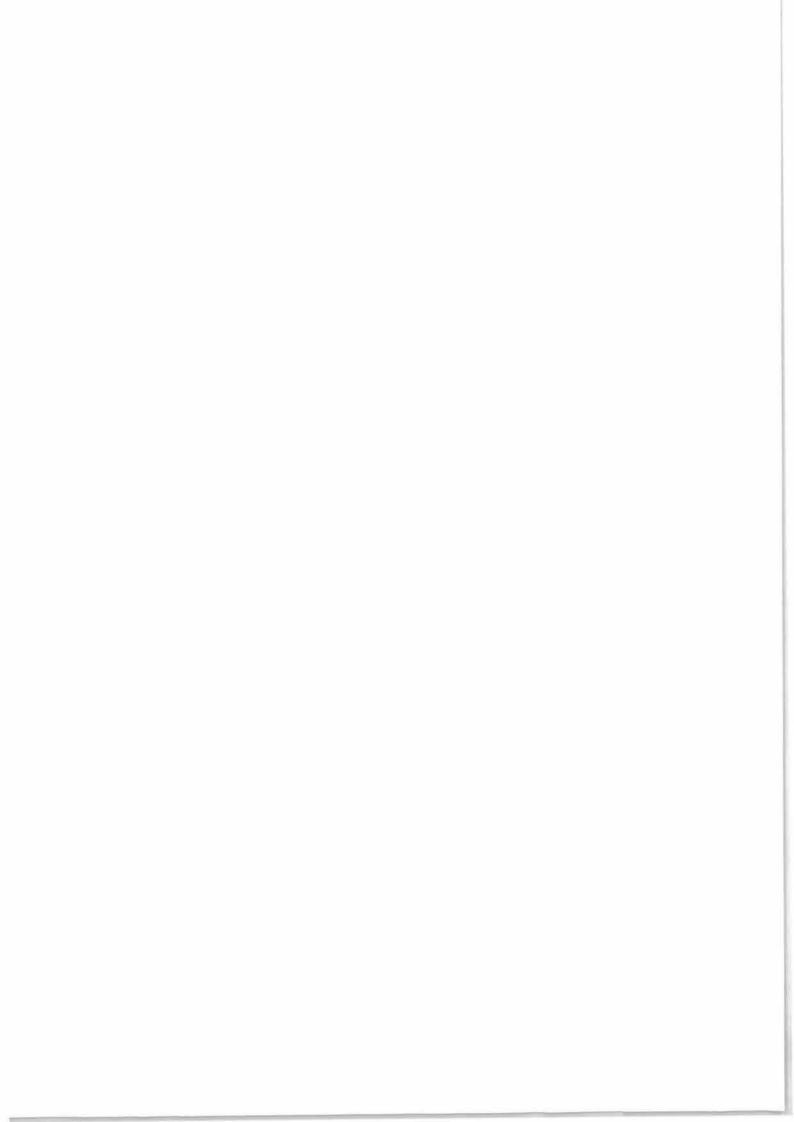
### SCHOOL OF HEALTH SCIENCES

### **COLLEGE OF HEALTH SCIENCES**

### UNIVERSITY OF KWAZULU-NATAL

### WESTVILLE CAMPUS

#### **NOVEMBER 2020**



### DECLARATION

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Perceptions of adult aural rehabilitation services for a patient with an acquired hearing loss post multidrug-resistant tuberculosis (MDR-TB) treatment: A case study

Represents my original work in conception and execution. The explorative study performed for this dissertation was under the guidance and supervision of Mrs. Zandile Shezi.

The study is the work of the author and has not been submitted in any form to another tertiary institution.

Signed:	

Date: 30/11/2020

### ACKNOWLEDGEMENTS

From the bottom of my heart, I would like to thank the following people for assisting me in the completion of this project:

- To God, for everything He has done to make my dream a reality
- To my parents, Authar Brijlal and Vasanthie Brijlal, my sister Natasha Brijlal and my brother Nilesh Brijlal, for your motivation and support
- To my research supervisor, Mrs. Zandile Shezi, for understanding my passion behind this project and for her continued guidance and support
- To Thulani Dube, Khayelihle Dlamini, Ntombentsha Maphanga, Sihle Meyiwa and Veronica Chamane, for assisting me with my transcriptions and translations

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#### ABSTRACT

Background: There is a problem regarding the provision and accessibility of aural rehabilitation (AR) in South Africa (SA). Statistics suggest a discrepancy between number of audiologists in relation to number of patients who present with an acquired hearing loss post multidrug-resistant tuberculosis (MDR-TB) treatment requiring AR services. Although there is evidence of patients receiving some form of AR, a gap in literature regarding the extent to which AR is provided post hearing aid fitting exists. Therefore, the objective of the study was to explore the perceptions of a single participant who had an acquired hearing loss post MDR-TB treatment towards adult AR services.

Method: The participant, a 41-year-old female, was randomly selected from King Dinuzulu Hospital Complex (KDHC) based on the study's inclusion and exclusion criteria. As a result of MDR-TB treatment, she presented with a severe to profound hearing loss bilaterally and received hearing aids. A qualitative case study was adopted via a face to face semi-structured interview, using an interview schedule and audio recorder. Three interviews were conducted in total, with a duration of 8 hours 30 minutes. Data analysis was facilitated via thematic analysis.

Results: The study's findings found that adult AR appears to be currently not facilitated at KDHC, especially for patients with hearing loss post MDR-TB treatment. The absence of intervention beyond hearing aid fittings contributed to the participant's lack of awareness regarding AR services. Although there was willingness to participate in AR, challenges were evident, such as transport constraints, communication partner nonattendance and health issues. Perceptions of adult AR services were established as helpful by the participant in assisting with better communication.

Conclusion: There is a need for the provision of AR for patients with an acquired hearing loss post MDR-TB in SA. The lack of literature pertaining to AR service provision in SA is highlighted. It is hoped that by more audiologists being involved in providing AR services, more patients become aware of such services and therefore interested to participate. Study implications and recommendations are discussed.

<sup>•</sup>Keywords: ototoxic management, multidrug-resistant tuberculosis, adult aural rehabilitation, hearing loss, multidisciplinary team, audiologist, public health care

### 1.1 Abbreviations:

ADL: Activities of Daily Living

AR: Aural Rehabilitation

BDQ: Bedaquiline

CI: Cochlear Implant

**CPD:** Continuing Professional Development

EBP: Evidence-Based Practice

FM: Frequency Modulation

HPCSA: Health Professions Council of South Africa

ICF: International Classification of Functioning, Disability and Health

KDHC: King Dinuzulu Hospital Complex

KZN: KwaZulu-Natal

MDR-TB: Multidrug-Resistant Tuberculosis

MDT: Multidisciplinary Team

NAL-NL1: National Acoustic Laboratories', Non-linear Fitting Procedure, Version 1

QoL: Quality of Life

**RR-TB:** Rifampicin-Resistant Tuberculosis

SA: South Africa

SASL: South African Sign Language

TB: Tuberculosis

WHO: World Health Organization

XDR-TB: Extensively Drug-Resistant Tuberculosis

### **Chapter 1. Introduction**

### **1.2 Introduction**

Ototoxic hearing loss is inner ear damage that is caused by drugs that result in hearing impairment (Khoza-Shangase & Stirk, 2016), the prevalence of adults affected globally being unknown due to variability among studies (Graydon, Waterworth, Miller, & Gunasekera, 2019). Those who suffer from the condition may require interventions, which for an adult patient generally entails amplification and orientation to a device that improves their ability to hear. However, aspects of the rehabilitative process, such as the participation in adult aural rehabilitation (AR) services, are often under-researched in the context of ototoxicity. According to Gagné and Jennings (2000), while AR often only focuses on prescription and hearing aid fitting, it needs to expand far beyond that. This is particularly the case in the South African (SA) context, where multidrug-resistant tuberculosis (MDR-TB) is still an epidemic, its treatment being one of the causes of hearing loss in affected adults. The current study focused on the perception of an adult patient with an acquired hearing loss post MDR-TB treatment regarding the AR services they received. This chapter focuses on the use of adult AR and various factors that may affect the successful delivery and participation of such services. It provides a background to the study, details the terminology and associated definitions used in this research and outlines the chapter structure of the study.

### 1.3 Study background

MDR-TB is defined as a type of tuberculosis (TB) that is resistant to the standard firstline treatments antibiotics of rifampin and isoniazid (Bastos, Hussain, Weyer, Garcia-Garcia, Leimane, Leung, Narita, Penã, Ponce-de-Leon, Seung, Shean, Sifuentes-Osornio, Van der Walt, Van der Werf, Yew, & Menzies, 2014). According to Shin, Alcantara, and Fanner (2008), under such circumstances, the second line of treatment is then utilized to combat the resistance and treat the patient. Verma and Mahajan (2007) state that it is the second-line treatment of MDR-TB that result in ototoxicity. Prior to 2015, these antibiotics were used to treat MDR-TB as the first-line defence, but due to it being ototoxic in nature and causing hearing loss, this was changed to the second-line option, In 2015, there was a change in policy that resulted in bedaquiline (BDQ) being regarded as the first-line drug due to its greater efficacy and fewer side effects in the MDR-TB treatment regime in SA (Jones, Mudaly, Voget, Naledi, Maartens, & Cohen, 2019). The National Department of Health then transitioned patients with MDR-TB onto the new drug by 2018 (South African Government News Agency, 2018). According to Cox, Furin, Frick and Lessem (2018), 1 016 patients received BDQcontaining treatment regimens between 2014 and 2016, and since then approximately 15 000 patients with rifampicin-resistant TB (RR-TB) were reported to have received or presently receiving BDQ by 2018 (South African Department of Health, 2018). BDQ has since been the preferred choice of treatment as it prevents hearing impairment (TB CAB, 2018) compared to the injectable drugs previously used to treat MDR-TB, which caused hearing impairment for approximately 50% of patients with MDR-TB (Cox, Reuter, Furin, & Seddon, 2017). However, despite now using the new first-line formulation BDQ, patients continue to present with hearing impairment as a result of having previously used the antibiotics.

Adult AR can be defined as "the reduction of hearing-loss-induced deficits of function, activity, participation, and quality of life through sensory management, instruction, perceptual training, and counselling" (Boothroyd, 2007, p. 63). Traditionally, adult hearing loss therapy has consisted of two areas: (a) aural training and (b) lip-reading (Alpiner, 1978). Over the years, however, more areas have been included to address the issues faced by patients accessing adult AR services. Boothroyd (2007) states that four components form the foundation of successful adult AR: counselling, perceptual training, sensory management and instruction.

Firstly, counselling focuses on the effect that impairment has on routine activities and function in participation, including quality of life (QoL) (Boothroyd, 2007). This principle is applicable to this study, where an acquired permanent hearing loss adversely affects a person's lifestyle. As hearing loss is regarded as a disability that is invisible and not considered equivalent to other disabilities by hearing individuals, it is difficult to understand what individuals with hearing loss experience (Boothroyd, 2007). Audiologists are responsible for explaining and validating the information related to the patient's audiological status and AR (Health Professions Council of South Africa (HPCSA) Audiological Management of Patients on Treatment That Includes Ototoxic Medications Guidelines, 2018). Therefore, counselling becomes important for not only the person with hearing loss, but for those with whom they associate, specifically their family members. Counselling can address the feelings associated with the presence of a hearing loss and its effects, and can aim to provide information and educate patients about the different ways hearing impairment and its effects can be minimized. Counselling, paired with perceptual training, can be implemented within an AR program.

Secondly, perceptual training refers to targeted activities such as improving perceptual skills (auditory and/or auditory-visual), especially skills required for perception of spoken language and aims to promote activity by enhancing the knowledge gained from their daily communication interactions (Boothroyd, 2007). For the current study, perceptual training addresses how activity can be facilitated using communication strategies learned as a result of a hearing loss. While activities facilitate improved communication interactions and aims to minimize such breakdowns, it needs to be conducted when sensory management has been implemented.

Thirdly, sensory management aims to improve auditory abilities (Boothroyd, 2007), with Makhoba and Joseph (2016) describing it as the provision of access to hearing through hearing devices. Hearing aids and other listening devices, such as cochlear implants (CI), assist with improved participation and function, for which AR is recommended. AR needs to be taken into consideration in order for the hearing impaired individuals to obtain the maximum benefit of amplification. Sensory management includes trying to overcome barriers after a hearing aid fitting, such as the individual's auditory environment and cognitive ability, which can be attributed to a poor correlation between hearing aid measurement and improved function, benefit and satisfaction (Boothroyd, 2007). Sensory management is not limited to hearing aids, and can include other auditory devices, such as CI, which may not be readily available in public hospitals in resource-constrained settings. In addition to sensory management, instruction also plays an important role in the successful delivery of AR services.

Fourthly, instruction promotes and improves the progressive results of sensory management (Boothroyd, 2007), and is useful for increasing positive outcomes for sensory management (Boothroyd, 2007). This information results in greater usage of the devices, with a resulting higher level of activity and function over time (Boothroyd, 2007). This principle becomes applicable to the study, as the focus is on adult AR.

According to the American Speech-Language-Hearing Association (ASHA) (2017), adult AR is defined as a service that helps individuals cope with living with a hearing impairment, and allows for the maximal use of hearing aids/assistive devices and conversational strategies for optimal communication (ASHA, 2017). Adult AR should comprise of educating the patient on their hearing loss, ensuring that their family understands the loss and providing support through groups (ASHA, 2017). In addition, orientation to the hearing aid or listening device, listening and conversational training strategies, utilization of visual cues and coping with background noise away from the home environment should also be implemented (ASHA, 2017). Arrangements that enable an optimal conversational setting and exercising of legal rights, such as accommodating hearing-impaired individuals in public places and at work, should also be a part of AR (ASHA, 2017). However, the success of an adult AR program needs to take into consideration other patient variables that are specific to their environment to foster the benefits of AR. There are many benefits to adult AR programs, such as higher self-confidence, increased communication abilities, an improved lifestyle, and a state of well-being (Spangler, Houston, & Bradham, 2015). Furthermore, the HPCSA Audiological Management of Patients on Treatment that Includes Ototoxic Medications Guidelines (2018) states that the multidisciplinary team (MDT) needs to set up the rehabilitation plan within a month post-diagnosis of a hearing loss. Therefore, with a time-frame of one month to establish rehabilitative services, the effects of coping with an acquired hearing loss, as well as the assistance required for dealing with a hearing impairment, can be implemented earlier than during this process.

For a patient who presented with normal hearing before the treatment of MDR-TB, these benefits are critical, as they enable them to return to improved communication interactions with family, friends and colleagues, and facilitate an overall improved QoL. However, there needs to be realistic expectations from the patients regarding amplification, with McCarthy (2017) indicating that creating communication goals for different communicative environments, adjustment counselling for amplification, and follow-up post-amplification should be included in the rehabilitation process. These guidelines are essential as a starting point when introducing the concept of AR to a patient who presents with an acquired hearing loss due to MDR-TB treatment. It facilitates the minimization of uncertainty, allows for adjustment to the hearing loss, and creates an opportunity for the patient to understand the effects of the hearing loss as well as the benefits of AR. Particularly for those patients who present with tinnitus, its management can be facilitated, thus making the AR relevant.

It is important to consider tinnitus management strategies in an AR plan, with Sweetrow (2013) stating the condition is a common problem and requires both audiologists and patients to come together to decide on a treatment approach. Ototoxic medication, such as aminoglycosides (Schellack & Naude, 2013) used to treat MDR-TB, can result in tinnitus (Wium & Gerber, 2016). Although its severity differs, affected patients indicate changes in lifestyle (Schlee, Hall, Canlon, Cima, de Kleine, Hauck, Huber, Gallus, Kleinjung, Kypraios, Langguth, Lopez-Escamez, Lugo, Meyer, Mielczarek, Norena, Pfiffner, Pryss, Reichert, Requena, Schecklmann, van Dijk, van de Heyning, Weisz, & Cederroth, 2018). In more severe tinnitus, mental disorders and signs of sleeplessness, depression, lack of concentration and anxiety can harm the life quality (Schlee et al., 2018), which results in patients either taking sick leave or receiving a disability income (Friberg, Jansson, Mittendorfer-Rutz, Rosenhall, & Alexanderson, 2012). Therefore, tinnitus management strategies in an AR program are essential, with the inclusion of psychological support being important for patients who present with an acquired hearing loss.

The psychological support aspect is essential in any successful AR plan, and should be the ultimate goal and basis for any intervention. A study by Yang, Park, Jang, Yang, Kim, Moon, Byun, Lee, Kim and Kang (2017) investigated the treatment side effects for MDR-TB patients in South Korea. Of the 256 participants, 95 were detected to have various side effects to the MDR-TB medication, with 5.5% having a resultant psychiatric disorder (Yang et. al, 2017). Better Hearing (2017) also states that the consequences of a hearing loss that is left untreated can adversely affect development, health and cognition, and have psychological and social effects.

The New York Hearing Center (2018) discusses stages that patients experience when presented with a hearing loss as similar to the five stages of grief described by Elisabeth Kübler-Ross in 1969, i.e. denial, anger, bargaining, depression and acceptance. The stage of denial describes patients experiencing disbelief upon the life-altering diagnosis of a hearing loss. The anger stage presents the acknowledgement of a hearing loss accompanied by emotions such as anger and resentment. The bargaining stage describes patients feeling anxious, guilty and stressed that their loss of hearing is now permanent, and the tendency to bargain with others, God and themselves. The stage of depression is when the reality of the situation becomes apparent, and emotions of loneliness, sadness, loss of hope, lack of motivation and despair are felt. Acceptance is the final stage, where the patient does not experience the emotions from the previous stages and decides to get assistance and comply with suggestions regarding their hearing impairment. However, the five stages can sometimes follow different orders and have varying time frames, with some patients experiencing all stages, one stage only, a repetition of stages, or have simultaneous experiences (The New York Hearing Center, 2018). Therefore, providing psychological support and helping a person deal with the hearing loss first provides the stepping stone towards successful adult intervention. Particularly with the five stages experienced as a result of hearing impairment, audiologists must tailor each AR program to consider where the patient is emotionally. This will help to overcome the emotional challenges and enable them to deal with their hearing loss better, adhere to the program and feel more motivated with regards to participation in such services. For this attainment comes the responsibility regarding the roles that patients should play.

Patients have a role to play in the successful delivery of rehabilitative services posthearing aid fitting. Some patients do not regularly visit their audiologists for follow-up auditory training sessions and may even find other hearing aid related issues inconvenient, such as getting new batteries (Loavenbruck & Madell, 1981). These findings indicate that patients assume that they do not require follow-up services following a hearing aid fitting, with the contributing factors related to their participation in the AR program being unknown. Therefore, particularly for patients post MDR-TB treatment, the current study explored the possible contributing factors that are associated with accessing an AR program. Schum (2009) also states that patients have different personalities, which also indicated by Garstecki and Erler (1998), who conducted a study on the impact of device control, demographic factors and hearing loss on older adults' utilization of hearing aids. Older adults accepting of hearing professionals' advice on acquiring hearing aids and using them were referred to as adherents, and those who chose to ignore the advice were termed non-adherents. The study reported differences between the adherence groups as well as actions based on gender. For example, female adherents portrayed less depressive tendencies and greater ego strength compared to female non-adherents. Male adherents had less stigmatization of hearing aids and a greater acceptance of hearing impairment than females (Garstecki & Erler, 1998). Therefore, if patients' personalities are taken into consideration when planning an AR program, the success rate of the program, in terms of patient commitment, is likely to improve. This requires a collaboration between the audiologist and the patient to set individualized goals together.

The setting of goals is especially important for patients post MDR- TB treatment, where their QoL has been drastically affected as a result of the side effects of ototoxic medication, which include tinnitus, volatility, difficulty with recognizing speech in the presence of background noise, and a hearing loss that is permanent and sensorineural (Wium & Gerber, 2016). According to Hearing and Speech-Language Services (HASA) (2019), adult AR is aimed at assisting people adjust to hearing impairment. AR goals include patient education on biological factors related to hearing impairment, managing hearing impairment, communication and auditory skill development, and decreasing the hindrance and segregation experienced as a result of hearing loss (HASA, 2019). The current study aimed to ascertain the patients' awareness and knowledge of the aforementioned goals post MDR-TB treatment in an AR program to determine their perceptions towards participating in adult AR services.

According to Petersen and Rogers (2015), ideal therapy for patients post MDR-TB treatment commences post-discharge from hospital ie. after in-patient admission for the management of cochleotoxicity, with audiologists offering services such as counselling, fitting hearing aids and providing communication strategies. Figure 1 represents a flowchart of the ideal management of a patient with cochleotoxicity (Petersen & Rogers, 2015, p. 81).

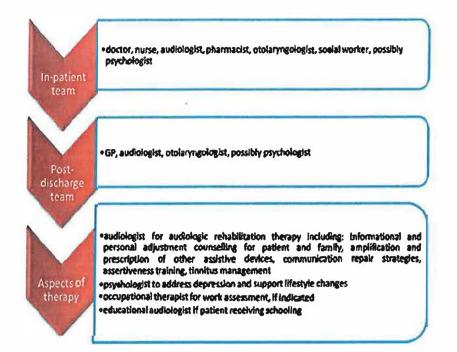


Figure 1. Idealised scheme of professionals and services required for the management of a patient with cochleotoxicity (Petersen & Rogers, 2016, p. 81)

Audiologists are also expected to ensure that proper rehabilitation services are provided for patients with hearing impairments that are disabling and ototoxic (HPCSA Audiological Management of Patients on Treatment that Includes Ototoxic Medications Guidelines, 2018). Some form of AR is should be received in the form of hearing aid orientation, as its inclusion at that stage allows for the audiologist to provide a more personalized, patient-focused perspective on amplification (Duldulao & Ramsey, 2013). This could increase patients' hearing aid use and appreciation (Duldulao & Ramsey, 2013), and provide them with an acquired hearing loss post MDR-TB treatment to better deal with their misfortune and achieve a more optimum QoL. However, there are other facets, such as auditory training and sound therapy (ASHA, 2020), which can contribute to a more successful therapy outcome. The availability of such services is limited for patients in the SA context who seek health care from the public sector (Pienaar, Stearn, & Swanepoel, 2010). The problem related to the access of AR services arises when there is a lack of awareness or availability of AR services, which could further impact on why patients are less likely to seek or participate in such activities.

Many patients with an acquired hearing loss post MDR-TB treatment are not accessing the available adult AR services in SA. Although there is evidence of patients receiving some form of service, there is a gap in the literature regarding the extent to which they are provided with post hearing aid orientation. There seems to be no evidence specific to patients who acquired a permanent hearing loss post MDR-TB treatment in terms of accessing AR services, due to there being limited as well as imbalanced literature with regards to its provision in the SA context (Olusanya, 2004, as cited in Makhoba & Joseph, 2016). This could have been a contributory factor in terms of the inability of these patients to access AR services. Due to relevant limited literature locally (Olusanya, 2004, as cited in Makhoba & Joseph, 2016) and the paucity of justifiable reasons in research regarding the availability and accessibility of these services, research in this areas is needed. Within this context, there is limited research on patient's perceptions in the eThekwini Municipality of KwaZulu-Natal (KZN) Province regarding adult AR services post MDR-TB treatment in the public health sector.

Access to AR services is essential for patients post MDR-TB treatment, as hearing impairment due to ototoxicity is associated with a high-frequency hearing loss (Clason, 2017), which is irreversible and could lead to a hearing handicap due to speech frequencies being involved for some patients (Duggal & Sarkar, 2007). This reiterates the significant role played by AR services and further highlights why such services should be available, accessible and affordable. Such services address the inability to hear certain sounds, and the difficulty of discriminating between sounds in the presence of background noise, with can also be associated with high frequency hearing losses (Eyvazzadeh, 2020). Hearing aids are not always able to

provide adequate amplification for high frequencies and cannot always amplify high pitches adequately to be heard accurately (Boys Town National Research Hospital, 2020). Due to the nature of the hearing loss associated with MDR-TB treatment, hearing aids may therefore not be a viable solution. In this regard, CI assist moderate-profound hearing loss bilaterally where hearing aids do not provide enough benefit (Cochlear, 2019). They are also designed to retrieve sounds that are missed via clarity, which aids in better hearing and speech understanding (Cochlear, 2019). Therefore, CI are able to provide optimal amplification for high frequencies and offer improved speech discrimination ability.

Particularly for patients who present with severe to profound hearing impairment post MDR-TB treatment, CI may be the best sensory device for sensory management. According to the South African Cochlear Implant Group (2020) website, the devices are available in both the public and private sector across SA, with the exception of KZN Province, which does not have this program within the public sector. The absence of such a program further contributes to the limited intervention options available for patients with hearing loss post MDR-TB treatment. Considering the CI candidacy criteria, patients who receive CI should attend AR after the fitting. This is supported by research, that indicates that adults with CI have enhanced understanding in speech as well as sounds when making use of AR (UNC School of Medicine, 2020). Their availability and accessibility in the public sector could facilitate their inclusion within an AR program. Advocating for the start of more sustainable and economical AR services in the public sector, despite the evident resource restrictions (Pienaar et al., 2010), could assist in their provision. Thus, the need for AR services becomes just as important as the fitting of a listening device. Currently, there are various challenges regarding patients who have an acquired hearing loss post MDR-TB treatment receiving adult AR services. There is limited literature explicitly focusing on service availability and accessibility for adult patients with an ototoxic related hearing loss, especially in the SA context. Therefore, it is essential to consider adult AR in the context of ototoxicity to improve coping with their symptoms. The aim of the study was therefore to explore the perceptions of a patient who had an acquired hearing loss post MDR-TB treatment towards adult AR services in the SA public health sector. The implications for this gap and data not being available impacted on patients, audiologists and service delivery. Patients with an acquired hearing loss post MDR-TB treatment were not accessing adult AR services due to the unavailability of services and statistics suggested a discrepancy between the number of audiologists currently registered with HPCSA in relation to the number of patients who presented with an acquired hearing loss post MDR-TB treatment requiring AR services.

According to authors Makhoba and Joseph (2016), adults with hearing loss are amongst the main disabilities that occur worldwide. The management of hearing loss is by means of AR, although there is paucity of available literature in the SA context (Makhoba & Joseph, 2016). In SA, hearing loss in adults are caused by various factors, such as noise exposure, ototoxicity and HIV/AIDS, all of which cause damage to the hair cell (Khoza & Ross, 2002, as cited in Makhoba & Joseph, 2016). However, when considering the burden of disease, one of the most common illnesses of the SA population are as a result of HIV/AIDS. KZN presents with patients who have received MDR-TB treatment and due to the ototoxic nature of MDR-TB, there is an expectation of hearing loss. The literature review has provided information from various researchers regarding the topic being investigated, such as the current audiological assessment and management for ototoxicity in comparison to the universal guidelines for monitoring for patients with MDR-TB. Many researchers have also looked at the accessibility of AR services for adult patients, for example, tele-audiology and computer-based AR services. However, since literature has shown that AR is not accessible for adult patients in general, which is inclusive of adult patients who have acquired an ototoxic hearing loss as a result of MDR-TB medication, the current study was designed to explore what options are available specifically for an adult patient with a hearing loss post MDR-TB treatment. The aim of the study was to explore the perception of an adult patient with an acquired hearing loss post MDR-TB treatment towards adult AR services in the SA context. The main objectives of the study were to ascertain the willingness of the participant to participate in AR services and the factors that motivated or hindered participation.

#### 1.4 Terminology

The following terms and definitions apply for this study:

- Acquired hearing loss: A hearing loss that is acquired can be defined as a one occurring post birth that can take place at any time. An acquired hearing loss can be associated with injury, genetic influences or illness (ASHA, 2020).
- Assistive listening device (ALD): An assistive listening device or systems are amplifiers that assists in the transportation of sound to the ear. These devices separate background noise and speech, which enables the recipient to hear better. ALDs can assist individuals with mild to profound hearing impairments, and those who do or do not use hearing aids and CI. ALDs decreases the space between receiver and origination of sound, decreases background interference and supersedes poor acoustics. The types of ALDs include infrared, inductive loop tools and frequency modulation (FM) (National Association of the Deaf, 2020).

- Aural rehabilitation (AR): AR can be defined as perceptual training in audition and speech, sensory management and counselling for hearing impaired individuals, as well as their communication associates. The aim of AR includes lessening the effects of hearing loss on activities of daily living and communication (Jessen, 2015).
- Centralised Drug-Resistant (DR-TB) Units: There is a minimum of one specialized hospital per province for DR-RB in SA that supports as well as supervises the MDR-TB program for outpatients. The hospital also assists in technical advice for decentralised sites for MDR-TB (sub-district/district/provincial hospital) (Department of Health, 2019).
- Cochlear implants (CI): Can be defined as a complex, portable electronic device that assists with the sensation of sound for individuals who are severely hearing impaired or profoundly deaf. The implant has an external part that can be found at the back of the ear and a surgically implanted part underneath the skin. The implant is made up of a microphone (picks up environmental sound), speech processor (chooses and then organizes sounds from microphone), transmitter stimulator or transmitter receiver (coverts signals to electric impulses from speech processor) and electrode array (directs collected electric impulses produced by stimulator to different parts in auditory nerve). CI aid deaf individuals to understand speech, and while it provides a clearer depiction of environmental sounds, it does not return the individual's hearing to normal (National Institute on Deafness and Other Communication Disorders (NIDCD), 2017).
- Decentralised Drug-Resistant (DR-TB) Units: There are several health units in all nine SA provinces that are responsible for initiating and managing patients with DR-TB within a certain geographical area. Patients are initially admitted as inpatients and

when appropriate, become outpatients. Units may be made up of an entire hospital, a wards or a section in a hospital (sub-district/district/provincial hospital) (Department of Health, 2019).

- Extensively drug-resistant tuberculosis (XDR-TB): XDR-TB is defined as an uncommon category of MDR-TB. XDR-TB that is unresponsive to the drugs rifampin, isoniazid, any type of fluoroquinolone and a minimum of one of the injectables kanamycin, capreomycin or amikacin second-line treatments (Centers for Disease Control and Prevention (CDC), 2016).
- Hearing aids: Hearing aids can be defined as a portable electronic device that is worn either inside or behind the ear. A hearing aid amplifies sounds so that individuals' may listen and communicate better, and become more involved in activities of daily living (ADL) in noisy or quiet environments. A hearing aid is made up of a microphone (aids in the reception of sound), amplifier (receives sound waves converted into electrical signal from the microphone) and a speaker (receives amplified signals from the amplifier and sends to ear) (National Institute on Deafness and Other Communication Disorders (NIDCD), 2017).
- Multi-drug resistant tuberculosis (MDR-TB): MDR-TB is defined as a type of TB which is resistant to rifampicin as well as isoniazid, and does not respond to at least isoniazid and rifampicin, two of the strongest drugs used to treat TB (World Health Organization (WHO), 2018).
- Ototoxicity: Toxicity is defined as causing damage or being poisonous to the structure of the ear. Medically, ototoxicity denotes medications or substances that damage the ear's auditory nerve or vestibular system. Ototoxicity can be temporary or even

permanent, and the intensity may range from mild to severe. The symptoms of ototoxicity range from hearing impairment, tinnitus, poor coordination, unsteadiness when walking and dizziness (Stöppler, 2018).

- **Rifampicin-resistant tuberculosis (RR-TB):** RR-TB is defined as a type of TB that is resistant to rifampicin, which presents as MDR, XDR, mono-resistance or poly-resistance. RR-TB can be detected via phenotypic methods as well as genotypic methods, including or excluding the resistance to additional drugs for anti-TB (WHO, 2020).
- **Tinnitus:** Tinnitus is defined as the ringing or noises experienced in one/both ears. The cause of tinnitus is typically due to underlying conditions, for example, hearing loss due to age, ear injury or circulatory system problems. Tinnitus can sometimes improve as a result of treatment for the underlying conditions or treatment aimed at reducing or masking the noise, causing tinnitus to become less noticeable (Mayo Clinic, 2021).
- **Tuberculosis (TB):** TB is defined as a disease that originates from the air-borne bacteria known as Mycobacterium tuberculosis and most commonly affects the lung region. However, TB can be prevented and cured (WHO, 2020).

### **1.5 Chapter outlines**

The study is presented in the following chapters:

- **Chapter 2: Literature Review.** This chapter provides an in-depth literature review for the study, such as MDR-TB statistics, management of ototoxicity, components and benefits of adult AR services, and the different types of AR services that are available and could be implemented. The chapter also includes the theoretical and conceptual framework for the study.
- **Chapter 3: Methodology.** This chapter details the methods used to meet the Aims and Objectives of the study, namely the study area and population, sample, data collection tools, process and analysis methods. It outlines the study design, participant selection, sampling technique, data collection and data analysis and the ethical considerations taken into account to ensure data validity and reliability.
  - **Chapter 4: Results.** This chapter presents the results of the study with respect to the five Objectives: to determine the influence of an acquired hearing loss on QoL post MDR-TB treatment, to explore the awareness of participation in an adult AR program following the hearing aid orientation, to explore the willingness of an adult to participate in an adult AR program following the diagnosis of a permanent hearing loss, to explore the personal and environmental factors that influence the accessibility of adult AR services and to explore the perceptions regarding the availability and accessibility of the three groupings of services, i.e. audiological counselling services, sensory management and communication intervention (Makhoba and Joseph, 2016) for an adult with acquired

hearing loss post MDR-TB treatment. This chapter also provides the results for the study, which is described in an in-depth and detailed descriptive narrative.

- Chapter 5: Discussion. This chapter discusses the study findings in relation to studies conducted elsewhere and the significance of the findings with respect to the study objectives.
- **Chapter 6: Conclusion.** This chapter presents a summary of the study and addresses the extent to which the Aim and Objectives were met. The strengths, limitations, implications and recommendations of the study are discussed.

### **Chapter 2. Literature Review**

## **2.1 Introduction**

Patients with an acquired hearing loss post multidrug-resistant tuberculosis (MDR-TB) treatment are currently not accessing aural rehabilitation (AR) services in South Africa (SA), in KwaZulu-Natal (KZN) Province through the public health care sector, although KZN is still considered one of the provinces with the highest number of MDR-TB patients in the country (Loveday, Wallengren, Reddy, Besada, Brust, Voce, Desai, Ngozo, Radebe, Master, Padayatchi, & Daviaud, 2018). In most intervention programs, audiologists prefer to fit hearing aids, with the focus of AR to a lesser degree (Naidoo, 2006, Sweetrow & Palmer, 2005, as cited in Makhoba & Joseph, 2016). Therefore, the current study aimed to explore the perceptions of a patient with an acquired hearing loss post MDR-TB treatment towards adult AR as a service in KZN. Furthermore, study aimed to explore the awareness of adult AR services and willingness to participate in such intervention services. The current study focused on determining if AR could be a service that the patient would like to access, therefore indicating the need for audiologists to make them available. The current literature review also focusses on the need and benefits of AR services as well as factors that support their provision. This chapter centred around literature available in understanding any contributing factors to the limited or absence of adult AR service provision by audiologists in SA, factors that contribute to or influenced patients in participating in AR services, the relevance and role of audiologists in the multidisciplinary team (MDT) that works with individuals who present with TB and are on treatment, and the applicability of this strategy for practice in SA.

## 2.2. MDR-TB statistics and the number of audiologists in SA

Approximately 558 000 new patients were tested positive for MDR-TB in 2017 globally, with 139 000 of these initiating treatment for MDR-TB (World Health Organization (WHO), 2020). Prior to this, in 2010, WHO had estimated a 75 000 increase in new cases of MDR-TB in Africa alone (National Center for Biotechnology Information (NCBI), 2017). This estimation was disputed, as almost 60 000 annual cases of MDR-TB were reported in sub-Saharan Africa (SSA) in 2015 (Lukoye, Ssengooba, Musisi, Kasule, Cobelens, Joloba, & Gomez, 2015). Particularly in SA, 19613 patients were diagnosed with MDR-TB in 2015 with 12 527 of these beginning treatment for MDR-TB (Cox, Dickson-Hall, Jassat, Moshabela, Kielmann, Grant, Nicol, Black, Mlisana, Vanleeuw, & Loveday, 2017). The prevalence of a permanent sensorineural hearing loss for patients with MDR-TB in SA was reported as approximately 57%, with severity ranging from slight to profound hearing loss (Harris, Peer, & Fagan, 2012, Ramma & Ibekwe, 2012, as cited in Ramma, Nhokwara, & Rogers, 2019). The statistics reveal that a substantial number of people have been exposed to ototoxic medication thus making them vulnerable to hearing impairment. Considering the effect of MDR-TB treatment on hearing sensitivity, the critical role of audiologists as part of the MDT that contributes to the management of MDR-TB is indicated. However, the possibility of meeting this need is influenced by the number of audiologists available to assume this role.

With only 781 audiologists registered in SA, as reported by the Health Professions Council of South Africa (HPCSA) (HPCSA Publications, 2020), in relation to the number of people affected by MDR-TB treatment, the feasibility of effectively managing the medication effects on hearing is questionable. In addition, the recommended staff for a centralized drugresistant tuberculosis (TB) unit is 1 audiologist per 100-bed unit (Department of Health, 2019). For a decentralized drug-resistant TB unit, the recommended (part-time) staff is 1 audiologist for every 10-40 patients (Department of Health, 2019). Considering the number of registered audiologists compared to the number of people affected by MDR-TB and the audiological services needed, the practicality of providing individualized adult AR as a service for patients post MDR-TB is debateable. These statistics illustrate the reality of accessible audiological management services to patients affected by MDR-TB in the SA context. Therefore, the audiological management framework, in terms of recommendations for patients with MDR-TB at centralized and decentralized institutions, needs to be reviewed. In addition, the management of patients post MDR-TB treatment includes only a fraction of the overall number of those who audiologists would see over and above the other services they are expected to provide, which may place less focus on patients with MDR-TB when receiving optimal treatment, such as including AR services during intervention. Therefore, it is important to ascertain the current audiological assessment and management of patients with MDR-TB in the SA context.

# 2.3 Audiological assessment and management of ototoxic monitoring in patients with MDR-TB

It is important to understand the current assessment and management of ototoxicity in order to establish if AR is offered as a service and if so, to what extent, as its monitoring does not have any accepted universal procedure guidelines (Harris et al., 2012). Although there are guidelines available for ototoxic monitoring in SA, such as the HPCSA Audiological Management of Patients on Treatment that Includes Ototoxic Medications Guidelines (2018), not all guidelines are adhered to. This is further supported by a study by Govender and Paken (2015), which concluded that although audiologists in SA practice in ways allowing maximal utilization of resources so that high-quality health care can be provided, they do not always use evidence-based guidelines of practice, such as from the American Speech-Language-Hearing Association (ASHA) and the American Academy of Audiology (AAA). This requirement is needed for standard procedures of ototoxic treatment monitoring for patients post MDR-TB (Govender & Paken, 2015). Therefore, the HPCSA and the SA National Department of Health require the development of guidelines for appropriate monitoring of ototoxicity for audiologists to advance case management (Govender & Paken, 2015). This includes the delivery of audiological services that are standardized for patients who have MDR-TB nationally (Govender & Paken, 2015).

The identification of current ototoxic monitoring procedures and factors influencing the implementation of these procedures in SA hospitals is therefore essential (Khoza-Shangase & Stirk, 2016). If ototoxic management procedures are adhered to, patients presenting with associated hearing loss can receive assessment, management and intervention services timeously, which would not only assist with their treatment, but allow better control of their hearing impairment. While the literature also suggests that patients receiving ototoxic drugs need to have one or two sessions per week to monitor their audiological status (Khoza-Shangase & Stirk, 2016), this is currently not happening. A study by Khoza-Shangase & Stirk (2016), which investigated audiological testing with regard to ototoxic monitoring for adults who had TB in Gauteng Province, SA, state hospitals, found that the majority did not have medical interventions implemented following the identification of the condition. Medication readjustments occurred in instances where ototoxic monitoring did occur (i.e. 34% of the sample) (Khoza-Shangase & Stirk, 2016), the implications of this resulted in reduced early hearing loss identification.

The benefits of early identification give authority to medical practitioners to reduce and prevent hearing loss before the need for AR or alternative communication (Khoza-Shangase & Stirk, 2016). Additionally, recommendations such as other less ototoxic medication, terminating treatment that has ototoxic agents as well as altering dosage also assist in preventing hearing loss (Khoza-Shangase & Stirk, 2016). In cases where a patient indicates that they are experiencing aural fullness, tinnitus, reduced hearing or dizziness, ototoxic and audiological monitoring referrals need to be conducted (Khoza-Shangase & Stirk, 2016). Audiological assessments play an important role by identifying differences in hearing for frequencies affecting speech, so that the effect of hearing loss on communication can be reduced and alternate medication prescribed by should variations be noticed (Khoza-Shangase & Stirk, 2016). These suggestions would be made by the audiologists, which illustrates the need for them to be part of the MDT for such patients, as well as the critical need for monitoring to take place. This could reduce the effects of the hearing loss, as its severity could be minimized if monitoring was done and the necessary changes are implemented.

In addition, audiological monitoring becomes important for helping patients and their families to deal with the hearing loss (Khoza-Shangase & Stirk, 2016). This can include counselling, the introduction and maintenance of communication strategies, and the possibility of amplification after treatment has been completed (Khoza-Shangase & Stirk, 2016), which can help with the management of and coping with a hearing loss. At this stage, the concept of AR could be introduced and implemented if a need arose regardless of the severity of the hearing loss. Although audiological assessment and monitoring is vital and provides the foundation for AR intervention for patients with MDR-TB, this is not however a reality for the majority of the affected SA population. The above-mentioned study by Khoza-Shangase and Stirk (2016) found that one fifth of the state hospitals recruited for the study implemented a program for ototoxic monitoring. Therefore, the evident lack of implementation of such procedures by audiologists has an adverse effect on their scope for advocating their role in ototoxic monitoring programs and referrals.

Audiologists play an important role in both assessing and managing patients with MDR-TB. According to the HPCSA Audiological Management of Patients on Treatment that Includes Ototoxic Medications Guidelines (2018), the audiologist has a role to play in designing as well as implementing management programs for ototoxicity using frameworks of the International Classification of Functioning, Disability and Health (ICF) and Primary Healthcare, which includes patient rehabilitation. However, a study by Makhoba and Joseph (2016) found that most intervention services provided by audiologists in SA included 81.4% fitting of hearing aids, 69.8% training of communication strategies and 79.8% related to informational counselling. Other aspects of AR, such as informing family members on hearing loss and support groups (ASHA, 2017) are missing. These aspects could lead to decreased adherence in coping with hearing loss and in turn adherence to an AR program. Makhoba and Joseph (2016) indicate that some form of AR takes place for certain auditory pathologies in the SA context, with service provision for MDR-TB patients post treatment being unknown. It is important to determine AR service provision for MDR-TB patients post treatment and the contributing factors that influence their accessibility. AR service provision and accessibility for MDR-TB patients post treatment is linked to the inclusion of audiologists in the MDT that caters to these patients, and their critical role in assessment and management of the hearing loss.

# 2.4 Awareness of intervention services and the audiologists role in the MDT

There are many reasons as to why patients are unaware of AR services, a main one possibly being attributed to the deficiency in routine referrals to audiologists by other health professionals who should also be members of the MDT, such as medical doctors (Wium & Gerber, 2016). The effective role of audiologists in assessing and managing patients with MDR-TB is influenced by referrals to them from doctors, which does not always happen (Wium & Gerber, 2016). This could be attributed to time constraints, unawareness of potential ototoxicity of certain medications, as well as the unawareness of the referral pathway to audiologists or pharmacists (Wium & Gerber, 2016). This absence of referral begins with the exclusion of audiologists as part of the MDT that services patients with MDR-TB. This affects patient care standards and impacts on those patients who have the possibility of developing a hearing loss (Professional Board for Speech Language and Hearing Professions, 2015, as cited in Wium & Gerber, 2016). If patients with ototoxic hearing impairment are not referred to audiologists, they may never know the role of the audiologist or what AR services exist. This is despite audiologists being obliged by their scope of practice to play a role in assessing and managing patients who present with a hearing loss post MDR-TB treatment. Therefore, it is the audiologist's responsibility to plan as well as implement programs on auditory monitoring for ototoxicity (Govender & Paken, 2015).

According to the HPCSA Audiological Management of Patients on Treatment that Includes Ototoxic Medications Guidelines (2018), the team of professionals that collaborate during ototoxic management should include doctors, nurses, social workers, clinical psychologists, speech therapists, occupational therapists, pharmacists and physiotherapists. Although audiologists have a role to play regarding the designing and execution of programs for ototoxic monitoring (HPCSA Audiological Management of Patients on Treatment that Includes Ototoxic Medications Guidelines, 2018), they are not included as part of the management team. Additionally, a study by Ramma et al. (2019), which investigated patients with MDR-TB utilization of ototoxic monitoring in Western Cape, SA, found that outpatientbased services were more likely to improve with early identification of hearing loss and close monitoring. If audiologists are included as part of the team for ototoxic management at the beginning, patients hearing abilities can be monitored. If this happens, audiologists can detect changes in hearing at the beginning stages, such as a mild hearing loss, and advise doctors on the medications that need to be used for treatment. This would prevent a deterioration of hearing levels to severe and profound hearing impairment, or audiologists interacting with the patient only when they require a hearing aid. Therefore, the precautionary measures to reduce hearing loss by including audiologists in the MDT should have more emphasis than the treatment of a hearing loss when it extends to severe and profound levels.

Audiologists should therefore expand their roles to advocate for inclusion in the MDT in hospitals, where they should continue advocacy to create awareness among doctors on the importance of ototoxic screening and monitoring referrals (Wium & Gerber, 2016). A study by Makhoba and Joseph (2016), which investigated audiologists practices as well as views for adult patients with an acquired hearing impairment towards AR services, found that most audiologists in the study did not feel adequately trained in the majority of AR services. However, there was a high level of interest in AR generally (Makhoba & Joseph, 2016), which could mean that there is a chance for it to be implemented, if proper training and exposure to such services are facilitated. Audiologists should be given opportunities to expand their knowledge to be better equipped to expand their roles. There are also many implications when implementing AR services that need to be taken into consideration by audiologists. According to Hlayisi and Ramma (2019), these include the need to advocate in increasing the budget allocated for hearing devices and exploring in more affordable hearing devices or rehabilitation interventions in developing countries. If audiologists do not prioritize AR services in terms of budget and service provision, the treatment of patients with an acquired hearing loss could end after the fitting of and orientation to hearing devices. This could lead to patients being unaware of such services being offered, which could result in their not participate in AR services.

#### 2.5 Challenges providing AR services in SA

According to Statistics South Africa General Household Survey (2018), 71.5% of SA households accessed public health care facilities, with 27.1% using private health care and 0.7% seeking treatment from traditional healers. However, there is limited literature about service provision of AR in the two sectors in SA (Makhoba and Joseph, 2016), which could be a result of how many audiologists are trained in AR, how many positions are available in the public/private sector or how many audiologists are willing to work in the public/private sector.

For patients with MDR-TB, the limited availability of AR services may be due to their not being given sufficient resources, including staffing posts, due to a perceived need to provide treatment for more pressing disease. Therefore, emphasis needs to be placed on audiological monitoring and interventions (Appana, Joseph, & Paken, 2016), which includes the areas of communication intervention, rehabilitation technology and counselling (Appana et al., 2016). Audiologists need to motivate for the provision of AR services through evidence-based practice (EBP), which delivers the MDT approach for clinical practice (Ferguson, Maidment, Henshaw, & Heffernan, 2019), this being the integration of clinical expertise that is independent, patient values, as well as preferences, together with the best evidence of clinical research that is available (Ferguson et al., 2019). Together with sound evidence in clinical research, EBP can assist with decision-making, including procedures in a clinical setting (Ferguson et al., 2019) and the rationale for AR services. The study by Makhoba and Joseph (2016) found many challenges regarding the provision of AR in the SA context. Although informational counselling, hearing aids and training in terms of communication strategies were the most frequent AR services delivered (Makhoba & Joseph, 2016), many challenges were also reported by audiologists. The challenges regarding AR service delivery included client compliance (28.57%), limited training, knowledge and skills (23.8%), language barriers (19.04%), unrealistic client expectations (9.52%), individual differences with clients (9.52%) and cost to clients (9.52%). Time constraints, lack of compliance and absence of reimbursement could be some of the contributing factors for infrequent AR provision of services (Jessen, 2015). Furthermore, undergraduate training, in frequency modulation (FM) systems and cochlear implants (CI), speechreading and auditory training, counselling, such as psychosocial adjustment and training for communication partners, were frequently also found to be a challenge for audiologists (Makhoba & Joseph, 2016).

It is evident that there are many challenges for audiologists in providing AR in SA, with non-compliance possibly also affecting treatment outcomes (Jin, Sklar, Min Sen Oh, & Chuen Li, 2008) if the full benefit of such services is not achieved. Limited training, knowledge and skills in AR could affect the outcome of therapy if audiologists do not undergo the training to assist the population that they serve. Language barriers have an adverse effect on the provision of healthcare (Ali & Watson, 2018) and therefore affects the outcome of therapy. Unrealistic client expectations may also pose difficulty for both audiologist and patient, as if these are not met, it could foster non- or sub-optimal compliance (Lateef, 2011). In addition, patient preferences differ, such as the inclusion in either individual, group therapy or support groups (McRae, 2013). What may work well for one patient may not be the same for another patient (McRae, 2013), which should be considered when providing AR services. With the high unemployment rate faced by SA citizens (27.32% in 2019) (Plecher, 2020), not many patients will be able to afford the costs associated with participating in AR, such as transport, access to resources or other forms of therapy, such as tele-audiology, which could also contribute to why some clients may not participate in AR services. However, there are also specific challenges related to the provision of AR services in SA.

The challenges regarding AR provision in SA included affordability, language barriers, limited resources, finances and time, and inadequate knowledge and skills on the audiologist's part (Makhoba & Joseph, 2016). While challenges surrounding language barriers, limited knowledge as well as skills have been discussed above, it is important to draw attention to affordability, limited resources, finances and time. With the increased burden of disease and unequal resource distribution also adding to the challenges in SA health care systems (Maphumulo & Bhengu, 2019), little can be done by audiologists alone. However, according to Breytenbach, Kritzinger and Soer (2015, p.1), "*in future, the South African Department of Health aims to purchase services from accredited private service providers. Successful private audiology practices can assist to address issues of access, equity and quality of health services*". This method could assist in increasing the likelihood of providing AR services for patients with an acquired hearing loss post MDR-TB treatment. However, there are also challenges in how patients access and receive AR services when they have acquired hearing impairment.

According to Makhoba and Joseph (2016), the possible challenges associated with patient participation in AR services included reduced motivation and compliance. According to Ginta (2016), a reduction in motivation (in general) could be related to depression, as well as struggling to coping with issues or having an experience that affects their self-confidence (Ginta, 2016). Due to these challenges, patients may not adhere to AR services and become non-compliant, which can be defined as a patient's lack of motivation in following treatment options related to a certain condition/diagnosis (Linton, 2017). A patient's intentional refusal may be caused by a number of factors, such as denial, cultural issues or ignoring advice given by the healthcare professional (Jones, 2016). Patient non-compliance with therapy due to costs associated with personal time or effort is therefore a challenge in providing services such as AR (Sweetrow & Sabes, 2010). Challenges such as reduced motivation and non-compliance from patients also impacts on the successful delivery of AR services, although it is important to consider other factors that are independent of those experienced by audiologists and patients, such as contextually relevant resources.

The majority of tools for AR have been developed in developed countries, namely the United Kingdom, United States of America or Australia, having been adapted for the SA context in the absence of relevant resources (Pascoe & Norman, 2011). Limited literature that discusses the challenges related to AR in SA (Makhoba & Joseph, 2016) in terms of service provision and accessibility may also affect delivery, such as the requirements for its successful implementation for patients post MDR-TB treatment. However, some restrictions in the provision of AR services may not be unique to patients post MDR-TB treatment in SA, as there appears to be a global shortage of skilled healthcare professionals, infrastructure and resources, resulting in hearing healthcare services not being available for many people in need (Swanepoel, Clark, Koekemoer, Hall, Krumm, Ferrari, McPherson, Olusanya, Mars, Russo, &

Bajaras, 2010). Therefore, in addition to the shortage of healthcare professionals, it also becomes important to understand the challenges with hearing aid fittings, counselling and AR to ascertain if these challenges can be overcome. Sooful (2006) described some of these challenges in the SA context:

- (a) Multilingualism, due to there being 11 official South African languages (Sooful, 2006), with South African Sign Language (SASL) still to be introduced as the 12<sup>th</sup> (LAW FOR ALL, 2020). This can cause a language barrier if the patient and audiologist do not speak the same language, and could affect AR in terms of not being able to communicate effectively at the time of consultation.
- (b) Cultural background, where some cultures may discard the idea of using hearing devices or participating in AR services (Amedofu, Awuah, Ocansey, Antwi, & Brobby, 2004, as cited in Sooful, 2006). As AR requires the use of hearing aids as a starting point, their non-acceptance in some cultures may adversely affect patients' uptake.
- (c) Limited interpreting services, where audiologists rely on client's relatives for interpretation, which could lead to misinterpretation, hence misunderstanding (Evans, 2001, Fisch, 2001 & Swartz, 1998, as cited in Sooful, 2006) being relayed during AR sessions, which defeats the purpose of the session if information is not conveyed correctly. If patients are unable to attend therapy sessions with a friend/family member, the difficulty in communication between audiologist and patient could increase, hence adversely affecting the facilitation of AR services.
- (d) Service centre locations, where audiologists are mainly based at local hospitals rather than community clinics (Sooful, 2006), which could disadvantage patients living far away. Therefore, patients requiring AR services may not be able to attend therapy sessions due to transportation and cost difficulties. Ramma et al. (2019) indicated that although MDR-TB outpatient-based services for ototoxic monitoring were mainly

centrally located (i.e. equal distance between patients from different areas accessing service), the services were still underutilized, therefore the location of service centres was not the problem. This means that while the services are made available, the reasons for their underutilization are unknown.

- (e) Literacy, where some patients cannot benefit from the written information that are provided with (Sooful, 2006). Some patients cannot read the information given to them due to their inability to read or not read in the language in which it is provided, which could affect the facilitation of AR.
- (g) Remembering information relayed during the fitting of hearing aids (Sooful, 2006), where only approximately 50% of information from healthcare providers is remembered by patients (Margolis, 2004). Certain conditions cause patients to forget 40%-80% of the information (Margolis, 2004) and from the information that is recalled, half is incorrect (Margolis, 2004). The patients' ability to remember can relate to patient factors, such as familiarity of information, understanding of diagnosis-related issues, anxiety and stress (Margolis, 2004). This could affect the ability of patients to maximize the use of their hearing aid, and their ability to absorb important information regarding hearing aid use or information distributed during AR intervention.

These factors make it essential that possible solutions in providing AR services in the SA context are explored.

# 2.6 Possible solutions for providing AR services in SA

2.6.1 Awareness of AR services and the various sectors that constitute AR

2.6.2 Technology-based adult AR services

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#### 2.6.1 Awareness of AR services and the associated sectors

While the use of hearing aid devices is most common for treating hearing loss (Victory, 2019), what needs to be understood is that these divides alone are not adequate to facilitate treatment of the effects of the hearing loss. Nonetheless, hearing aids are part of a comprehensive intervention program that can be designed to overcome or minimize the effects of the hearing loss on communication and quality of life (QoL). Following hearing aid selection and fitting is hearing aid orientation, and education, which includes aspects related to use, care and realistic expectations of the amplification device (ASHA, 2020). The use of hearing aids solely to repair communication difficulties is not always a solution (ASHA, 2020), with patients using them continuing to face challenges, such as difficulties with speech understanding (ASHA, 2020). Therefore, AR services become important as well as patients' awareness of the benefits of these services.

Various parts of an AR plan that should be taken into consideration, as it is different for each individual (Audiology and Hearing Centre of Cookeville and McMinnville, 2020). Furthermore, there are factors that can influence the participation of patients, such as identifying their knowledge, beliefs and values (Vahdat, Hamzehgardeshi, Hessam & Hamzehgardeshi, 2014). Therefore, the current study investigated patients' perceptions towards adult AR services, as it is evident that their participation is influenced by inherent factors. By taking patients interests into consideration and providing information on the different options available, such as individual or group therapy, or other facets such as increasing strategies for communication, accessories for hearing aids or maximizing the use of hearing aids (Audiology and Hearing Centre of Cookeville and McMinnville, 2020), they are more likely to adhere to or be interested in participating in an AR program.

## 2.6.2 Technology-based adult AR services

The technology based AR services available in SA are tele-audiology, computer-based AR, social media and e-platforms, each of which will be explored further.

## 2.6.2.1 Tele-audiology

Technology-based AR includes the use of tele-audiology, which can increase the delivery of hearing related health care, such as clinical care, service accessibility, costefficiency as well as sustainability (Swanepoel et al., 2010). Tele-audiology could also be a source of potential education or training for professionals in the field of audiology, paraprofessionals, hearing impaired adults, parents, auditory disorders screening, hearing loss diagnosis and services, such as interventions (Swanepoel et al., 2010). With the increase in global connectivity, audiological services can be provided using telehealth models (Swanepoel et al., 2010). This could increase not only the accessibility of AR services but the training for audiologists in the field of AR, especially in the form of audiology support groups. With limited literature available on utilizing tele-audiology in providing AR (Makhoba & Joseph, 2016), it becomes an area to explore regarding service delivery, as its need in SA. This is due to the high demand in comparison to capacity challenges faced in the country, as well as increasing audiologists skills regarding managing hearing-related conservation programs (Khoza-Shangase & Moroe, 2020).

While tele-audiology could be a platform in service delivery for these platforms (Khoza-Shangase & Moroe, 2020), various factors could hinder its implementation, such as licensing, certification, reimbursement, quality control and jurisdictional responsibility (Swanepoel et. al, 2010). Specific to the SA context, where the technology is relatively new (Makhoba and Joseph, 2016), and with the contact restrictions required due to the Covid-19 pandemic, it could be a means of providing AR services (Makhoba & Joseph, 2016). With many barriers affecting access to health care, such as entry into the health care system, geographic availability and cost of accessing of services, patients being able to trust and communicate with a health professional, and cultural competence of practitioners (Office of Disease Prevention and Health Promotion (ODPHP), 2020), tele-audiology could make AR services more accessible in a way that overcomes many obstacles. This is particularly relevant in the initial stages of AR, when patients have to frequently visit audiologists, who may be located at some distance, for which transport and the associated costs becomes an issue. Furthermore, the accessibility of health services can impact on patients physical, mental and social health overall, thereby affecting their life quality (ODPHP, 2020). The barriers to accessing health care can result in health needs that are not met, the inability to receive preventative care, care delays, preventable hospitalizations and financial costs (ODPHP, 2020). Therefore, alternative forms of AR, such as tele-audiology or other technology advanced therapy, such as computer-based AR, should be considered.

## 2.6.2.2 Computer-based AR

In a mixed methods study conducted by Henshaw, McCormack and Ferguson (2015), the motivation of adults with a mild hearing impairment to use rehabilitative technology was explored in the United Kingdom. The study used a phoneme discrimination software called Computer-Based Auditory Training (CBAT), a computer-based training program loaded onto a laptop (specifically for the use of the CBAT) for participants to use at home and participants were required to select characters with the misfit phoneme sounds. Test sessions assessed participants' performances on self-reported hearing, speech perception and cognition. Posttraining sessions included feedback questionnaires (divided into statements, descriptor words and open-ended questions) administered to participants during an interview in order to ascertain participants' opinions and usability and interest in the CBAT training software. The study results indicated that participants were eager to use CBAT, some intrinsic motivations towards its use being ease, interest and satisfaction of using the program, while some extrinsic motivations included participants wanting to improve their hearing status.

There is limited knowledge on the use and practical training of computer-based services in SA (Makhoba & Joseph, 2016) for the four more regular programs used in AR, i.e. listening and communication enhancement (LACE), computer-assisted tracking simulation (CATS), computer-assisted speech-perception testing and training at the sentence level (CASPERSent) and computer-assisted speech training (CAST) (Sweetrow & Sabes, 2007). Using a less common program, such as CBAT, may not be as promising in terms of its user-friendliness, affordability and training. However, CBAT could be a solution for patients who have a hearing loss and possess the necessary tools to access such a program, as it is a less time-consuming AR program on the audiologist's part, and more cost effective method of adult AR for patients in the public sector, and may be covered by private medical aids. The current study explored patients who were on MDR-TB treatment, with CBAT possibly allowing these patients to access therapy sessions from electronic devices, such as mobile phones and/or computers. Using an Android platform for mobile devices would support such interventions, as some of the benefits of Android phones included lower costs and communication, with 85% of smartphones being used globally (Gartner, 2015, as cited in Lopez, Costa, & Ferrari, 2016). In addition, 20-22 million SA citizens utilize smartphones, which is equivalent to a third of SA's population (O'Dea, 2020). Although computer AR interventions may not be feasible in SA at this stage, the use of interventions that are computer-based could provide a solution in optimizing service delivery in the country, with a current lack of literature on the topic (Makhoba & Joseph, 2016). These interventions could include the availability of social media and e-platforms as a means of providing AR services.

#### 2.6.2.3. Social media and e-platforms

Since the advancement of computer technology, social media (Vlaescu, Calbring, Lunner, & Andersson, 2015) and e-platforms (Choudhury, Dinger, & Fichera, 2017) have played a role with hearing aid and CI users. Especially when accessing services such as AR, hearing aid internet interventions have been beneficial in assisting hearing impaired individuals (Malmberg, Thorén, Öberg, Lunner, Andersson, & Kähäri, 2018). Services can be made available with the click of a button, which could remove some of the challenges faced by both audiologists and hearing impaired patients accessing them. According to Grobler and Dhai (2016), eight out of ten people who use the internet search for information on health. Choudhury et al. (2017) explored the utilization of the social media in hearing aid societies and found that users accessed social media for information on services, support, information distribution and advice. This could be adapted in terms of providing counselling and information on AR services. AR support groups could also be made available on such platforms, as internet social interactions could decrease social isolation in older adults who have a hearing loss (Simpson, Clarke, Šarkić, Smullen and Pereira, 2018). Therefore, participants would not only be able to receive AR services but also communicate with those in a similar predicament, thereby supporting each other and adhering to AR interventions.

A study by Vlaescu et al. (2015) investigated the usage of an e-platform as a form of rehabilitation for hearing impaired individuals. The aim was to establish the practicality of a web-based platform for life quality enhancement for individuals with tinnitus or hearing impairment. The results indicated that patients with psychological and hearing impairments benefitted from the utilization of an e-platform, with an increase in quality of life (QoL). The study indicated that an e-platform could be a viable option when implementing adult AR services in SA due to the fact that 36.54 million (Clement, 2020) of the population of 58 950 510 (Worldometer, 2020), using the internet, of which mobile internet consumers totalled 34.93 million (Clement, 2020). While the use of an e-platform is beneficial for patients accessing an alternate avenue of AR, it is unclear as to how many audiologists or patients would be willing or interested to participate in such services.

To conclude, there are many advantages and disadvantages of using social media and e-platforms as a form of therapy. The advantages include easy access to information, specifically for individuals living in remote areas or with physical limitations, convenience, affordability and providing an educational source for factors such as coping strategies (Cherry, 2020). Additionally, a study by Malmberg et al. (2018), which investigated the experiences of patients with hearing aids utilizing an AR program that was internet-based, found that participants had positive experiences and gained knowledge. The disadvantages include whether online therapy will be covered by certain health insurances, issues related to privacy or confidentiality, as well as ethical and legal concerns (Cherry, 2020).

# 2.7 Theoretical/Conceptual Framework

The current study is grounded/embedded on the International Classification of Functioning, Disability and Health (ICF) model which forms the theoretical framework of the study. This model relates to the following objectives of the study:

## **Table 1. Objectives**

Ob	ives o determine the influence of an acquired hearing loss on quality of life (QoL) post multidrug-resistant	
1	To determine the influence of an acquired hearing loss on quality of life (QoL) post multidrug-resistant (MDR-TB) treatment.	
2	To explore the awareness of participation in an adult aural rehabilitation (AR) program following the hearing aid orientation.	
3	To explore the willingness of an adult to participate in an adult AR program following the diagnosis of a permanent hearing loss	
4	To explore the personal and environmental factors that influence the accessibility of adult AR services	
5	To explore the perceptions regarding the availability and accessibility of the three groupings of services, i.e. audiological counselling services, sensory management and communication intervention (Makhoba and Joseph, 2016) for an adult with acquired hearing loss post MDR-TB treatment	

The ICF framework is used by the World Health Organization (WHO) in order to estimate health as well as disability for individuals and groups of individuals (WHO, 2018). According to the WHO (2001), the ICF is a classification system based on the health and functioning, and not just the disabilities of the human body.

The WHO recognises that the "*ICF puts the notions of 'health' and 'disability' in* a new light. It acknowledges that every human being can experience a decrement in health and thereby experience some disability. This is not something that happens to only a minority of humanity. ICF thus 'mainstreams' the experience of disability and recognises it as a universal human experience. By shifting the focus from cause to impact it places all health conditions on an equal footing allowing them to be compared using a common metric – the ruler of health and disability." (WHO, 2002, p. 3)

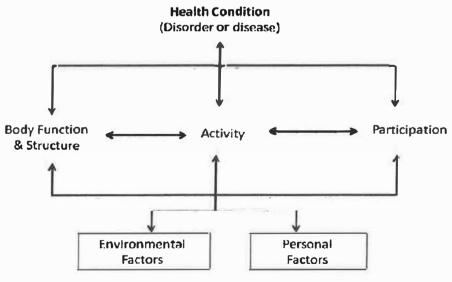
The aim of the ICF is to provide a clinical instrument for rehabilitation, assess needs and vocations, evaluate outcomes, and utilize treatments for specific health conditions (WHO, 2001). These aims are applicable to the current study, as it allows for patients who are deaf post MDR-TB treatment to receive appropriate rehabilitation, indicate how an acquired permanent hearing loss has affected their communication abilities, lifestyle and quality of life (QoL); as well as to evaluate the outcomes of aural rehabilitation (AR) services. Consequently, planning for rehabilitation requires consideration of various factors. The practice of determining deficits and relevant context is dependent on the audiologists and their experience. Hence a framework such as the ICF is useful to ensure consistency and to find that balance between participation and restrictions, or activities and limitations. The current study focused on adult clients who acquired a hearing loss post MDR-TB treatment and its effects/impact on participation and activities and the limitations. The use of the ICF in the current study highlights AR service provision and its influence on QoL. The principles of the ICF were incorporated in the Practice for Audiology scope in 2004 (Sharma, 2016), the intention being to motivate audiologists to implement this in rehabilitation development for hearing impaired adults (Sharma, 2016). The emphasis was to strategize outcomes of rehabilitation by

considering difficulties faced by the person under real-life circumstances (participation restrictions), personal limitations in task completion (activity limitation), including the person's physical and social environment (Sharma, 2016).

It is important to note that "Studies show that diagnosis alone does not predict service needs, length of hospitalization, level of care or functional outcomes. Nor is the presence of a disease or disorder an accurate predictor of receipt of disability benefits, work performance, return to work potential, or likelihood of social integration. This means that if we use a medical classification of diagnoses alone we will not have the information we need for health planning and management purposes. What we lack is data about levels of functioning and disability. ICF makes it possible to collect those vital data in a consistent and internationally comparable manner." (WHO, 2002, p. 5)

The ICF is a combination of two conceptual models of disability, these being the medical model and the social model (WHO, 2002). In the medical model, a disability is caused by a condition, trauma or disease, with interventions or treatments being required to address the problem. Disability is regarded as a socially constructed problem in the social model, and is defined by the limitations or deficiencies of a person, but regarded as being created by the attitudes and features of their unaccommodating social and physical environments (WHO, 2002). Both models have appropriate responses to the problems related to disability, their combination better reflecting different approaches to the complexities of disability and the health, which are affected by various components, such as physical, personal, social and environmental factors (WHO, 2002). However, a more functional use of the model to address disability is the biopsychosocial model, which forms the basis of the ICF (WHO, 2002). The

biopsychosocial model is a combination of both the medical model and social model and discusses the various aspects of health, such as biological, individual as well as social factors (WHO, 2002). This framework is referred to as the biopsychosocial model due to its consolidation of the medical, social and individual health perspectives (WHO, 2002). The purpose of the framework is to concentrate on well-being as well as functioning as opposed to disability and disease (Sharma, 2016). The emphasis of the ICF is on participation and function (Sharma, 2016). The ICF views disability and functioning as outcomes of the interaction between the disability condition and the contextual factors, which contends with both individual personal factors (age, gender, education, experiences, coping styles) and environmental factors (social structure and attitudes, living circumstances) (WHO, 2002). Three levels of human functioning, these being the affected body part (impairment) within the context of the whole persons, the resulting activity limitations and its implications for participation, both affect and are affected by the contextual and health condition (WHO, 2002). Figure 2 presents the ICF model of disability used in this study (WHO, 2002, p. 9).



**Contextual factors** 

Figure 2. ICF model of disability (WHO, 2002, p. 9)

The ICF states that an impairment to an anatomical or physiological structure can have an impact on how an individual executes certain activities and how they participate in certain actions (WHO, 2002). For the current study, the following table illustrates the components of the ICF and definitions that will be discussed in relation to the objectives of the study:

Table 2. The formal definitions of these components of ICF (WHO 2002, p. 10)

- Body Functions are physiological functions of body systems (including psychological functions).
- Body Structures are anatomical parts of the body such as organs, limbs and their components.
- Impairments are problems in body function or structure such as a significant deviation or loss.
- Activity is the execution of a task or action by an individual.
- Activity Limitations are difficulties an individual may have in executing activities.
- Participation is involvement in a life situation.
- Participation Restrictions are problems an individual may experience in involvement in life situations.
- Environmental Factors make up the physical, social and attitudinal environment in which people live and conduct their lives.

For the current study, the focus has been applied to all 8 levels of the ICF i.e. body functions, body structures, impairments, activity, participation, activity limitations, participant restrictions, and environmental factors (WHO, 2002). Particularly for the current study, focus is on patients who use ototoxic MDR-TB treatment and are susceptible to damaging the ears (body function). The ear is responsible for hearing and balance (body function), however for the current study, focus will be on hearing. The effects of ototoxic medication used to treat MDR-TB have an adverse effect on the hearing ability and this leads to a hearing loss (impairment). Regardless of the degree of the hearing loss, an individual's execution of a communicative activity (activity) and involvement in daily routines (participation) will be affected. This results in individuals who present with a pernanent hearing loss to experience limitations and restrictions with communicative activities and participation (activity limitations and participation restrictions). These limitations and restrictions impact on the quality of life of the individual which directly influences the environmental factors.

The effects of the hearing loss cannot be measured by the pure tone audiogram. Therefore, clinical audiologists are aware that the level of difficulty experienced by two different people diagnosed with a hearing loss differ. Another perspective on the use of the ICF includes, patients' expectations and needs, impact of hearing loss on family and quality of life. Figure 3 below illustrates the QoL of a person using a modified model of the ICF "as a composite emergent and changing phenomenon of all aspects of functioning that may be impacted by a person's health condition, other personal factors and environmental factors" (McDougall, Wright, & Rosenbaum, 2010, p. 208).

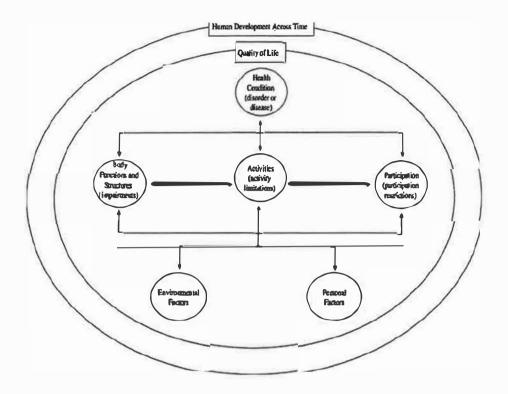


Figure 3. A modified version of World Health Organization's model of functioning and disability (McDougall et al., 2010, p. 208).

For the current study, focus is on a permanent hearing loss acquired due to ototoxic MDR-TB treatment. As mentioned above, the focus of the ICF is on clinical provision of rehabilitation. "The focus was to plan rehabilitation outcomes with consideration of the difficulties the person faces in real-life situations (participation restrictions), personal limitations that the person may have in completing a task (activity limitation), and the physical as well as the social environment in which the person lives" (Sharma, 2016, p. 161). Particularly for the current study, AR was explored as auditory training aims to enhance auditory functioning and auditory behaviours as well as the approach to auditory tasks (Pratt, 2005). Therefore, AR aims to alleviate the effect of the hearing loss on communication interactions and quality of life.

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The absence of AR services impacts the individuals QoL. Therefore, for the current study, the researcher aims to determine how hearing impairment influences/affects the QoL of an adult who presents with an acquired hearing loss due to ototoxic MDR-TB treatment. With AR aimed at addressing the effects of the hearing loss, it is important to determine if patients are aware of AR services that extend beyond a hearing aid orientation and if they are willing to participate within an AR program to address the activity limitations and participation restrictions. The current study aimed to also explore the factors that may influence individuals to access AR services, e.g. socio-economic factors, cultural factors, linguistic factors, domestic factors. Additional to these factors, is the exploration of the perceptions that an individual with an acquired hearing loss may have towards the accessibility of the different components of AR services.

## 2.8 Summary

The chapter covered important theory related to the provision of ototoxic monitoring programs as well as the provision of AR services by audiologists, and participation in such services by patients. Issues relevant to the SA context were also discussed, as were the challenges faced and literature to overcome them, such as awareness of AR services and technologically available programs that may/may not work in the SA context. The framework was also discussed, with the WHO's ICF forming the basis of enquiry to address the study Objectives. In the next chapter, the methodology section of the study will be discussed.

#### **Chapter 3. Methodology**

## **3.1 Introduction**

Research methodology refers to the methods followed by researchers in order to carry out their study (Sileyew, 2019). This chapter outlines the framework constructed in meeting the aims and objectives of the study. This includes the study design, participant selection, sampling technique, data collection and analysis, validity, reliability and ethical considerations.

## **3.2 Research Aims**

The aim of the study was to explore the perceptions of an adult patient who had an acquired hearing loss post multidrug-resistant tuberculosis (MDR-TB) treatment towards aural rehabilitation (AR) services at a public sector clinic in KwaZulu-Natal Province (KZN), South Africa (SA).

The objectives of the study were:

 To determine the influence of an acquired hearing loss on quality of life (QoL) post MDR-TB treatment.

2. To explore the awareness of participation in an adult AR program following the hearing aid orientation.

3. To explore the willingness of an adult to participate in an adult AR program following the diagnosis of a permanent hearing loss.

4. To explore the personal and environmental factors that influence the accessibility of adult AR services.

5. To explore the perceptions regarding the availability and accessibility of the three groupings of services, i.e. audiological counselling services, sensory management and communication intervention (Makhoba and Joseph, 2016) for an adult with acquired hearing loss post MDR-TB treatment.

# **Table 3. Objectives and Methods**

Ob	Objectives	
1	To determine the influence of an acquired hearing loss on quality of life (QoL) post MDR-TB treatment	Interviews
2	To explore the awareness of participation in an adult AR program following the hearing aid orientation	
3	To explore the willingness of an adult to participate in an adult AR program following the diagnosis of a permanent hearing loss	
4	To explore the personal and environmental factors that influence the accessibility of adult AR services.	
5	To explore the perceptions regarding the availability and accessibility of the three groupings of services, i.e. audiological counselling services, sensory management and communication intervention (Makhoba and Joseph, 2016) for an adult with	

## **3.3 Research Design**

A descriptive, exploratory, qualitative study design was used, as it describes research problems that are usually best understood by the exploration of an idea or phenomenon (Creswell & Creswell, 2018). The process of a qualitative approach includes: raising of questions, data collection typically from a participant's setting, analysis of data from specific to common themes and the elucidation of data by the researcher (Creswell & Creswell, 2018). This research approach was deemed suitable for the current study as the researcher explored the phenomenon of availability and accessibility of AR services for a patient with an acquired hearing loss post MDR-TB treatment. Case studies use all types of methods to collect data, such as testing and interviewing (Astalin, 2013). As case studies aim to understand one or a limited number of individuals or circumstances in-depth within a demarcated time frame (Leedy & Ormrod, 2013), this approach was considered to be most suitable. Furthermore, single case studies, through multiple qualitative or quantitative research procedures, "provide a nuanced, empirically-rich, holistic account of specific phenomena" (Willis, 2014, p 4). A single case study is less appropriate for phenomena which require substantive quantification (Willis, 2014), therefore being more appropriate for a qualitative study. A single case study is also more practical than theoretical (Willis, 2014). Therefore, there is scientific evidence for selecting a single case study.

### **3.4 Participants**

# 3.4.1. Setting

The study was conducted at an audiology clinic at King Dinuzulu Hospital Complex (KDHC), previously known as King George Hospital, in Durban, a tertiary level public sector facility that is the referral facility for specialized care across the KZN Province. KZN has a population of approximately 11.3 million people (Statistics South Africa (Stats SA), 2019), this facility therefore being one of the six hospitals categorized as a specialized TB provincial hospitals in KZN (KwaZulu-Natal Department of Health, 2020). In addition to KZN, patients from the Eastern Cape are also treated at the hospital (A.B. Mzizi, personal communication, June 30, 2020).

On being suspected of having tuberculosis (TB), patients are sent to KDHC for testing, and on confirmation of the bacillus, are put on a course of bedaquiline (BDQ) medication if it is established that they are drug-resistant (S. Mbhele, personal communication, March 13, 2020). If patients are resistant to TB medication between 1-2 weeks, they are considered resistant to treatment (A.B. Mzizi, personal communication, June 30, 2020). Furthermore, patients who have been on TB treatment for 6 months and fail treatment are sent for MDR-TB testing (A.B. Mzizi, personal communication, June 30, 2020). If test results are positive for MDR-TB, patients will have to spend 3-4 months in the MDR-TB ward and once discharged, they will have to attend the MDR-TB outpatient clinic for  $\pm$  18 months (A.B. Mzizi, personal communication, June 30, 2020). Patients are treated for TB at KDHC and once discharged, those living far away access treatment at their base hospitals or clinics (S. Mbhele, personal communication, March 13, 2020). Those with MDR-TB are treated at the TB clinic and with hearing loss attend the audiology clinic if they are referred by the doctor (S. Mbhele, personal communication, March 13, 2020).

Patients attending the MDR-TB clinic include those who have medical aid, as KDHC is considered an MDR-TB referral site (I. Master, personal communication, June 30, 2020). Furthermore, private hospitals do not treat MDR-TB, therefore patients are sent to public hospitals for treatment (I. Master, personal communication, June 30, 2020). The study participants were accessed from KDHC, being a provincial level facility that is situated in the eThekwini Health District (KwaZulu-Natal Department of Health, 2020). KDHC specializes in family planning, orthopedic spinal column surgeries, psychiatry and MDR-TB services, including those with complicated TB (KwaZulu-Natal Department of Health, 2020).

KDHC started providing BDQ treatment towards the end of 2013 (I. Master, personal communication, June 30, 2020), which only those patients who are extensively drug-resistant TB (XDR-TB) getting it (I. Master, personal communication, June 30, 2020). According to Stop TB Partnership (2017), the hospital's TB clinic treated almost 1 800 cases of MDR-TB per month in 2017. Master (2017) reported that 1670 patients started BDQ treatment at KDHC that year, according to the KZN Bedaquiline Program Data (3/9/2017). KDHC was selected due to there being medical records of patients who received aminoglycoside as treatment for MDR-TB prior to 2017, and who consequently presented with an acquired ototoxic hearing loss. As King George V Hospital is the largest national TB facility specializing in MDR- and XDR-TB (Mail & Guardian, 2011), the current study attempted to ascertain if these patients were provided with any AR services and what their perceptions were. The audiology department has two full-time audiologists (S. Mbhele, personal communication, March 13, 2020) and provides a variety of audiology services, such as diagnostic testing, fitting hearing

aids (S. Mbhele, personal communication, March 13, 2020), and newborn screening (A.B. Mzizi, personal communication, June 30, 2020). Patients who are walk-ins and those from the wards are referred by the doctor to the audiology department for intervention if they report a hearing loss (A.B. Mzizi, personal communication, June 30, 2020). In addition, all patients with MDR-TB are referred for a baseline audiogram and all neonates are referred for hearing screening (A.B. Mzizi, personal communication, June 30, 2020).

# 3.4.2. Selection criteria for participants

A qualitative sample size is usually reduced due to the nature of the in-depth and meaningful data obtained (Dworkin, 2012). The focus of the sample size should not be on the overall qualitative research but rather the case study. Leedy and Ormrod (2005) state that the focus of a qualitative research design should include one or a limited number of cases in the participant's natural setting. Furthermore, authors Leedy and Ormrod (2013) state that one case can be adequate to increase the understanding or information for certain circumstances, but may include two cases or more to enhance theory, comparisons and possible generalizations. Therefore, the sample consisted of one case study (one participant), as this was regarded as being sufficient to obtain in-depth information to understand the perceptions of patients who have an acquired hearing loss post MDR-TB treatment towards AR services.

According to Patton (2007), the nature of qualitative research is the in-depth single case or small sample size focus that is selected purposefully. A non-probability, purposive sampling technique was utilized during participant selection (Lærd Dissertation, 2012), this methods being used when the study is conducted for a specific reason or research problem (Leedy & Ormrod, 2013). Purposive sampling can be described as using the researcher's judgement when selecting units, such as people (Lærd Dissertation, 2012). This sampling technique is deliberate in participant selection in relation to the study, as they can provide information on the problem at hand. For the current study, the research aimed to understand the perceptions of a patient who acquired a hearing loss post MDR-TB treatment towards AR services. An appointment was made with the audiologists at the hospital, who were briefed on the purpose of the study and requested access to patient file numbers between 2015 and 2016. The researcher reviewed the patient information from the hearing aid surgical appliance forms between 2015 and 2016 of potential participants for the study based on the selection criteria. Possible participants needed to have completed treatment for MDR-TB during this period, present with an acquired permanent hearing loss as a result and be fitted with hearing aids.

### 3.4.3. Material/apparatus for selection of participants

Once participants who fitted the selection criteria were identified, the researcher requested to view their files from the administration department, as the older files had been archived and could not be accessed. Originally, a list of 10 potential participants was derived from the patient files based on hospital record keeping and the inclusion and exclusion criteria. The researcher and interpreter (where required) requested the possible participant's permission to participate in the study by contacting and informing them telephonically and via short message service (SMS) about the study, and their family members/significant others were also informed telephonically. Due to the nature of the hearing loss associated post MDR-TB treatment, where a telephonic conversation with the participant was not possible, the participant's family members/friends/significant others were asked to assist with communication. However, some potential participants and their next of kin could not be contacted, some preferred not to participate, and others lived too far away and did not want to travel to the nearest hospital/clinic for the interview. Some were too ill to

participate and others had demised. At the end of the recruitment process, two out of the four potential participants were met: one for the pilot study and the other for the main study. The remaining two participants were excluded due to the researcher being unable to get hold of them either telephonically or via SMS.

The two participants who were willing to participate in the study were scheduled for an interview with the researcher on a convenient day, time and venue for them and the researcher (one for the pilot study and one for the main study). They were encouraged to bring a family member/friend/significant other to the interview, as this would have provided support, add to the information gathered during the interview session as well as improve communication between participant, researcher and/or interpreter. The interpreter called the participants prior to the both interviews to confirm their attendance and an SMS was sent as a reminder. The researcher organised the interviews at a site convenient site for the participant, with transport being arranged for the participant and/ or their significant other/family member/friend if required.

# 3.4.4. Procedures for selection of participants

The participant in this study was selected based on the following inclusion and exclusion criteria.

To be included in the study the participant needed to:

- Be 18 years and older, as the study focused solely on adult AR. Laws in SA state complete legal capacity as a person of 18 years, whereas a minor is a person who is below 18 years of age (YAMBU, 2017). Therefore, a person at/over the age of 18 years can be defined as an adult.
- Have completed aminoglycoside MDR-TB treatment, as the focus of the study was on the perceptions of a patient who had an acquired hearing loss post MDR-TB treatment. According to Appana et al. (2016), patients post MDR-TB treatment have a hearing loss that is between the severe and profound categories.
- Have a confirmed hearing loss as a result of MDR-TB treatment, as AR assists with the adjustment of a hearing loss, the use of listening devices, conversation management and improved communication (Borgia, 2019). MDR-TB management includes the utilization of second- line treatment (Kanabus, 2018), which causes hearing impairment (Seddon, Godfrey- Faussett, Jacobs, Ebrahim, Hesseling, & Schaaf, 2012).
- Have received audiological management between 2015 and 2016 at KDHC. The file numbers between 2015 and 2016 were also selected, as patients diagnosed with MDR-TB after this period received the BDQ drug. According to South African Government News Agency (2018), patients who were diagnosed with MDR-TB would receive BDQ as part of the new treatment regime.
- Be willing to participate.

To be excluded from the study the participant needed to:

- Be <18 and  $\geq$  65 years old,
- Be on MDR-TB inedication, as amplification and rehabilitation occur post discharge (Petersen & Rogers, 2015).
- Be on or post BDQ medication, as the drug does not result in an acquired hearing loss (Treatment Action Campaign, 2018).
- Be on or post TB treatment.
- Be on or post XDR-TB treatment. Shah, Auld, Brust, Mathema, Ismail, Moodley, Mlisana, Allana, Campbell, Mthiyane, Morris, Mpangase, van der Meulen, Omar, Brown, Narechania, Shaskina, Kapwata, Kreiswirth, & Gandhi (2017) state that the treatment success of XDR-TB is below 40%, which could cause difficulty in finding and recruiting participants.
- Be too ill to participate in the study,
- Have normal hearing bilaterally
- Not be willing to participate

# 3.4.5. Description of participant

Once the pilot study had been completed, the data analysed to establish validity and reliability, and modifications made to the questionnaire and process as required, an arrangement was made with the participant for the main study to attend an interview at Red Hill Clinic. The participant will be referred to as X, who was a 41-year-old African female and a first language isiZulu speaker and unemployed at the time of the study. She lived in Durban, within the eThekwini Health District in KZN, was unmarried, and lived with her long-time partner, while her two children lived in Johannesburg. Due to financial constraints, she dropped out of school during Grade 7 and did not further her studies. She was diagnosed with MDR-TB in August 2015 and completed the aminoglycoside treatment July 2017. After noticing a decrease in her hearing, she was referred by the doctor to the audiology department at a hospital in Johannesburg in December 2017, where she was diagnosed with a severe to profound sensorineural hearing loss bilaterally and fitted with hearing aids. Upon her return to KZN, she was fitted with different hearing aids bilaterally at KDHC.

## 3.5 Material apparatus for data collection

In-depth semi-structured interviews are used for this study and consist of conversations with the researcher and participant (DeJonckheere & Vaughn, 2018). The interview protocol is flexible, with the addition of comments, follow-up enquiries and probes that enables qualitative, descriptive data to be obtained that explores the participants' beliefs, understanding and emotions on a specific topic (DeJonckheere & Vaughn, 2018). In addition, a semi-structured interview allows for direct questions as well as an adaptation of questions for more particular responses, which creates a more instinctive and accepted dialogue (Austin & Sutton, 2014). A semi-structured interview schedule with open-ended questions was adopted for the

current study with individual face-to-face interview. Responses from the participant were written down as well as audio recorded during the one-on-one interview session.

The interview protocol followed and adopted the layout as described by Creswell and Creswell (2018):

- (a) Basic interview information: information to organize the database, such as interview's details (date, time, location, duration), names of researcher and participant, transcriptions and digital copies of audio recordings.
- (b) Introduction: This included the researcher's instructions, such as an introduction of the researcher and interpreter, the study's purpose, information sheet and signed informed consent and interview structure (e.g. beginning of interview, amount of questions, duration of interview). The participant was asked if there were any questions prior to commencement and principal terms used throughout the interview were defined.
- (c) **Opening question:** The ice breaker question included goal-directed, non-personal questions about the participant to relax them e.g. hobbies, occupation and roles.
- (d) Content questions: The sub-questions related to the study objective and were phrased in a friendly manner and were used to allow the participant to provide information that was specific to their settings (Glottopedia, 2014).
- (e) **Probes:** Probe questions were included to prompt for more information or to request for explanations regarding ideas. Probes lengthened the interview time, however it allowed the researcher to gather more useful information.
- (f) **Closing instructions:** This included thanking the participant for their participation, responding to final questions, assuring confidentiality, requesting a follow-up interview

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if clarity was needed, and discussing how they would like the study's results to be made available.

In addition, two types of questions outlined by Bolderston (2012) were also used during the interview:

- (a) **Main questions:** These questions draw attention to the study's primary objectives and were asked to set the tone of the conversation
- (b) Spontaneous questions: These questions, also known as follow-up/ bonus questions, were asked after the researcher heard the first responses to questions. These were asked to motivate the participant to elaborate on the information they provided. Persistent, thoughtful spontaneous questions, were used to increase the data's validity.

Six question types make a good interview: background/ demographic, feelings, behaviour/ experience, knowledge, opinion/ belief and sensory (Patton, 2014, as cited in IndianScribes, 2018). Three out of the six question types were applicable and therefore used in the study: background/demographic, feelings and behaviour/experience. Table 4 presents the descriptions and motivations of the questions used in the interview schedule.

Table 4.	Sections	of the	interview	schedule
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Area	Motivation
Section A: Background information & medical	Demographic: age, gender, date of birth.
history	Clinical: general well-being, degree of hearing loss,
	perceived benefit of the hearing aid.
Section B: Objectives 3 & 4 Perceptions and	To ascertain how the participant felt towards an acquired
feelings towards the availability and	permanent hearing loss in relation to the accessibility of
accessibility of AR services and influencing	audiological counselling services, sensory management
factors	and communication intervention. Experience questions
	were included to elicit information on how the hearing loss
	affected her quality of life (QoL). Some questions were
	related to influencing factors.
Section C: Objective 5 Impact or effect on	To ascertain how the participant's life was impacted as a
quality of life (QoL), adapted from the following	result of the hearing loss and the different communication
questionnaires:	methods used and challenges faced.
The Hearing Handicap Inventory for Adults	
(HHIA) by Newman, Weinstein, Jacobson	
and Hug (1990)	
The Flanagan Quality of Life Scales (QOLS)	
by Flanagan (1970)	
<ul> <li>The Tinnitus Handicap Inventory (THI) by</li> </ul>	
Newman, Jacobson and Spitzer (1996)	
The Dizziness Handicap Inventory (DHI) by	
Jacobson and Newman (1990)	
Section D: Objective 1 Awareness of AR	To ascertain the participant's awareness of AR services
services	and contributing factors associated with adherence to an
	AR program.

Section E: Objective 2 Perceived impact	To ascertain participant's perceptions towards adult AR as
towards Adult AR as a service	a service, the benefits and challenges she may have
	experienced. Feelings questions were included to elicit
	information on the willingness of the participant to
	participate in AR services.
Section F: Other	To ascertain any additional information that they wanted to
	add that was not addressed in the interview schedule.

According to Farooq (2013), an interview schedule comprises of a list of questions and organized answers that is used as a plan to direct and guide the researcher. According to Eckerdal and Hagström (2017), questionnaires in qualitative research provide productive and ethical techniques during information gathering and recording on topic areas, such as everyday life. Therefore, the researcher used a combination of questions included in the interview schedule from the literature related to the current topic of the study as well as from four standardized questionnaires to address the five objectives, and questions derived from the theoretical framework, with only those relevant for the current study being used. The questions were adapted so that they were open-ended in nature, which was suitable for a semi-structured interview. According to Creswell (2012), questions that are open-ended allow the participant to provide answers and do not compel responses. These questions are useful when researchers are unaware of the possibilities of the response and have want to explore options (Creswell, 2012). The current study made use of and adapted the following questionnaires to address Objective 1 (QoL):

- The Hearing Handicap Inventory for Adults (HHIA) by Newman et al. (1990) (8 questions): is a self-assessment tool that covers areas regarding social or situational and emotional reactions to an adult's hearing impairment. It allows for the description of a hearing loss by the patient that cannot be adequately ascertained by audiometric results only (Newman et al., 1990).
- The Flanagan Quality of Life Scales (QoLS) by Flanagan (1970) (6 questions): According to Burckhardt, Anderson, Archenholtz and Hägg (2003), it is an important tool to include when dealing with patients who have a chronic health condition. It allows for assessing health care influence when there is no cure for the disease available. The questions were selected to ascertain how participants viewed their hearing impairment (Objective 1-QoL) and its effects on their lifestyle.
- The Tinnitus Handicap Inventory (THI) by Newman et al. (1996) (2 questions): According to O'Carroll (2016), the THI was established to measure the severity of a patient's tinnitus and the level at which it becomes problematic. The questions addressed objective were selected to establish if patients experienced tinnitus, and if so, its severity, effect on their lifestyle and how were they dealt with it (Objective 1-QoL).
- The Dizziness Handicap Inventory (DHI) by Jacobson and Newman (1990) (2 questions): measures the physical, emotional and functional effects of dizziness (Yorke, Ward, Vora, Combs & Keller-Johnson, 2013) and its severity, its effect on their lifestyle and how were they able to deal with what they experienced.

# **3.6 Procedures for data collection**

The main study was conducted at a community clinic requested by the participant as it was in the vicinity of where she lived thus being convenient for her to travel. Prior to the interview, the researcher met with the community clinic manager to explain the study and requested permission to accommodate the researcher, interpreter and participant. Once permission was granted, the date and time of the interview was confirmed with the participant. On the day of the interview, the researcher informed the security guards, nurses and receptionists at the clinic of the interview. They were requested to assist in directing the participant to the area designated for the interview while the researcher and interpreter set up. The researcher also waited at the main entrance of the clinic for the participant for the interview and the procedures followed during the pilot study were implemented for the main study. Recommendations from the pilot study were also implemented for the main study.

After the initial face-to-face interview, there were an additional two interview sessions with the participant in order to obtain more in-depth information or gain clarity on the data collected. Prior to the interview sessions, the researcher requested permission from the participant to participate in the additional interview sessions. However, an adaptation of the interview platform was made due to Covid-19 restrictions, with the latter two interactions being conducted via a WhatsApp group created by the researcher. The WhatsApp group included the researcher, interpreter and participant. The sessions entailed the researcher typing out the questions in English, the interpreter typing out the questions in isiZulu and the participant responding via text or voice notes. Once all data was gathered, the researcher transcribed all three interviews word for word, with the assistance of an interpreter for translations and back-translations.

# 3.7 Procedures for data analysis

The recorded data was transcribed verbatim in both English and isiZulu; the latter being **t**ranslated in English by the translator. This increased the validity of data and provided rich, realistic results (Creswell and Creswell, 2018), which was enhanced by asking probe questions. According to Nowell, Norris, White and Moules (2017), qualitative research investigations necessitates thorough and systematic methods due to its complexity in order to yield valuable outcomes. Thematic analysis is applicable in qualitative research (Nowell et al., 2017), and can be defined as a process that includes "identifying, analysing, and reporting patterns (themes) within data" (Braun & Clark, 2006, p.6). Thematic analysis also helps to minimally organize as well as describe data in detail (Braun & Clark, 2006). Furthermore, the inductive approach in thematic analysis uses data obtained from the study to determine themes (Caulfield, 2019). The six phases to undertake thematic analysis to qualitative data (Nowell et al., 2017) were adhered to during analysis for the study:

- (a) Phase 1: Data Familiarization: As the source of qualitative data varies (Thorne, 2000), it is important that raw data is archived for accurate analysis of the data and its interpretation at a later stage (Halpren, 1983, Lincoln & Guba, 1985, as cited in Nowell et al., 2017). The researcher reviewed the raw data before coding (Braun & Clarke, 2006) to familiarize herself with the data to create ideas and patterns (Braun & Clarke, 2006). The raw data was reviewed by the researcher thoroughly to ascertain the various underlying themes that were present before the next phase of thematic analysis.
- (b) **Phase 2: Initial code generation:** The researcher is required to create initial codes drawn from repetitively revisiting the data (Nowell et al., 2017). Qualitative coding allows the researcher to think and interact with the data (Savage, 2000, as cited in

Nowell et al., 2017), and for an emphasis and simplicity of precise expressions (Nowell et al., 2017).

- (c) Phase 3: Theme exploration: This phase allows for organizing and categorizing the coded data into different themes (Braun & Clarke, 2006). According to DeSantis and Ugarriza (2000), a theme can be defined as giving identity and significance to an abstract unit.
- (d) Phase 4: Theme review: The researcher refined the themes created (Braun & Clarke, 2006), which included reviewing the coded data from each theme in order to articulate a clear pattern (Norwell et al., 2017), and to create a strong link between the coded data and themes.
- (e) Phase 5: Theme definition and name: The researcher is required to identify each theme's area of interest and write a thorough investigation about each theme in order to inform the reader how the theme and data blend into the research study and objectives (Braun & Clarke, 2006). Therefore, the researcher defined and named each theme in order to accurately label the different codes in relation to the different themes created using transcriptions.
- (f) Phase 6: Report production: The researcher clearly categorizes each theme in order to finally analyze and create the report (Braun & Clarke, 2006). The thematic analysis report should be of interest and include logic, clarity, conciseness and non-repetition (Braun & Clarke, 2006), the final report being based on the amalgamation of each refined theme.

### 3.8 Pilot study

According to Song, Sandelowski and Happ (2010), the purpose of pilot studies includes measuring the feasibility of the study, analyzing the target population (such as cultural appropriateness), ascertaining the attention and time spent on participants, and examining the outcome in order to estimate the significance of the study. For the current study, the pilot study allowed for the evaluation of the interview schedule, the ease, difficulty, clarity of the questions, the estimated time to conduct the interview, the skills of the interviewer, the use of an interpreter, placement of the audio recorder, the utilization of the interview schedule and field notes as data collection tools. Hence the findings of the pilot study were used to improve the methods where necessary. The pilot study included one participant only, who was not included in the main study, as there was a possibility that participants could alter their behaviour at a later stage if they were previously involved in the study (Cadete, 2017). The interview was conducted at the audiology department at KDHC.

- The advantages and disadvantages of the pilot study were also noted to ensure that these were taken into consideration to improve the outcome of the main study. Any interview schedule and logistical amendments that were required during the pilot study were considered for the main study, which were not conducted on the same day.
- Directions to the interview site were provided, arrangements included the hospital shuttle to fetch the participant from the main entrance of the hospital and drop them at the audiology department, and the receptionists and security guards were informed about the interview so that they could direct participants who could not find the interview site.
- The participant for the **pilot study** came to the interview alone, and was informed about the goals of the study and the interview process. Areas that were covered included signed informed consent, the presence of an interpreter, the use of an interview schedule and the use of an audio recorder and field notes. This was explained verbally

to the participant as well as on an information sheet provided on the day of the study. The participant was then provided an opportunity to participate in the study at their own free will, with no disadvantage should they wish to withdraw from the study. An information sheet in isiZulu (Appendix J) was provided to the participant. A consent form in isiZulu (Appendix K) was also provided to the participant. The researcher and interpreter also went through the information sheet and signed consent process verbally with the participant prior to the interview. The participant was informed that if they were illiterate, they could seek help from the researcher or interpreter. This was discussed prior to the participant signing informed consent. The signed informed consent was requested as proof that the participant granted permission and that the information recorded on their behalf was true and accurate.

• The participant was given a travelling and meal allowance, and was provided with refreshments and hand sanitizers during the interview. According to the Centers for Disease Control and Prevention (CDC) (2019), using hand sanitizers when soap or water is unavailable is useful for protection of oneself and others during the coronavirus outbreak. According to the World Health Organization (WHO) (2020), COVID-19 is spread via respiratory droplets as well as contact. Contact transmission can take place when contaminated hands meet certain areas of the body, such as the eyes, mouth or nose mucosa (WHO, 2020). Similarly contact transmission can occur indirectly and be transferrable if contaminated hands touch surfaces (WHO, 2020). Therefore, hand hygiene becomes of paramount importance (WHO, 2020).

The interview was recorded via audio recordings, which was later translated and transcribed, the data was saved on a Universal Serial Bus (USB) memory stick. According to Jamshed (2014), recording an interview is deemed more reliable as opposed to written transcriptions, which is somewhat unreliable. Interviews that are audio recorded provide accuracy and clarity because there is a saved reference of answers from the participant and remarks from the researcher (Jain, 2013). Another advantage of audio recordings is using digital recorders. Digital recorders assist transcription e.g. by preventing files from getting damaged over time, allowing for easier backup of files, allowing unlimited replay of recordings and allowing the researcher to skip through interviews in order to obtain specific information (Tessier, 2012).

The audio recorder used during the interview session was visibly placed on the table between the participant, researcher and interpreter. A cell phone was also used as back up should there be any malfunctions with the audio recorder. As audio recordings require protection of the participant's identity, consent and agreement (Institutional Review Board for Social and Behavioral Sciences University of Virginia, 2012), the audio recorder and cell phone were only used once signed informed consent had been given to the researcher by the participant.

### 3.9 The interpreter

An interpreter was included in the interviews as the participants' home language was isiZulu and they could not be assumed to want to answer the questions in English. As isiZulu is not the home language of the researcher, it was decided to use the services of an interpreter to ensure that the questions were correctly conveyed to the participant and that translated them accurately to enable the researcher to ask follow-up questions. An interpreter needs to have knowledge and skills in a particular language and type of interpreting, which includes language expertise, background knowledge on the research topic and language proficiency skills (Language Connections, 2016). The interpreter was a 31-year-old male engineering student who was proficient in both English and isiZulu. He was selected based on his prior assistance with translations for the study, which provided him with background knowledge and familiarity. He was also selected on his ability to understand and interpret the languages spoken by the researcher and participant, both verbally and in literacy. His role included interpreting the questions and answers during the interview and probing, rephrasing, clarifying and elaborating on questions where required.

Prior to the interview, the researcher explained the research study and the interview process to the interpreter, who had the opportunity to familiarize himself with the interview schedule and asked questions about the interview process where there was unfamiliarity. He was trained by the researcher in terms of the aims and objectives of the interview, structure of the interview and understanding his role in the interview. The following guidelines by Winter and Katrivesis (2016) were adhered to when training the interpreter:

- The researcher discussed the seating arrangements to facilitate better communication, i.e. the researcher faced the participant with the interpreter positioned next to and marginally behind the researcher in order to create a triangular design.
- Prior to the interview, the researcher discussed with the interpreter concepts that may pose difficulty in interpreting or cause unsavoury situations for the participant.
- The researcher also discussed areas such as cultural, gender, and ethical considerations that needed to be considered during the interview process with the interpreter. Probing sensitive issues were also covered. Consideration was taken into account by monitoring the interview in order to analyze the emotional effect or response from the participant (Fahie, 2014).
- The researcher and interpreter decided on simultaneous interpretation, with one sentence by the researcher being thereafter interpreted for the participant, and likewise for the participants' responses
- The interpreter did not summarize the information given by the participant.
- The researcher explained that after the interview, the interpreter was required to review and discuss the interview with the participant.

The Upper Midwest Translators and Interpreters Association (2019) guidelines were also incorporated when training the interpreter:

- The researcher and interpreter decided on the allocated time for the interview.
- Emphasis was placed on the researcher and interpreter being in the same room at the same time to avoid a situation where the interpreter and participant were left alone.
- The researcher confirmed that the interpreter interpreted everything that was said by the participant including unrelated and repetitive remarks.
- The researcher and interpreter managed the pace of the interview, such as pausing.

- The researcher and interpreter probed questions singularly as opposed to probing a sequence of questions simultaneously.
- The interpreter ensured that the participant understood the question.
- The interpreter phrased questions from the researcher at a level that could be understood by the participant that excluded the use of abbreviations and expressions/ phrases.

In addition to the above, guidelines from the Refugee Health Technical Assistance Center (2011) were also incorporated, such as speaking directly to participant and not the interpreter, and informing the interpreter to alert the researcher should cultural misunderstandings arise. Table 5 below represents the results of the pilot study.

# Table 5. Pilot study

Procedure	Outcome	Recommendations	
1. To adhere to extra precautionary measures as a result of the outbreak of the coronavirus.			
1.1. The precautionary measures outlined by the CDC (2020)	1.1. Items in contact with the researcher, interpreter and	1.1. The researcher, interpreter and	
were adhered to during the pilot study. These included:	participant were disinfected using clean tissues	participant increased the seating	
Informing the interpreter and participant on how the	soaked in disinfectant and dried with clean tissues.	distance and spoke more loudly	
coronavirus spread	Items included wiping the table, chairs, pens,	and clearly so that distance was	
Protection against the coronavirus eg. frequent washing of	clipboards, audio recorder and cell phone.	maintained and the quality of the	
hands and avoiding close contact with others	1.2. A hand sanitizer was provided, with demonstration	audio recordings were maintained	
• Protection of others e.g. staying home if sick, covering the	from the researcher on how to clean hands.	1.2. The researcher reiterated	
mouth when coughing and the nose when sneezing, wearing	1.3. Due to the placement of the audio recorder, larger	precautionary measures during th	
a facemask if sick and cleaning/disinfecting surfaces	seating distances between the researcher, interpreter	interview to ensure that everyone	
	and participant could not be maintained as this would	adhered to them	
	have affected the quality of the voice recording.		
2. To determine the proper placement of the audio recorder			

1.3.	Prior to recording, the researcher tested the sound quality	2.1. The voice recordings on the audio recorder and cell	2.1. During audio recording, the
	of the audio recorder, which was placed in the middle of	phone were able to pick up the researcher,	researcher ensured that background
	the table between the researcher, interpreter and	interpreter and participant's voices clearly.	noise was minimized or reduced.
	participant. A cell phone was also used to record.		This was achieved by making sure
1.4.	Doors were closed and secured by a bench to ensure that		windows closer to the traffic or
	wind from the open windows did not cause them to bang.		school were slightly open or closed
1.5	Face masks were removed prior to the interview, as it		for the duration of the audio
	caused speech to become less audible. There was also no		recording.
	need to wear facemasks as the researcher, interpreter and		2.2. The venue for the interview had a
	participant confirmed that they were feeling well enough to		sign to indicate that interviews were
	continue with the interview. According to CDC (2020),		in progress. This prevented patients
	facemasks are not a requirement if the person is not sick,		and staff from opening doors
	unless taking care of another person who is unwell and		randomly, which contributed to
	cannot use a facemask.		background noise.

Procedure	Outcome	Recommendations
. To assist the interpreter with interpretations and ex	planations to the participant.	
3.1. The researcher assisted the interpreter with	3.1. The researcher clarified any queries that the interpreter and	3.1. A resource file with information
interpretations and explanations to the participant.	participant had and provided more information as required.	related to the study was provided to
	3.2. The researcher also helped with probing questions,	the interpreter form them to gain an
	rephrasing questions and clarification where required.	understanding of the study. This
	3.3. Scenarios and examples were offered with explanations to	allowed them to interpret and explain
	facilitate better understanding.	to participant. This process saved
	3.4. Additional information was available for further explanation.	time, as the interpreter did not have
	3.5. The interpreter and participant were encouraged to request	to depend solely on the researcher
	as much information as required before asking a question	for explanations.
	or answering a question.	
	3.6. The participant was encouraged to ask for repetition of	
	questions if the participant was unsure of what the	
	question was.	
4. To validate the use of an interview schedule as a r	esearch instrument.	

2.3. The researcher used an interview schedule during	3.1. Most questions were easy to understand, with some	3.1. The interview concluded with asking	
the interview process. The interview was available in	requiring more clarity, as the participant was not familiar with	if there was anything that the	
English and isiZulu.	terms associated with adult aural rehabilitation services.	participant wanted to add, related to	
	3.2.A stop watch was used to guide the duration of the	the interview questions only.	
	interview.	1	
5. To ascertain if the pilot study process can be replicated for the main study.			
3.3. The researcher designed the pilot study and the	4.1. The researcher was able to obtain in-depth information from		
main study to include the same data collection	one case study during the pilot study that met the aims and		
process.	objectives. This indicated that the data collection method		
	and procedures were realistic, achievable and could be		
	applied to the main study.		

### 3.10 Audio recorder

The interview was digitally recorded for later transcription. The Bell Voice Recorder DVR 6006 is a digital recorder that has a microphone built in to the device with 300 hours of recording time (Laptop Direct, 2020). It was selected for the study, due to it being a light handheld device that was simple to use, with 8 gigabytes of internal memory and battery life that lasted a maximum of 15 hours (Laptop Direct, 2020). The recording feature was activated by pressing the record button for voice recordings and pressing the play button for recording play back (Laptop Direct, 2020). In addition to the voice recorder, a Huawei P20 Pro cellphone was used for back up recordings. The cellphone was selected for the study as it had a battery life of 1.5 to 2 days, good speakers (sound quality), storage of 128 gigabytes and being light weight (180 grams) and small (dimensions of 155 mm x 73.9 mm x 7.8 mm) (Williams & Kronfli, 2019).

In terms of microphone placement, the guidelines outlined by The Open University (2005) was adhered to during audio recordings. This included placing the microphone with an equal distance between each person (ie. researcher, interpreter and participant) at a distance of approximately 30 cm between each person to prevent distortion of sound (The Open University, 2005). Additionally, the microphone was placed levelled at the mouth of each person so that speech was clearly recorded (The Open University, 2005).

### 3.11 Validity and Reliability

The validity of a qualitative research design indicates the suitability of the instruments, procedures and data yielded (Leung, 2015). Credibility, trustworthiness and authenticity are terms related to qualitative literature (Creswell & Miller, 2000, as cited in Creswell & Creswell, 2018). Using multiple validity processes is recommended for the accuracy of data (Creswell & Creswell, 2018). The validity of the study adopted the following procedures:

- (a) Content validity: The questions addressed during the interview were derived from literature or content on the area being investigated. The International Classification of Functioning, Disability and Health (ICF) framework and several studies were specifically considered when formulating the interview schedule e.g. Makhoba and Joseph (2016), Khoza-Shangase and Stirk (2016) and Ramma et al. (2019), etc.
- (b) Member checking: The key step in establishing credibility (Lincoln & Guba, 1985), member checks is the process where the research participants evaluate the authenticity of the research study by proving the accuracy of credibility in terms of the qualitative data yielded and the results (Smith & McGannon, 2017). Member checks were achieved by verbally relaying the data and/or the results to the participant, and feedback was requested on the accuracy of the data and/or the results collected regarding the portrayal of her experiences (Smith & McGannon, 2017). Once confirmation from the participant was received, the findings of the study were regarded as credible, therefore the research can be regarded as valid (Smith & McGannon, 2017). A follow-up interview with the participant was conducted to probe further, obtain more information and clarifying data recorded at the initial interview.
- (c) Member reflections-clarifying biases: This includes the researcher's interpretations of data shaped by their own background, history, gender, socioeconomic origin and culture (Creswell and Creswell, 2018). This was achieved by the researcher verifying the

interpretations with the interpreter and participant during the interview process and prior to recording data. The information provided during the initial interview, clarifications and interpretations made based on the data were verified by the researcher confirming the data recorded with the participant with the help of the translator.

The reliability of a qualitative research design denotes the precise replicability in terms of procedures and results (Leung, 2015).

According to Cypress (2017), the concept of reliability in a social science study poses a difficulty, as scientifically reliability indicates repeatable measures that yield the same outcome each time. Human behavior and communication can never be identical, therefore exact measurements and interpretations may never be correct (Cypress, 2017). As the results of qualitative research are not statistical, the reliability of the study is based on an in-depth documentation of the whole research procedure, consistency, applying the correct research practices and keeping an open mind with regards to the possibility of limitations in the study (Cypress, 2017). Documentation of steps and procedures of case studies, including details on protocols for the case studies as well as databases are important for qualitative research (Yin, 2009, cited in Creswell and Creswell, 2018). Therefore, the reliability of the study adopted the following procedures:

(a) A skilled and properly-trained investigator: According to Squires (2009), interpreters in studies assist in eliminating the language barrier between interviewer and interviewee. This was achieved by having a researcher and an interpreter who understood the focus of the study, and worked together in acquiring as much information as possible without losing the skill of neutrality.

- (b) **Cross-checking of mechanically recorded data:** According to Tessier (2012), interviews are frequently used for qualitative research. Combining audio recordings and transcriptions with technology can be advantageous. Therefore, the researcher made use of the voice recorder to cross-check the mechanically recorded data, to ensure that data obtained from the various methods i.e. audio recordings and interview schedule, are reflected accuracy.
- (c) Checking transcripts: This step is done to ensure that there are no errors during the transcription process (Creswell & Creswell, 2018). This was achieved by the interrater reliability process, which is responsible for checking the accuracy of the transcripts (Appendix N).

According to Pacific International Translations (PACTRANZ) (2020), back translation follows a 3-step method, i.e. translation of a complete translation into its original language, comparison of new translation to original text and reconciliation of significant differences between texts.

- (a) Definition of codes: Continuous comparison of data with associated codes by writing notes on codes and code definitions (Creswell & Creswell, 2018). This was achieved by the researcher manually creating codes for code generation.
- (b) Pilot study: According to Srinivasan and Lohith (2017), a pilot study replicates and leads the main study. The main purpose of the pilot study was that it allows the researcher to ascertain if there are any errors with the measuring tool or questionnaire (Srinivasan and Lohith, 2017).

(c) Inter-rater reliability: This refers to the degree to which different raters/judges have consistent estimates regarding the exact same phenomenon (Frey, 2018). The researcher could also include raters providing scores, such as scores for verbal responses (Frey, 2018). The inter-rater reliability process was conducted by a college officer at UKZN due to her extensive experience with Health Science students and her familiarity with the Health Science academic programme. The inter-rater randomly selected 40% of data (voice recordings only) that covered all sections of the interview schedule (Section A to Section G) and transcribed it thereafter. The initial translation and transcription done by the inter-rater were then compared by the inter-rater in order to derive a percentage for the number of agreements and disagreements. The inter-rater score obtained was 99.5% (Appendix O), which resulted in the data obtained being used for the study. The formula used for inter-rater agreement calculations were as follows (Schlosser, 2003 cited in Joseph, 2008):

Inter-rater = <u>Number of agreements</u> x 100%

Number of agreements and disagreements

An inter-rating of between 20-40% is regarded as adequate (Schlosser, 2003 cited in Joseph, 2008).

In addition to the above, qualitative research also requires trustworthiness, which can be subdivided into four categories of credibility, transferability, dependability and confirmability (Lincoln & Guba, 1985), and was applied to the current study:

- (a) Credibility: The demonstration of whether the original data from participants correctly interpret the original views of the participants. This was achieved by checking the accuracy of data obtained from the interview schedule to ensure the findings of the study were credible (Statistics Solution, 2020). The credibility of data was confirmed via the translation (isiZulu to English), back-translation (isiZulu to English and English to isiZulu) and inter-rater reliability (checking the accuracy of transcripts) processes.
- (b) Transferability: The extent to which the results obtained from the qualitative research are transferrable to contexts involving other respondents. This was achieved by the researcher making use of thick descriptions from the participant in order to enable the study's findings to be applicable in other contexts and circumstances (Statistics Solution, 2020). According to Korstjens and Moser (2018), this process is achieved with the researcher delivering rich descriptive data, for example, the research context, setting, sample size, inclusion criteria and exclusion criteria, interview procedures, interview topics and changes to interview questions that changed due to the iterative process in research. In addition, there is evidence that a single case study can be transferred. Single case studies can produce more intricate theories compared to multiple case studies as researchers are able to organize theory precisely into the various details for a specific case (Eisenhardt & Graebner, 2007, as cited in Mariotto, Zannie & Moraes, 2014). Therefore, the usefulness of one case study can contribute

importantly to the development of theory if case specificities are regarded as opportunities for further adjustments (Mariotto et al. 2014).

(c) **Dependability:** The secureness of the results obtained over time, being achieved by having another person to examine/review the research and data analysis process to guarantee the findings to be consistent and repeatable (Statistics Solution, 2020). This process is also achieved by verifying if the data analysis process was in keeping with the research design's accepted standards (Korstjens and Moser, 2018). The researcher achieved this process by following the data analysis process for qualitative research from various authors who were an expert on the topic, as well as from guidance from the research supervisor.

(d) **Confirmability:** The accuracy of the results obtained from the study can be verified by further researchers, with the researcher having an audit trial to highlight the steps used in data collection and analysis to obtain a rationale in decisions made (Statistics Solution, 2020). The inter-subjectivity of data needs to be secured (Korstjens & Moser, 2018). Data interpretation has to be found in data and not from the researcher's preferences or points of view (Korstjens & Moser, 2018). Therefore, this process was achieved by transcribing the data word for word without any influence from the researcher's preferences or point of view.

### 3.12 Data Management

Data was collected from the KDHC, and was stored and locked in a secure cabinet at the department of audiology at the University of KwaZulu-Natal (UKZN) Westville Campus. The researcher, interpreter (if required) and research supervisor had access to the raw data. The data (audio recordings and transcriptions) were saved on a USB stick with an access code/pin code to gain access to the data. The Institutional Review Board for Social and Behavioral Sciences University of Virginia (2012) states that research records need to be kept for a minimum of five years, after which they will be destroyed or shredded, depending on the format.

### **3.13 Ethical Considerations**

The following ethical considerations were applied:

Nijhawan, Janodia, Muddukrishna, Bhat, Bairy, Udupa and Musmade (2013) describe informed consent as a legal as well as ethical pre-requisite when conducting research that includes human participants. This allows for the participant to be informed about the study prior to confirming voluntary participation (Nijhawan et al., 2013). "Most ethical issues in research fall into one of four categories: protection from harm, informed consent, right to privacy, and honesty with professional colleagues" (Leedy & Ormrod, 2005, p.111). Ethical considerations for the study followed the World Medical Association Declaration of Helsinki (JAMA, 2013) principles. The following ethical and legal considerations were adhered to as described by on Beauchamp and Childress in 1979: beneficence, autonomy, justice and nonmaleficence (Jahn, 2011). The current study acknowledged the following legal and ethical considerations:

- Gatekeeper permission was requested from the medical manager (Appendix B) and audiologists (Appendix C) at KDHC and a permission letter from the medical manager at KDHC was received (Appendix D),
- Permission was also requested to conduct the study from the KwaZulu-Natal Department of Health (Appendix E)
- After receiving permission from the Department of Health (Appendix F), final ethical clearance was provided by the UKZN HSSREC Research Office (Appendix G) to conduct the study.
- Respect for participants: All participants in the study were respectfully treated. This was reflected by how the researcher addressed them e.g. referring to participants instead of "subjects". The researcher also took into consideration the cultural diversity of the participants and respected their right to privacy and confidentiality (Wilson & MacLean, 2011).
- Physical harm: The researcher accepted her duty of caring for participants, who took their time to participate in the study, and ensured that they were protected from undue risks that could result from participation in this study.
- Psychological stress: The researcher considered the potential risk of emotional and psychological distress. However, this was regarded as minimal, but the availability of a social worker was ensured before the interviews began in the event that they should experience any distress during the process and needed to be referred.
- Privacy and confidentiality: The researcher guaranteed that the privacy of participants was respected, with the data obtained being coded to ensure that the two participants could not be identified. Data was kept in a locked and secure place, and will be kept for a period of five years and thereafter destroyed. The researcher maintained confidentiality,

as participants' responses were anonymous. Data was carefully coded and stored. No names were recorded on the data collection instruments and codes were used in the place of names (participant = X). The researcher explained the research procedure prior to participants' participation in the study to address any concerns with regard to confidentiality.

- All participants provided informed consent to participate and were provided with detailed information about the study. This allowed them to make an informed decision regarding their willingness to participate.
- Participants were informed about the procedures, purpose and duration of the study, and that they could withdraw at any point without providing an explanation. Risks, potential discomfort or adverse effects as a result of participation in the study, possible benefits, confidentiality limits, incentives and contact details that participants could use to address any queries or issues that may have arose were provided to all participants.
- The name of the participant was not published in the research write up and she was denoted as X. This allowed in keeping participation anonymous, private and confidential.

### 3.14 Summary

A research approach that was qualitative was chosen for the study, with one case being used for the pilot and one for the main study. The participants (pilot and main study) were selected based on inclusion and exclusion criteria and were accessed via the audiology department at KDHC. Convenient interview dates and times were scheduled with the hospital, audiologist, participants and interpreter. The interview schedule enabled the researcher in obtaining information that was relevant to the aims and objectives of the study. An audio recorder and cell phone was also used for recordings during the interview. Data was thematically analyzed with the support of the interpreter to ensure that the contents were correct. Ethical considerations and legal considerations were implemented and validity procedures and reliability procedures were examined.

### **Chapter 4. Results**

# 4.1 Introduction

The results for the current study were obtained via an in-depth interview with the female who is referred to as participant X. Data was analyzed using the interview schedule, which addressed the research Objectives and the Aim, i.e. to explore the perceptions of patients who have an acquired hearing loss post multidrug-resistant (MDR-TB) treatment towards adult aural rehabilitation (AR) services. The Objectives of the study were also addressed during the interview process through the different themes that emerged, as indicated in Table 6. The results are presented with respect to the five Objectives.

Objectives		Themes
1. To determine the influence of an acquired hearing loss on		Lifestyle changes
quality of life (QOL) post multidrug-res	istant (MDR-TB)	Abusive experiences
treatment		Communication experiences
		Self-taught communication strategies
2. To explore the awareness of participation in an adult aural		Little awareness of adult AR services
rehabilitation (AR) program following th		
orientation		
3. To explore the willingness of an adult to participate in an adult		Eager to participate in an adult AR
AR program following the diagnosis of	program	
loss		
4. To explore the personal and	1. Personal factors	Health
environmental factors that influence	2. Environmental	Travel and inadequate health information
the accessibility of adult AR services	factors	

Table 6. Objectives and corresponding themes

5. To explore the perceptions regarding	1. Audiological	Improve communication
the availability and accessibility of the	counselling services	Feelings and emotions
three groupings of services:		Unrealistic expectations
1. audiological counselling services,	2. Sensory	Perceptions towards hearing loss
2. sensory management and	management	Feelings towards hearing loss
3. communication intervention		Sensory management of hearing loss
(Makhoba and Joseph, 2016) for	3. Communication	Troubleshooting the hearing aid
adults with acquired hearing loss post		Awareness of other hearing devices
MDR-TB treatment		Communication
MDR-TB treatment		Communication

## 4.2 Objective 1: To determine the influence of an acquired hearing loss on quality of life (QOL) post multidrug-resistant (MDR-TB) treatment

Four themes emerged from this question, these being that she had lifestyle changes, abusive experiences and communication challenges, which results in her developing self-taught communication strategies.

## Theme 1. Lifestyle changes

Prior to her hearing loss, X had a very different quality of life (QOL), and enjoyed being around people. She loved spending time with and talking to her friends and family.

Before the hearing loss I had friends. I used to sit with them and chat with them. And at home I used to spend time with my family and talk to them. Before the hearing loss, X's friends would visit each other, and spent their time sitting and chatting together. She attended parties and frequently went to town, where she could get fresh air and look at things in the shops. However, since the diagnosis of the hearing loss, she was no longer close to her friends. She felt that they did not understand each other during communication interactions, as they frequently experienced communication breakdowns. Her friends also had to repeat the same information to her because she did not understand most of the conversation. She indicated that she was unsure if they were trying to repair the communication breakdown, were laughing at her or making a joke about her.

I loved spending time with my friends, like visiting each other and I used to attend a lot of parties most of the time. I also enjoyed going to town a lot. That's what I did most of the time just to get some fresh air and look at things in the shops. Now it's difficult. I'm embarrassed by these things (hearing aids) that I wear because people keep staring at me and talking about me.

The interactions with X and her children were limited and she did not sit and talk with them like she used to before the diagnosis of the hearing loss. However, she reported that her children were sympathetic towards her hearing loss.

Particularly with my children... they are sympathetic towards my situation.

X no longer liked to travel or go out, the hearing loss having restricted her to the extent that it caused her to do things that she did not enjoy doing before. She now preferred to stay indoors, where she occupied herself by cleaning the house, washing and going outside to watch her environment. Other changes associated with the impact of the hearing loss on her QOL included changes to her lifestyle, such as going to sleep to avoid communication interactions and using self-isolation as a coping mechanism. She explained that she behaved this way because she could not hear anything at all, and by sitting alone, she felt she was protecting herself from being hurt, especially when someone tried to communicate with her and she could not hear.

The hearing loss has made me to remain indoors and clean the house. I love cleaning the house. I love doing the washing. Those are the things that keep me busy.

X had become so accustomed to staying indoors and doing chores, during the week days and on weekends, as she finds that her hearing loss does not affect her daily routines.

My weekdays and my weekends are all the same. There's no difference between my weekdays and my weekends... The hearing loss doesn't affect my daily routines.

### Theme 2. Abusive experiences

After the diagnosis of the hearing loss, X's longtime partner (she never married) and the father of her children started to abuse her. She indicated that when she said 'huh', her partner thought that she was making him a 'fool'. She felt that her partner was 'happy' that she had a hearing loss, as when she was around him he spoke his secrets in her presence to his friends, thinking that she could not hear him. This caused her to feel sad and hurt because she could hear what her partner was saying.

It's because the father of my children... it's like he's happy that I have a hearing loss. Because even when I'm around, he speaks about his secrets or things that he shouldn't speak in my presence to his friends and he thinks that I can't hear. And the sad part is that I get so sad is because I can hear what he's just said and it's painful.

X reported that her partner was surprised when she was able to hear what he said because he felt that her hearing aids were not helping her. He only realized that her hearing aids do help her when she responded. Her partner deliberately lowers his voice when he speaks to other people, during which times she cannot hear anything, even when using her hearing aids, and this hurts her.

I'm referring to secrets, things that I'm not supposed to know. I am referring to things I am not supposed to know. I hear him speak about these things and then he gets surprised when I respond to things that he is saying. He doesn't/ didn't think hearing aids are helping me, he just realizes only when I respond that I actually heard him. Another thing that hurts me is sometimes I see him lowering his voice when speaking to other people. And when does that I can't hear anything when using the hearing aids. That hurts me.

Due to her hearing loss, X's life was threatened when she was left in a compromising situation. She reported that she was taken advantage of by a man who knew that she had a hearing loss, as he came into her house and abused her. She opened a case against him but almost lost her case due to her hearing loss influencing the communication interactions at the court case. She reported that she struggled to hear

questions posed to her and information conveyed due to the hearing loss. This attributed to communication breakdowns during the hearing as no one was assigned to help her with communication. Furthermore, there were three people present at the court, herself, the accused and the magistrate, and the accused took advantage of the situation as he was the only one who knew that she had a hearing loss. It was only when she was given a piece of paper to communicate in writing towards the end of the case that she was awarded an opportunity to be included in the court case. This option contributed to the success of her court case as she was able to obtain a protection order.

The man that abused me, however, knew that I have a hearing loss, and that I don't hear at all. What's the most painful thing is that there was a man who came into my house and abused me and I went to open a case against him. I almost lost the case because of the hearing loss because some of the things that they were asking at court I wasn't responding to and it's because it's just that I couldn't hear them. What helped me to get through this case was that I was asked to write down everything when I went back to court and then they found out that I have a case and a successful case and I got a protection order.

### **Theme 3. Communication challenges**

X also found it difficult to sit and interact with people, as she felt like a 'fool' in their presence, feeling excluded during communication interactions as people tended to ignore her. She found life to be difficult as it was hard for her to engage with other people, and felt that her hearing loss controlled her. As a result, she disliked spending time with people and avoided them as much as possible.

I feel like I do not have control over it (hearing loss), it (hearing loss) controls me... Now it's difficult for me to sit and interact with people because I feel like a fool in their presence... Sometimes you can see that a person wants to communicate with me, but because of my hearing loss they move on to communicate with somebody else. But you can see that they want to communicate with me. And they choose to ignore me. I feel excluded when they do that and that is very painful for me... I even prefer to be on my own because people treat me like I am crazy.

X also indicated that the hearing loss has affected her ability to secure employment. Prior to her hearing loss, she had worked as a domestic worker and at a tuck shop in Johannesburg, but had to leave because her employer passed away. Since her hearing loss, she had struggled to find employment, and while she had recently found a job looking after a granny, there were communication breakdowns between them. The granny shouted at her and complained that she could not hear her and on the 8<sup>th</sup> day she was asked to leave.

Like I said, I was looking for a job, there is a place (that) employed me, I was promised. I went to test for (the) corona (virus) and the results came back negative, I started working from the 6<sup>th</sup>. This month was looking after a granny, she was old, she always shouts at me because I always say I don't (can't) hear her, she said she gets tired of me having to repeat a conversation, on the 8<sup>th</sup> they said I must go, they have found someone else. When the person arrived I stopped, I don't have the knowledge why they made me stop working because I did well everything they said.

#### Theme 4. Self-taught communication strategies

To improve her quality of life, specifically related to communication interactions X reported that she still experiences communication breakdowns due to the hearing loss even with the use of hearing aids. She indicated that she uses self-taught communication strategies, which included lip-reading and use of her cellphone to communicate via WhatsApp and short message service (SMS). Furthermore, she always carries a pen so that she can ask people to write things down when she experiences a communication breakdown. Although writing was her preferred mode of communication that allowed her to respond to what was being communicated more accurately, there were also challenges when writing. She used writing as a repair strategy only if she felt the information being communicated was important.

I look at their lips to see what they are saying. And if I struggle with the lip-reading I ask them to write it down but even with that I will tell them if it is something important then write it down. If it's not, leave it... If there's nothing for writing, if I don't have anything to write on, I try and lip-read. That's better.

X also indicated that she did not like to ask her communication partners to repeat information nor did she indicate a communication breakdown. She felt hurt when she had to ask for repetition and therefore preferred to keep quiet and sit alone where a communication breakdown occurred. She expressed eagemess to learn sign language to compensate for communication breakdowns but indicated that her communication partners would also need to learn so they could communicate with her. That's exactly what I hate, to keep saying 'huh', 'huh', 'huh' to the person I am communicating with. That's why I just prefer to keep quiet and stay alone. The part of me saying 'huh', 'huh' all the time is exactly what hurts me the most.

X reported that she experienced the most difficulty with hearing when there were a lot of people around her. She indicated that she needed a controlled listening environment for communication purposes, as she found it easier to hear when she was alone. Although she liked being around people and was able to follow the majority of the conversation, she was afraid of sitting with them. She attributed her fear to the possibility that the hearing loss would 'kick in' and she would not be able to hear or follow the conversation afterwards. She reported that her children were sympathetic towards her hearing loss and preferred to write information down for her when they wanted to communicate with her. However, her partner and father of her children disliked writing for her, which resulted in fights when they experienced communication breakdowns.

... if there is something that they (my children) want to communicate with me, they prefer writing it down. My baby daddy/father of my children on the other hand, he doesn't like writing down things for me and if there is a communication breakdown, that results in fights in the house.

# 4.3 Objective 2: To explore the awareness of participation in an adult aural rehabilitation (AR) program available following the hearing aid orientation

Only one theme emerged for this Objectives, that being that she had little awareness of the services that she should have been able to access at the time the hearing aid was fitted.

#### Theme 1. Little awareness of adult AR services

X indicated that she had limited awareness of adult AR services that she should have had access to, and which should have been available in the facilities she attended (Durban and Johannesburg). The only intervention option she was made aware of by the audiologists who assisted her was the hearing aids. As audiologists are the only health care professional that aid patients in the hearing aid fitting process, she would only receive assistance from such a person. Her file indicates that she was seen by an audiologist to fit a hearing aid but no information is recorded regarding what other information she was provided with regarding AR services. She was not informed that there were other services available beyond the hearing aid fitting. Despite having attended follow-up appointments as instructed, and frequently visited the audiology department for assistance with troubleshooting post hearing aid fitting, she did not understand what was required of her to access the services. She does not recall being provided with any aspects of AR, such as an intervention plan, hearing aid orientation, auditory training, telephonic training and communication strategies. Her lack of awareness regarding AR services contributed to the challenges she experienced due to the hearing loss. The researcher informed her about the AR services she could access and their benefits, with the participant reporting that she felt cheated/deprived that she was not made aware of them when the aid was fitted.

They only told me that hearing aids will help me. I didn't know about it (AR), it helps, I didn't know about it.

## 4.4 Objective 3: To explore the willingness of an adult to participate in an adult AR program following the diagnosis of a permanent hearing loss

Only one theme was identified regarding her willingness to participate in an AR program, which was that she was very willing to make use of such services.

### Theme 1. Eager to participate in an adult AR program

Once X had been informed of the other adult AR services that she could access, such as troubleshooting, auditory training, telephonic training and communication strategies e.g. sign language and lip-reading, she expressed an eagerness to access them, indicating that she hoped that she would receive 'help' someday. She further indicated that she would like to work in individual therapy sessions as she found it easier to hear when she was alone and more difficult when there were lots of people or too much noise around her. Her challenge with communicating within a group of people discouraged her from wanting to engage in group therapy, despite its benefits. She indicated that one of the main reasons for participating in AR services was because she felt that she might be able to communicate better, such as learning sign language with her communication partners. As she felt that her hearing aids were not always helpful, especially when there was background noise, she hoped that learning different communication methods would assist her in situations where she found it difficult to hear. She understood that it would require her to go to a clinic on a monthly basis for such services, but felt that it would be worth it if it could improve her ability to communicate.

I hope someday I will get help, that's what encourages me (to participate in AR services).

## 4.5 Objective 4: To explore the personal and environmental factors that influence the accessibility of adult AR services

One theme emerged regarding the factors that influence her accessing adult AR services, these being personal and family related.

### Theme 1. Personal factors: Health

In terms of the personal factors, her health was less than optimal, as she had a pneumonectomy (the removal of one of her lungs), and due to the coronavirus pandemic, she could not attend sessions, with only having one lung putting her at risk of complications should she contract the virus. This restricted her mobility and made it difficult for her to travel. However, even if transport was provided, she was unable to travel due to possible post-operative complications after the surgery, such as being more susceptible to contracting viruses.

I will not be able to go to these programs while there is this corona(virus), my health situation does not agree. Even traveling to this program with stitches, I had a lung removed, I am left with one. I have to look after myself, and not get this disease easily...

## Theme 2. Environmental factors: Travel and inadequate health information

Regarding her family influences, her children lived in Johannesburg and could not assist her to travel to the clinic on a regular basis. Her partner was working full-time during the day and could therefore also not assist with getting her to the sessions. However, due to the abuse from her partner and her financial situation, she was going to live with her father in Umtata. In addition, her circumstances were such that she was unemployed and therefore not able to afford travel costs. When asked if she would be able to travel to sessions should situations after the coronavirus pandemic return to normal, she indicated that she was going to live with her father in Umtata due to her living situation and would not be able to attend sessions. However, her response was based on her impression that AR services were only available in Durban. Once it was explained to her that she was a candidate for cochlear implants (CI), which required AR services thereafter, and could undergo surgery at a hospital in Umtata, she was willing to travel.

Because I will travel when this disease is over, I am going to stay with my father at Mtata. It was my wish to go to this program.

4.6 Objective 5: To explore the perceptions regarding the availability and accessibility of three groupings of services, i.e. audiological counselling services, sensory management and communication intervention (Makhoba and Joseph, 2016) for adults with acquired hearing loss post MDR-TB treatment

Having indicated the challenges that X is likely to experience in accessing the services, she was then asked about her perceptions regarding the three types of services that she may find useful. Each of the services was described to her fully, with an indication of how it would benefit her, given the severity of her hearing loss and her communication circumstances, to enable her to decide if she would find them useful.

### 4.6.1 Audiological counselling services

In terms her perceptions about how audiological counselling would help her, three themes emerged: improve communication, her feeling and emotions, and unrealistic expectations.

## Theme 1. Improve communication

X's perceptions towards audiological counselling was that it would help her communicate with people better. She also believed that the services would help her to the extent that she did not have to use her hearing aids, as the stigma of having a hearing aids affected her. However, X did not have a preconceived conception of AR because she was unaware of such services and had never been trained. After the researcher provided X with information on aural rehabilitation, her perception on the service was positive.

The people (audiologists) that gave me the hearing aids never told me anything about aural rehabilitation. They didn't even mention it at all after giving me the hearing aid that there was an option for me to undergo aural rehabilitation... They didn't teach me anything. They diagnosed me. After that they gave me the hearing aids and that was the end of it.

### Theme 2. Feelings and emotions

The lack of emotional adjustment counselling following the diagnosis of the hearing loss heightened the feelings that X presented with. She reported that the presence of the hearing loss made her feel "different" from other people. Furthermore, X reported feeling "sad", "painful" and "not lovable". These feelings were attributed to the hearing impairment and its effects. She reported that she was struggling to accept that her life had changed due to the hearing loss.

I feel very sad... It (hearing loss) makes me feel painful. It makes me feel that I am different from other people... and I sometimes feel that I am not lovable.

## Theme 3. Unrealistic expectations

X reported that she was not provided with any informational counselling following diagnosis of a permanent hearing loss and the intervention provided by the audiologists did not extend beyond the hearing aid fitting. X reported that the audiologists informed her that hearing aids would improve her ability to hear and no hearing aid orientation was conducted. This information created a sense of unrealistic expectations, as X felt that her hearing would be restored back to normal. Although she did report some improvement with her hearing ability with hearing aids, she did report that she was almost knocked down by cars a number of times as she could not hear them. This also impacted on her ability to cope with the hearing loss in terms of speech, quality of life, work, communication partners and available intervention options.

They only told me that hearing aids will help me... Even with hearing aids, I couldn't hear. I actually almost (got) knock(ed) by cars quite a number of times.

Following the hearing aid fitting, X was able to hear people speak to her as well as sounds behind her, however, she also indicated that there were times when she could not hear and felt the hearing aids did not help her. This was especially in situations where it was noisy or had a lot of people.

They (hearing aids) helped me a lot. I'm able to hear people now, and any sound behind me... I can't hear when they are talking especially when it's a conversation in a group of people. I get disturbed by that. It's better if I am communicating or if I am conversing with one person or two people. X appreciated hearing some form of sound instead of not hearing any sounds. She reported that improved speech discrimination was a challenge even with the use of her hearing aids. She felt frustrated at the realization that she would live the rest of her life using hearing aids. This frustration was increased by the experiences she had encountered with the use of hearing aids, and include pain and hardship due to the embarrassment of the cosmetic appearance of the hearing aids as well as the stigma associated with hearing aids.

The problem is that I am using hearing aids and people see them they talk about me and laugh at me to my face... I'm embarrassed by these things (hearing aids) that I wear because people keep staring at me and talking about me.

## 4.6.2 Sensory management

In terms of sensory management, three themes emerged: perceptions towards hearing loss, feelings towards hearing loss and sensory management of hearing loss.

### Theme 1. Perceptions towards hearing loss

According to X, following the diagnosis of the hearing loss, she was under the impression that the hearing loss was temporary and treatable. This perception emanated as a result of the absence of informational counselling, as well as gaps in her knowledge and understanding of the hearing loss she presents with. In addition, she did not have a family history of hearing loss or any interactions with other people who are hearing impaired prior to the diagnosis, which has exacerbated her lack of knowledge and made it difficult to deal with the hearing loss.

What can I say, I just have that hope that I will get help...

X's perception towards her hearing loss was that it was temporary, it would be cured and she would be given medication (ear drops) that will "open" her hearing so that she could hear better. She did not think that her hearing loss was permanent or that she would be given hearing aids to hear. She had hope that she would be able to hear again and prayed that her hearing would be restored.

I thought that since now they know I have a hearing loss they will give me medication to open my ears so that I can hear... hear properly. I didn't think that the hearing loss wouldn't be untreatable and they would give me these things (hearing aids). Even with these things (hearing aids) I sometimes don't hear so these things don't even help me.

#### Theme 2. Feelings towards hearing loss

X reported that she had hope because she sometimes hears some things for quite a while with no communication breakdowns without the use of her hearing aids. However, after some time, she struggles to hear again. Although X initially had hope in getting help for her hearing impairment, she currently feels that she will never get the help that she requires and this realization has made X feel pain. However, she indicated that she would have to accept the situation by trying to adapt to the life that she is living now, which is a life with a hearing impairment. Even after wearing hearing aids for almost three years, X finds it difficult to accept that she has to wear hearing aids for the rest of her life, and is trying to get used to her new normal. I hope someday I will be able to hear again... I don't know, you know. I sometimes pray that one day that my hearing loss can be restored... my hearing can be restored... I really don't know. I really do wish that one day I will be able to hear. What makes me to have hope that maybe one day my hearing will be restored is that sometimes I hear some things. I hear for quite a long time with no communication breakdowns. But I will have to accept the situation because all this time I'm trying to get used to the kind of life I am living now.

#### Theme 3. Sensory management of hearing loss

X received bilateral hearing aids at Sizwe Tropical Hospital in Johannesburg and at King Dinuzulu Hospital Complex (KDHC) in KwaZulu-Natal (KZN), and at neither session does she recall receiving sensory management counselling on the permanency of her hearing loss, or that she would be using hearing aids for the rest of her life. She also felt that the audiologists 'forgot' about her after the hearing aid fitting. In addition, her feelings of inadequacy influenced the management of her hearing loss.

They (audiologists) just gave me the hearing aids and they forgot about me.

### **4.6.3 Communication intervention**

Three themes emerged from communication intervention: troubleshooting of hearing aid, awareness of other hearing devices and communication intervention.

## Theme 1. Troubleshooting the hearing aid

In addition, X found her hearing aids to be 'challenging' most of the time. As she does not know how to fix her hearing aid when it does not work properly, she has to frequently visit the hospital in order to get help.

... even hearing aids sometimes don't work, I even came to the hospital to tell them.

## Theme 2. Awareness of other hearing devices

Aside from hearing aids, X was unaware of other hearing devices available, such as cochlear implants. Although X received some form of amplification with hearing aids, she struggled with other aspects, such as speech discrimination. Once X was informed of the possibility of receiving a cochlear implant in Umtata (where she was going to live with her father), she indicated that she was willing to undergo surgery.

Thank you very much my sister. I will do it there (in Umtata) then.

## Theme 3. Communication

The findings from the current study revealed that X did not have access to communication intervention and this contributed to the communication difficulties experienced by X during communication interactions. Due to the hearing loss, visits to the clinic on a monthly basis for X are challenging, as people fight with her because of her hearing loss. Although the doctor and nurse know about her hearing impairment, other patients at the clinic do not know. X indicated that she did not inform them. Due to the visibility and cosmetic appearance of her hearing aids, people at the clinic treated her differently. Furthermore, the stigmatization with her hearing aids was evident when people stared and pointed at X, laughed at her, made fun of her, talked about her and pitied her.

In places like clinics, people fight me because of chairs and I can't hear so they fight with me... The doctor and the nurse know that I have a hearing loss but the people around me they don't know. I've never told the people around me at the clinic. They are the ones who look at me because I'm wearing hearing aids and then they gossip about me. They point at me. Others even go to the extent of laughing at me and others feel pity for me.

#### 4.7 Summary

The results of the study were obtained from three interview sessions with X on three occasions. From X's responses, it was confirmed that she had no prior knowledge or awareness of adult AR services. However, she was willing to participate in such services. X's perceptions towards her hearing loss and participation in AR services, as well as the factors that influenced the accessibility of AR services were also discussed.

#### **Chapter 5. Discussion**

## **5.1 Introduction**

The study's findings indicate that adult aural rehabilitation (AR) appears to be currently not facilitated at the study site, especially for patients with a hearing loss post multidrugresistant tuberculosis (MDR-TB) treatment. The following chapter is a discussion of the results obtained from the study, being presented per objectives with respect to the identified themes and sub-themes.

## 5.2 Objective 1. To determine the influence of an acquired hearing loss on quality of life (QOL) post multidrug- resistant (MDR-TB) treatment

The results of this objective suggested three themes, these being lifestyle changes, abusive and communication experiences.

## Theme 1. Lifestyle changes

X reported a drastic change in her quality of life (QOL) due to hearing loss, prior to which she was a sociable person who loved to go out or spend time with her family and friends. X reported that she used to have friends, communication interactions with her children were better and her relationship with her partner was healthier. Since being diagnosed with hearing loss, X indicated that her life has drastically changed and she no longer identifies as the person that she used to be, the change having negatively affected her quality of life. As per the International Classification of Functioning, Disability and Health (ICF) framework (WHO, 2002) and the applicability to X's case, there are now limitations in her participation in various activities as a result of her hearing impairment, which affects many aspects of her life.

According to BetterHealth (2017), hearing loss can impact on an individual's personal and work life, which could lead to fewer educational or career possibilities as a result of the reduced communication (BetterHealth, 2017). Hearing impaired individuals may also experience social withdrawal due to the limitations in accessing services and communication problems (BetterHealth, 2017). Furthermore, people suffering from hearing loss also experience emotional difficulties that are caused by reduced self-esteem and confidence (BetterHealth, 2017). The World Health Organization (WHO) (2020) contends that the impact that hearing loss has as either a functional impact (difficulty in communicating with other people), social as well as emotional impact (rejection during communication, which impacts quality of life, giving rise to feelings such as loneliness and isolation) and economic impact (where hearing losses that are not addressed cause a US \$ 750 billion annual cost worldwide). In addition, Masterson (2016) reported that the effects of hearing loss on QOL can start as minute and grow as it increases in severity. These effects include asking for repetition, which causes frustration and the difficulty of hearing conversations with background noise (Masterson, 2016). Social activities result in self-isolation due to not being capable of understanding or contributing to conversations (Masterson, 2016). The consequences of communication barriers could lead to limited interactions at work, as well as strained marriages and friendships (Masterson, 2016). Other effects of hearing impairment include lack of enjoyment, and the sounds that want to be heard now being mute or have no quality (Masterson, 2016). Furthermore, safety is compromised and the hearing impaired person may miss sounds (Masterson, 2016), such as alarms. In addition, mental health is also affected by hearing loss, which could lead to depression (Masterson, 2016).

#### Theme 2. Abusive experiences

There are also communication strategies applicable to communication partners, such as speaking more clearly, slower and naturally (Hearing HealthCare Centers, 2017). X experienced abuse from her partner due to her hearing impairment, as he was frustrated by her inability to hear and respond appropriately. This suggests that including communication partners in therapy could considerably improve communication outcomes.

## **Theme 3. Communication experiences**

X experienced communication breakdowns as a result of her hearing loss despite wearing hearing aids, and used self-isolation as a coping mechanism to reduce communication interactions. However, minimizing the side effects of a hearing loss is not solely dependent on the use of hearing aids, as the implementation of communication strategies is an integral part of AR. This indicates that various aspects of AR are omitted, and should strategies be available to patients with a hearing loss, it would make their communication interactions much easier. By including some aspects of AR in hearing aid orientation sessions, better communication can be facilitated, as this extends beyond the fitting, use, care and maintenance of hearing aids, and should also include communication aspects. According to the American Speech-Language-Hearing Association (ASHA) (2020), education and orientation to hearing aids included use, care and information being made available to patients, families or caregivers. This included areas such as telephone use, wearing schedule and routine maintenance (ASHA, 2020). Communication strategies are important, and although hearing aids may be optimal and the best form of treating a hearing impairment, the addition of communication strategies allows for their maximal usage and overcoming associated challenges (Hearing HealthCare Centers, 2017). Communication strategies training is an integral component of AR, as listeners who have a hearing impairment have frequent interactions with those who may not know about their listening challenges (Tye-Murray, 1991). Talkers may fail to realize that the person with the hearing impairment misinterpreted their speech and may be unable to correct the breakdown in communication (Tye-Murray, 1991). Hence, communication strategies training becomes important for the listener with the hearing impairment, in terms of developing self-confidence as well as skills (Tye-Murray, 1991). It is especially important for the listener with the hearing impairment to notify and provide instructions to the talker (Tye-Murray, 1991) in order to facilitate better communication between them.

## Theme 4. Self-taught communication strategies

X indicated that she developed lip-reading and writing strategies, which helped her during communication interactions. While lip-reading and writing do assist with better communication and repair strategies, there are other techniques that people with a hearing impairment could use, such as seating arrangements in noisy environments and requesting clarity (Hearing HealthCare Centers, 2017).

## 5.3 Objective 2: To explore the awareness of participation in an adult aural rehabilitation (AR) program following the hearing aid orientation

One main theme emerged from this objectives, that being there X had very little awareness of adult AR services.

#### Theme 1. Little awareness of adult AR services

The results indicate that X was not aware of adult AR services that she should have been able to access at the time her hearing aid was fitted and thereafter. This was partly attributed to the cessation of interventions after the hearing aid fitting, as X indicated that she was given hearing aids by the audiologists in absences of informational counselling and AR services. This appears to be in the context of a scarcity in the provision of AR services in South Africa (SA) (Makhoba & Joseph, 2016) in the hospitals that provided her with hearing related services, all of which contributed to X's lack of awareness. Although hearing aids contribute to minimizing the effects of a sensorineural hearing impairment on social, psychological and emotional aspects (Rutherford and Petersen, 2019), there have been positive outcomes in terms of AR as part of treatment selection (Abrams, Chisolm & McArdle, 2002, Hawkins, 2005, as cited in Rutherford and Petersen, 2019). These positive outcomes are illustrated in studies by Hawkins (2005) and Abrams et al. (2002). According to Hawkins (2005), who conducted an evidence-based review on the successfulness of counselling as well as communication strategy directed group therapy AR services, hearing aids cannot restore hearing back to normal for individuals with sensorineural hearing impairments. This is because there are other factors, such as disruptions in frequency discrimination or loudness perception, that affected by this type of hearing loss (Hawkins, 2005). In such instances, the hearing aid user has difficulty with residual hearing, especially in certain environments (Hawkins, 2005). Although hearing aid

interventions alone can be beneficial, optimal rehabilitation may not be achieved (Hawkins, 2005).

There is evidence that adults participating in AR programs can experience a brief decrease in self-perception of their hearing handicap (Hawkins, 2005). Furthermore, such participants could learn to utilize communication strategies and as well as their hearing aids more advantageously (Hawkins, 2005). Abrams et al. (2002) conducted a study on the use of hearing aids only compared to the use of hearing aids with the addition of brief group AR post hearing aid fitting AR, with the latter intervention being found to be more economical (Abrams et al., 2002).

Therefore, there is evidence in the literature that including AR as an addition to hearing aid fittings has better outcomes. The involvement in AR services could therefore allow for the reduction of activity limitations and participation restrictions.

However, in X's case, the audiologists did not provide her with informational counselling or discuss AR service as an option. This could be due to audiologists adopting a technocentric service delivery model (Montano & Spitzer, 2014, as cited in Spangler, Houston & Bradham, 2015). This model can be illustrated when audiologist service delivery centres around patient's hearing technology use, for example hearing aids or CI (Spangler et al., 2015). However, this model seems to addresses the physical problem model, which is regarded as the optimal solution, ie. medical model (Sharma, 2016), but is not supported by the ICF model as it does not take the non-medical components into account, ie. social model (Sharma, 2016). However, other areas are often overlooked, such as greater listening, communication as well as functional well-being (Spangler et al., 2015). The literature supports the contention that

patients in general are not made aware of AR, the results of the agreeing with this sentiment. It is therefore apparent that AR is a crucial component for improving the QOL of a person who has a hearing loss (Rutherford & Petersen, 2019). As such, the impact of AR on quality of life needs to be taken into consideration in promoting the awareness of AR services among patients with hearing impairment and motivating for their provision.

However, research into the practice of AR in Africa is limited (Rutherford & Petersen, 2019), with authors such as Pienaar et al. (2010) and Olusanya (2004) reporting on AR from SA and Nigeria respectively, the studies concentrating on AR services in terms of hearing aids (Rutherford & Petersen, 2019). The findings of both studies excluded the other elements of an AR program, such as counselling and environmental management (Rutherford & Petersen, 2019). The lack of literature could be one of the reasons why audiologists may not invest in the promotion of these services, as their perception of AR provision may not extend beyond the hearing aid fitting. This in turn could be a contributing factor in terms of patients' lack of awareness on the availability of such services. An additional factor that may contribute to the lack of awareness of services for patients with hearing loss could start with audiologists education as well as training on AR (Rutherford & Petersen, 2019). According to a study by Makhoba and Joseph (2016), most audiologists reported not feeling adequately trained in the majority of AR services. The sense of being ill equipped could be a reason why audiologists tend to ignore or neglect the provision of AR services. For audiologists to be confident as well as competent in the delivery of services, there needs to be theoretical learning and practical application from training institutions (Rutherford & Petersen, 2019).

Furthermore, audiologists need to have an interest in the provision of services, with Makhoba and Joseph (2016) stating that a high level of audiologists interest in the topic has been generally reported. Once interest in developing AR abilities has been determined, audiologists should focus on their professional development (Rutherford & Petersen, 2019), and can expand their knowledge through continuing professional development (CPD) activities. According to Brennan (2018), who explored the importance of CPD, although identifying the knowledge gaps can be difficult when learning, acknowledging some gaps could be an important part of practice. Additionally, if they have been practicing for a while, some initial training could be impaired and components forgotten (Brennan, 2018). This highlights the importance of audiologists refreshing their theoretical and practical techniques, and learning about developments on the topic through participation in CPD activities. This will give them an opportunity to expand their knowledge and therefore be better equipped to expand their roles. In addition, CPD activity development and presentation can be a team effort, with the collaboration of the various healthcare disciplines (Banotai, 2004, as cited in Wium & Gerber, 2016), such as the various professionals involved in assessing and managing MDR-TB patients.

The inclusion of CPD activities in a multi-disciplinary team (MDT) would also assist healthcare professions in learning from and about each other in terms of their scope of practice. In turn, this could facilitate the inclusion of audiologists in the MDT who specialize in working with patients with MDR-TB, and thus promote an awareness of the profession, the services they provide, and appropriate and timely referrals. Audiologists and other healthcare workers could benefit from CPDs through informational sharing, which could lead to cross referrals and improved service delivery, this being the ultimate goal. Through information sharing, doctors would be able to see the value of including audiologists in the MDT right at the beginning of patient intervention, which would prevent referrals at the end when the patient already has an irreversible hearing loss. This would also allow audiologists to explain to the patient the possibility of acquiring a hearing loss as a result of the MDR-TB medication, offering counselling, conducting baseline assessments and discussing the option of intervention services, such as AR services, should the patient experience hearing difficulties.

Although the current study did not explore the university curriculum, Rutherford and Petersen (2019) suggest universities or training institutions can also offer courses in AR, and interested parties can source free online resources to enhance their knowledge on the topic. The AR resources that are acquired through these courses could also be made available to those patients interested or attending AR clinics to improve their awareness. In addition, hearing health care prevention and promotion workshops could be used to create awareness on AR services for both audiologists and hearing impaired individuals. In a study by Maharaj, Ross, Maharaj and Campbell (2016), which assessed the attitudes and knowledge of out-patients at an MDR-TB institution in the eThekwini region of KwaZulu-Natal (KZN) in SA, it was found that knowledge on its diagnosis was satisfactory. One of the suggestions was that interventions for patients should also cover social aspects, such as the attitudes and education of patients. These recommendations are important for the current study, which found that if patients had more information on the effects of MDR-TB treatment and the option of participating in adult AR services, they would be better equipped to deal with an associated profound hearing loss. This could be achieved not only through the awareness of patients of adult about AR services post MDR-TB treatment, but the need for such services taken into consideration by health care practitioners when dealing with patients thereafter. According to Rural Health Information Hub (RHIhub) (2020), health education can be used to present information for target populations regarding specific health topics, such as health benefits (RHIhub, 2020). Some activities

include lectures or workshops, and strategies include presenting information via posters or books, or ensuring the proficiency of the program staff to adhere to models of the program (RHIhub, 2020). Therefore, health education can be used to improve the awareness of AR services for health care professionals as well as for patients with an ototoxic hearing loss.

## 5.4 Objective 3: To explore the willingness of an adult to participate in an adult AR program following the diagnosis of a permanent hearing loss

One theme emerged, that being X's eagerness to participate in an adult AR program.

## Theme 1. Eager to participate in an adult AR program

X's enthusiasm towards participation in AR services, learning alternative methods of communication and preference for individual rather than group therapy encourages not only patient participation in AR programs, but highlights the need to tailor suit interventions individually. According to Sweetrow (2015), there are advantages and disadvantages of both individual and group therapies, but in terms of the number of patients to the number of audiologists ratio in the SA context, group therapy would be the preferred method of providing AR services in general. Although the literature states many benefits of individual therapy, such as individual and group therapy would be a better option. This would allow X to benefit from the individualization of sessions (Sweetrow, 2015) in order to help her address specific issues. Group therapy would also be beneficial, as it facilitates self-advocacy, problem identification and communication strategies (Oestrich, 2018), which are areas that X struggles with. Furthermore, group therapy would be able to assist X in dealing with the stigmatization of hearing impairment (Hetu, 1996). As X has experienced social abuse, and as a result avoids interactions with people as much as possible, group therapy would have allowed her to be

included in supportive networks with other group members (Oestrich, 2018). This would assist X to reduce her feelings of loneliness, assist her in establishing healthy relationships with others and increase her self-confidence.

Additionally, interacting with other hearing impaired individuals could be a platform to share experiences, such as hearing challenges and social interactions (Oestreich, 2018). This would assist X in interacting with individuals who also have a hearing loss and therefore understood her difficulties, which could help further reduce her feelings of loneliness. Group therapy could also result in positive attitudes about oneself, learning coping strategies and understanding how to use them during interaction with others (Oestreich, 2018). Furthermore, group therapy would be beneficial for X in terms of learning how to deal with her problems with communication from the experience of others. This is because working in a group may help to resolve shared communication breakdowns as well as determine likely repair strategies (Oestreich, 2018). Group therapy also allows participants to describe their feelings with communication difficulties, such as frustration or embarrassment, which also allows others in the group to increase their insight as a result of these experiences (Oestreich, 2018). This could also help X to cope in situations where her hearing aids do not help her, for example in background noise, and her dependency on other modes of communication in these situations.

Furthermore, X expressed enthusiasm to learn alternate modes of communication, such as sign language, which is especially important for an individual with hearing impairment who cannot always rely on their hearing devices. According to Family Audiology (2018), sign language not only increases communication but helps to address gaps. It also aids in improving communication overall and assists with areas such as expressive communication (expression of words and feelings), improved body language interpretation, reduced frustration and the ability to communicate with everyone and not just people with hearing loss (Family Audiology, 2018). However, sign language may not be a viable option for X at this stage as she has an acquired hearing loss and already has spoken or verbal communication present. Furthermore, X would require that her frequent communication partners also learn sign language in order to facilitate better communication between them, which may not a possibility due to her partner's work commitments and her children living in a different province. In addition, sign language would be a completely new concept for X, and in order to sustain its familiarity, she would need to be able to use it frequently. Due to X staying at home all the time and self-isolating, she would not be able to practice the language she was learning. Although X had already implemented the use of lip-reading and note-taking through trial and error, it would have been beneficial for her to learn other ways to communicate, for instance, visual signals, gestures, visual aids, questions that are open-ended, rephrasing and repetition (National Deaf Center for Postsecondary Outcomes (NDC), 2019).

## 5.5 Objective 4: To explore the personal and environmental factors that influence the accessibility of adult AR services

Two themes were identified, which were the personal and environmental factors that influenced X's accessibility to adult AR services.

#### Theme 1. Personal factors: Health

The presence of the hearing loss affected X's QOL as there was a significant difference between before and after she lost her hearing. The difficulties she encountered encouraged her to be willing to participate in adult AR services. However, despite her willingness, she was unable to attend sessions for a number of reasons, including the post-operative stitches from the recent removal of her lung (pneumonectomy), which significantly reduced her mobility. Furthermore, the operation placed her at a higher risk of contracting illnesses, which was of concern for her, especially during the coronavirus pandemic.

#### Theme 2. Environmental factors: Travel and inadequate health information

Even if X was able to travel to and from sessions, transport constraints was another challenge. The literature indicates that logistics is a factor to consider during the implementation of AR services in the South African context, including the inability to afford transport costs to access them (Makhoba & Joseph, 2016). The literature also indicates that with technological advancements, AR, such as tele-audiology, has become more accessible, especially for remote and rural regions (Lawrence, 2012, Nemes, 2010, Swanepoel, 2012, as cited in Makhoba & Joseph, 2016). This is further supported by Africa's technological advances and increased mobile connectivity, which allows for audiological interventions, especially in communities without access to local services (Kruyt & Swanepoel, 2014). Although the expectation would be a surge in tele-audiology, due to the coronavirus pandemic,

audiology practices in the SA context is still challenging. This is because the majority of private practices were closed during the four months of government imposed lockdown, and telehealth can attend to existing patients only (Swanepoel, Clark, Yerraguntla, Aziz, & Al-Kofide, 2020).

Many public healthcare practitioners were redeployed to assist with the COVID-19 pandemic across South Africa, or were sent home until there services were required as per the lockdown regulation levels (Swanepoel et al., 2020). Despite a strong motivation to extend telehealth to attend to new and existing patients (Swanepoel et al., 2020), especially during the epidemic, to ensure limited contact and appropriate social distancing, not all those requiring AR have access to technology, and therefore cannot benefit from remote assistance, even if they are existing patients. Therefore, it is essential that audiologists make maximum use of face-to-face patient visits, especially when addressing queries related to hearing devices or providing educational handouts (ASHA, 2020), so that patients are not only informed of the various facets that compose AR but also have tasks that they could complete on their own. However, out of the 57 million people that constitute the SA population (Mogotsi & Bearak, 2020), statistics show that majority of the population do in fact have access to the internet (Clement, 2020). Therefore, a solution to providing AR services could be computer-based AR services, tele-audiology or tele therapy, as audiologists are in a good position to provide these services, given that more than half the population have internet access and could benefit from services remotely. These types of AR services could also minimize issues related to transport and time constraints, or for those patients who are working and cannot attend AR appointments at the hospital regularly. However, the study by Makhoba and Joseph (2016) found very little use of computer-based AR and tele-audiology, which could be attributed to limited knowledge and resources required to implement this technology (Makhoba & Joseph, 2016).

Another challenge for X was that her communication partners were also unable to attend sessions with her, which could have an effect on the outcome of therapy sessions. This is because the outcome of including communication partners in AR is significantly higher as opposed to individual participation in terms of the impact of hearing loss on QOL (Preminger, 2003). Furthermore, it is also important for communication partners to be trained in order to facilitate better communication. This is because communication with others is an experience that is shared and can be highly affected due to hearing impairment (Brooks, Hallam, & Mellor, 2001). Significant others can have difficulties with direct communication, and personal as well as social relationships (Brooks et al., 2001).

A study by Tye-Murray, Spehar, Sommers and Barcroft (2016) investigated auditory training amongst recurrent communication partners, with an auditory training computerized program used for 6-weeks being used with 10 couples. The spouse had recorded stimuli, and their hearing impaired partner concluded auditory training with their spouses' recordings. It was found that auditory training could possibly improve the hearing impaired older participants' ability to recognize their spouses' speech, which in turn could increase the couples' communication interactions. Therefore, communication becomes enhanced when parties make an effort to ensure the hearing and understanding of messages (Weinstein, 2016), making it important for audiologists to include both patient and communication partner when providing AR programs. While the study by Tye-Murray et al. (2016) used an innovative and technological method to facilitate auditory training, the benefits obtained by the participants may not be achieved in the SA context due to the absence/lack of auditory training computerized program. However, the focus is not on the program, but rather the idea that spouses play a central role in facilitating auditory training, their involvement contributing to improved auditory skills.

X was also unaware of cochlear implants (CI) and the advantages of it in comparison to hearing aids, as the latter was not helpful in terms of the severity of her hearing loss. However, CI are not always advantageous, with the risks including some users not receive any hcaring benefit, the loss of residual hearing, the inability to guarantee the understanding of language well after surgery and the associated expense, such as repairs (FDA, 2018). Furthermore, CI users require an inter-professional team for comprehensive care, which may include healthcare professionals such as otolaryngologists/otologists, audiologists and speechlanguage pathologists (ASHA, 2020). The availability and accessibility of services in public hospitals, and the limited options can reduce intervention for individuals with hearing loss. For example, specialized rehabilitation, such as CI, are not a prioritization for the South African National Department of Health (NDoH) expenditure due to other priorities, such as diseases that are life-threatening, hence the focus being more on primary health care (Kerr, Tuomi & Müller, 2012). Although the cost of CI systems and associated expenses, such as surgical fees, are high (Kerr et al., 2012), there is evidence that it is possible to implement in the South African context, with such measured being more often performed in the private health care sector. The earliest multichannel CI surgery occurred in November 1986 at the Tygerberg Hospital, University of Stellenbosch Cochlear Implant Unit (Kerr et al., 2012). This suggests that sufficient experience should had been gained in providing CI as an intervention option for patients accessing services in the public health care. However, only five provinces in SA who have CI implant programs and it appears that not all programs occur to the public sector (South African Cochlear Implant Group, 2020). Furthermore, there is evidence that developing countries also have ethical concerns as well as practical challenges when it comes to CI (Fagan & Tarabichi, 2018). Resource-constrained settings required to cope with CI technology, CI prioritization over limited hearing aid access, CI candidacy in destitute populations and unavailability of CI that are less complicated and more affordable for such populations raised

ethical concerns (Fagan & Tarabichi, 2018). Healthcare infrastructure, limited trained audiologists for the CI candidacy process and travel constraints contributed to practical challenges (Fagan & Tarabichi, 2018).

5.6 Objective 5: To explore the perceptions regarding the availability and accessibility of the three groupings of services, i.e. audiological counselling services, sensory management and communication intervention (Makhoba and Joseph, 2016) for adults with acquired hearing loss post MDR-TB treatment

A number of themes were reported for each of the three areas, these being detailed further.

## 5.6.1. Audiological counselling services

Three themes emerged under this service component, these being improved communication, feelings and emotions and unrealistic expectations.

#### Theme 1. Improve communication

Audiological counselling is considered to be a component of adult AR in terms of one of the three groupings of AR services, as discussed by Makhoba and Joseph (2016). The accessibility and perceptions towards audiological counselling for the current study was explored with focus on personal adjustment counselling and informational counselling. It was found that X was under the misconception that audiological counselling would help her during communication interactions without having to use her hearing aids and this was attributed to the fact that she had not received AR services. However, once the concept was explained to her, she had positive views and showed enthusiasm in participation.

## Theme 2. Feelings and emotions

It was evident that X was not provided with any personal adjustment counselling in terms of the permanency of her hearing loss, nor any coping strategies to deal with the emotions related to her condition. According to Taylor (2018), personal adjustment types of counselling define the way in which audiologists assist patients to cope with the social as well as emotional impact due to their hearing impairment. This form of counselling also allows audiologists to guide patients when dealing with the internal challenges that are associated with the diagnosis of a hearing loss (Taylor, 2018). Some methods provided by counselling related to personal adjustment include the audiologist devoting sufficient time to patients requiring hearing devices and related rehabilitation therapy, showing empathy and creating a comfortable atmosphere for them to discuss their feelings or emotions, and implementing communication skills, such as eye contact or reflective listening (Taylor, 2018). If X had received some form of personal adjustment counselling, it would have allowed her to deal with her negative feelings and emotions associated with her hearing loss.

# Theme 3. Unrealistic expectations

Unrealistic expectations contribute towards the contextual factors of the ICF framework (WHO, 2002). Many factors influence the satisfaction of hearing aid fittings, such as intrinsic and extrinsic factors. Intrinsic factors that could affect hearing aid satisfaction applicable to X include hearing loss, negative attitude, personality changes, hearing aid experience and expectation, self-perceived incapacity and handicap (Wong, Hickson, & McPherson, 2003). Extrinsic factors that could affect hearing aid satisfaction and are applicable to X include type of device, listening environments, difficulties, counselling, benefit and sound quality (Wong et al., 2003). However, these factors were expected regarding the hearing aids, as even powerful devices for individuals who have a severe-to-profound hearing loss are not optimal for speech

discrimination purposes. This concept is evident in the studies by Gambôa, de Sousa, Duarte and Oliveira (2018) and Hornsby (2012). Although high frequencies are affected first, as expected with an ototoxic hearing loss (Huth, Ricci, & Cheng, 2011), the low frequencies become affected when there is continued exposure to ototoxic medication, which in turn affects the speech spectrum (Gambôa et al., 2018). An increase in hearing loss results in a decrease in audibility in certain environments, which then results in further problems with speech understanding (Hornsby, 2012).

Furthermore, hearing aids that are well-fit, for example, that match prescriptive formula targets, such as National Acoustic Laboratories', Non-linear Fitting Procedure, version 1 (NAL-NL1) (Hornsby, 2012), may improve audibility or understanding, but do not promise the full restoration of audibility, as this may not be the goal for the majority well-known methods of prescriptive fittings (Hornsby, 2012). The rationale of the NAL-NL1 is the maximization of speech intelligibility in conjunction with restraining loudness at normal levels or lower (Byrne, Dillon, Ching, Katsch & Keidser, 2001). According to McKechnie (2017), having an unsuitable listening device affects quality and sound, causing discomfort and reduced benefit. In the event of powerful hearing aids still not being optimal for hearing impaired individuals, CI may be an option (Ehrenfeld, 2019), which are ideal and should be made available for such patients, as the literature indicates that these patients do well with this device. According to the U.S. Food and Drug Administration (FDA) (2018), the hearing range for CI spans from almost normal hearing levels to understanding speech. Most CI users have the ability to perceive sounds that are soft, medium or loud, and adult CI users often receive benefit instantaneously (FDA, 2018).

## 5.6.2. Sensory management

Three themes emerged from the above, ie. perceptions towards hearing loss, feelings towards hearing loss and sensory management of hearing loss.

# Theme 1. Perceptions towards hearing loss

X's perception of her hearing loss could be attributed to lack of information counselling. For example, X felt that she would able to hear again and that medication (ear drops) could be used to cure her hearing impairment. According to Taylor (2018), information counselling places an emphasis on educating individuals with a hearing loss, as well as their families, based on the results of their hearing tests. This also includes providing information on the repercussions of leaving hearing losses untreated and how hearing aids play a role during the treatment process (Taylor, 2018). Furthermore, counselling patients with ototoxic related hearing loss require audiologists to provide information to patients and families on ototoxicity symptoms, medication side effects, otoprotective strategies as well as hearing loss management (Wium & Gerber, 2016). This is done in order to equip patients when making informed decisions regarding treatment options in the event of a hearing loss (Wium & Gerber, 2016).

However, audiologists tend to lean more towards personal adjustment types of counselling instead of providing informational counselling (Taylor, 2018). The inclusion of informational counselling could have contributed to providing information to X in order to facilitate her in having a better understanding of her hearing loss. X may have gained information related to her hearing loss, the various types of technology in terms of listening devices, as well as services that are available (Tye-Murray, 2009, as cited in Ratanjee, 2014) such as AR. The lack of informational counselling led to false hope and unrealistic expectations. This portrays the management of hearing loss in the SA context, which seems to

lack informational counselling and is limited to hearing aids, which is supported by the absence of informational counselling provided to X in the two hospitals that she was attending. This questions the service provision pertaining to the management of hearing loss for patients with MDR- TB.

According to Saunders, Lewis and Forsline (2009), counselling prior to hearing aid fitting could contribute positively towards the outcome of hearing aid fittings, as it allows expectations towards life quality as well as self-image to be addressed. In addition, unrealistic expectations before the fitting of hearing aids should be addressed with caution in order to prevent reduced expectation, as this could lead to patient discouragement and demotivation (Saunders et al., 2009). However, this was contradicted in the current study, as X had unrealistic expectations towards her hearing aids, which led to increased expectations and false hope. The study by Saunders et al. (2009) showed data indicating positive expectations pertaining to the impact of hearing aids on psychosocial health, which is important for a more successful outcome of hearing aid use. From X's responses, it is evident that if patients are provided with counselling prior to hearing aid fitting, this not only helps with formulating realistic expectations, but also assists their coping with the effects of the hearing loss and five stages of grief that may be apparent. In addition, the counselling would motivate patients to be adherent to the use of their hearing aids, which could also help with positive psychosocial health benefits.

# Theme 3. Feelings towards hearing loss

It appears that service delivery of the hearing loss for patients post MDR- TB treatment does not extend beyond diagnosis and fitting of hearing aids as a form of intervention. Aminoglycosides is a drug that causes permanent hearing impairment (Selimoglu, 2007), and patients should be provided with information regarding the possibility of a permanent hearing loss as well as about the available options to manage it in order to minimise unrealistic expectations. Furthermore, it is the duty of clinicians to have discussions with patients to review the risks as well as benefits of the treatment (Edersheim & Stern, 2009). This can be done by the doctors who are prescribing the treatment, with the assistance of audiologists, when conducting assessment, management and intervention of hearing loss. According to a study by Ramma et al. (2019), which investigated the statistical factors related to the utilization of services for ototoxic monitoring by patients with MDR-TB at a Western Cape TB hospital, it was the duty of the medical and nursing staff to refer to audiology in order to obtain baseline assessments.

The study by Wium and Gerber (2016), which reported on doctors' knowledge and practices and audiologists' roles at a tertiary hospital, indicated that 32% of participants never referred patients to audiology, 48% sometimes did and 18% routinely referred them. A piloted study by De Andrade, Khoza-Shangase and Hajat (2009), which investigated the perceptions that oncologists had regarding cancer chemotherapy ototoxic effects at two Gauteng Province state hospitals, found that 50% of participants referred patients receiving chemotherapy to audiologists for management. These studies confirm that doctors are currently responsible for audiology referrals, and supports the need for audiologists to be included in the MDT to work specifically with patients who have MDR-TB, as their informational counselling can begin long before the hearing loss manifests.

The literature also supports the role of the audiologist in terms of counselling and their inclusion in the MDT. Due to doctors experiencing high caseloads and time constraints, it is audiologists who offer support to doctors who are involved in teams for ototoxic management (Wium & Gerber, 2016). This could be due to audiologists being more likely to consider patient communication as an important factor in health care, or the probability of having good communication skills due to their profession emphasizing on communication disorder management (Wium & Gerber, 2016). These findings further magnify the gap in the multidisciplinary (MDT) with the absence of audiologists, and provides a critical justification for them to be included as part of the team. Hence, the role of the audiologists should include addressing the factors related to ototoxic hearing loss, for example, by providing information in order to form realistic expectations and providing proper counselling.

Audiologists should also be responsible for referrals to a psychologist or psychiatrist, should these services be required. This is because the inclusion of the psychologist in managing patients who have cochleotoxicity can help them to address feelings of depression as well as support changes in their lifestyle (Petersen & Rogers, 2015). Psychologists would also be able to provide counselling on a regular an ongoing basis (Ryback, 2016). Furthermore, referring to a psychiatrist would allow for the diagnosis of mental illness or medical management, including writing prescriptions and providing services that can occur on a weekly/monthly basis (Ryback, 2016). If referrals by audiologists to psychologists or psychiatrists were taken into consideration during audiological intervention, patients would be able to better cope with hearing loss and its associated effects.

The benefits of counselling include better communication and interpersonal skills, providing depression and anxiety relief, improving self-esteem and confidence and resolving conflict (Hudson Valley Community College, 2019). Thus, many of the feelings expressed by X could have been addressed through counselling with the help of a psychologist or psychiatrist. X indicated that she was faced with many unpleasant situations as a result of her hearing impairment. These included abuse by her partner and people around her due to her not being able to hear, the use and perceived stigmatization of using hearing aids. Due to the emotional effects of having a hearing impairment, X became self-isolated and preferred to have no contact with other people. This relates to the ICF framework in that her normal social activity and participation in family and other functions was affected by the presence of a hearing loss and consequently resulted in adversely affecting her feelings, which contributed to personal factors.

X also felt that her hearing loss made her feel different from other people. She stated that although her children were supportive, she did not receive any support from her partner at all. These experiences and feelings indicated that X required counselling for the stigmatization of hearing loss and the use of hearing aids. According to Wallhagen (2009), those who suffer from a hearing impairment at times view themselves differently. However, for the hearing impaired person, the opinions of people that they are close to e.g. partners, children and friends, could also affect a person's opinions or choices with regards to their hearing health (Wallhagen, 2009). Some people may not understand the challenges faced by the hearing impaired individual and effective treatment benefits, and therefore perpetuate stigmatization (Wallhagen, 2009). This can be illustrated when a person with a hearing loss has a partner who has a negative approach to hearing aids, subsequently the person with the hearing loss would rather not visit the audiologist in terms of addressing the hearing loss (Wallhagen, 2009). In a more supportive environment, however, the person with the hearing loss would be motivated to move forward, discover the various treatment options and are able to use hearing aids minus the feeling of being judged or stigmatized (Wallhagen, 2009).

# Theme 4. Sensory management of hearing loss

Sensory management constitutes the three groupings of AR services, these being audiological counselling services and communication intervention (Makhoba & Joseph, 2016). The proper testing as well as fitting of a hearing aid is vital (Clason, 2019). While the fitting of a hearing aid is important to treat hearing loss related to inner ear damage (Mayo Foundation for Medical Education and Research (MFMER), 2020), the satisfaction of hearing aids needs to be taken into consideration. X's sensory management of her hearing loss was due to her receiving inadequate information transfer (environmental factors) and her feelings of inadequacy (personal factors) which relate to the ICF framework.

#### 5.6.3. Communication intervention

Three themes were derived, that being troubleshooting of hearing aid, awareness of other hearing devices and communication.

# Theme 1. Troubleshooting the hearing aid

X revealed that she experienced many problems with the hearing aids in terms of how they worked, changing the batteries, cleaning them and changing the loudness, and consequently visited the hospital for follow-up appointments frequently for troubleshooting, indicating issues with service delivery. If X had been given hearing aid troubleshooting tools during her follow-up appointments to the audiologists, this would have reduced the number of trips she made, saving time and money. The need for AR services would have also been considered, as X would have become aware of the possibility of participating in various activities and adhering to an AR program that focuses on topics such as hearing aid troubleshooting. X would have been able to assist herself at home and prevented the need for her to travel back and forth to the hospital. According to the National Institute for Health and Care Excellence (NICE) (2020), follow-up appointments to audiology play a key role for many reasons. This includes evaluating the adaptation to the hearing aids, resolving difficulties earlier rather than later, analysing individual care plans and providing additional advice regarding progress (NICE, 2020).

Having the preferred one-on-one therapy arrangements allows the audiologist to evaluate the fitting, use of and adjustment to the hearing aids, which, if the service was not provided, may result in patients not making use of their listening device, thereby reducing life quality, as communication as well as participation in activities of daily living diminishes (NICE, 2020). In addition, visiting an audiologist may also assist with surgical as well as medical interventions (Hubik, 2018) should they be required. However, frequent one-on-one therapy arrangements may not be viable in the SA public sector context, if the ratio of audiologists to patients they serve is taken into consideration. Other factors may also contribute to the frequency of visiting the audiologist, such as time, resource and transport constraints. Therefore, it is recommended that patients and audiologists make maximum use of follow-up sessions. Some methods of doing so is by taking the recommendations made for doctors in coping with trying situations for patients, such as open channels of communication, allocating questions or discussion time with patients', involving patients when making decisions and (Hardavella, Aamli-Gaagnat, Frille, Saad, Niculescu, & Powell, 2017).

## Theme 2. Awareness of other hearing devices

Aside from hearing aids, X was unaware of other listening devices, such as CI. Although hearing aids are mainly recommended for treating hearing loss (Clason, 2019), it is important to note that sensory management is a minimal component of AR. There seems to be an overlap between rehabilitation technology and AR, and it is the amplification/sensory devices that cause this overlap. This could be one of the reasons as to why the concept of AR has not gained as much prominence as hearing aids in terms of hearing loss intervention and communication intervention.

## Theme 3. Communication

According to Makhoba and Joseph (2016), the definition of AR is inclusive of communication, which is part of the three groupings of AR. X experienced communication challenges as a result of her hearing loss, and included the abuse she received from her partner and the social abuse she encountered with communication partners, e.g. friends, family as well as on a monthly basis when she visited the clinic. She found it difficult to hear when people spoke to her, specifically in noisy environments. The difficulties experienced are aligned with the characteristics of a sensorineural hearing impairment, which affects loudness, clarity of sounds and the understanding of speech, especially in background noise (Clason, 2019). This can cause frustration and exhaustion (Clason, 2019) for the person with the hearing loss, which is why participation in AR services becomes important to address these issues.

# 5.7 Summary

X indicated that she understood what AR was, how helpful it could be and that she was willing to participate in the service. This tied into the aim of the study, i.e. to explore the perceptions of a patient with an acquired hearing loss post MDR-TB treatment towards adult AR services. This was indicative that indeed a patient with a hearing lost post MDR-TB treatment is likely to be willing to participate in AR services, but in order to do so they need to be aware that such services are available. Furthermore, audiologists and the public health sector have a role to play in the support of AR services, as this is the main factor that contributes to the success or failure of rehabilitation for a person with an acquired permanent hearing loss.

# **6.1 Introduction**

This chapter establishes the extent to which the study Aim was achieved and the problem that necessitated addressed by outlining the main findings from each of the five Objectives. It also reviews the findings with respect to the International Classification of Functioning, Disability and Health (ICF) framework as a guiding outline for the way audiologists engage with patients with an acquired hearing loss post multidrug-resistant tuberculosis (MDR-TB) who require aural rehabilitation (AR) services. The implications of the findings are outlines and its strengths and limitations reviewed, this being followed by a number of recommendations for future research.

#### 6.2 Summary of the study

Currently, there are various challenges regarding patients who have an acquired hearing loss post MDR-TB treatment receiving adult AR services. There is limited literature explicitly focusing on service availability and accessibility for adult patients with an ototoxic related hearing loss, especially in the SA context. Therefore, it is essential to consider adult AR in the context of ototoxicity to improve coping with their symptoms. The aim of the study was therefore to explore the perceptions of patients who have an acquired hearing loss post MDR-TB treatment towards adult AR services in the SA public health sector.

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The results of Objective 1 indicate that her quality of life was considerably affected, with changes being experienced in her interaction with people both within the family and externally, results in her retreating into her home where she used self-isolation as a coping mechanism.

The study explored Objective 2, which was the awareness of adult AR services available within the South African (SA) public health system following the fitting of hearing aids for participants who have an acquired hearing loss post MDR-TB treatment. This was done due to the insufficient literature available in SA regarding AR services (Makhoba & Joseph, 2016). The results of the study indicate that the participant was unaware of adult AR services that should have been available to her since the time of her hearing loss diagnosis.

Objective 3 explored the willingness of participants who have an acquired hearing loss post MDR-TB treatment to participate in an AR program. It was established that there is an interest in participating in AR services, with the motivating factor being that the participant wanted help to facilitate better communication. The perception of AR was seen positively by the participant, which indicated that participants are willing to benefit from such services. This highlighted the importance of AR service provision post MDR-TB treatment. However, challenges such as less than optimal health and transport constraints for participants were identified. It also became evident that there were areas specific to an AR program that required more attention, such as communication and repair strategies and troubleshooting for hearing aids, as the attention given to these components was minimal or absent. Furthermore, there was no evidence of providing participants with communication interventions on how to deal with communication breakdowns. According to literature, it is evident that various factors influence participants' ability to access health services. Regarding the current study, Objective 4 addressed the factors that influence the accessibility of adult aural rehabilitation services for participants who present with an acquired hearing loss post MDR-TB treatment. This was explored to ascertain factors that would allow or prevent participation in an AR program. The factors included limited communication partner participation, transport constraints and personal health challenges. Participant X's communication partners, these being her children and living partner, were also unable to participate in AR services due to their living far away and working during the day. These findings supported the literature that indicates that communication training with frequent partners is inadequately provided in the SA context (Naidoo, 2006, as cited in Makhoba & Joseph, 2016). Although there are challenges specific to the SA context, such as service centre locations (Sooful, 2006) and the number of participants per audiologist, recommendations have been made, which include tele-audiology, computer-based AR, social media and e-platforms.

Objective 5 explored the perceptions regarding the availability and accessibility of the three groupings of services, i.e. audiological counselling services, sensory management and communication intervention (Makhoba and Joseph, 2016) for adults with an acquired hearing loss post MDR-TB treatment. The findings indicate that audiological counselling that includes personal adjustment counselling and informational counselling was absent. The absence of audiological counselling contributed to the participant's self-isolation and low self-esteem. Sensory management was only received in the form of bilateral hearing aids and information on the possibility of cochlear implants was lacking. However, there is limited literature in the SA context regarding alternate forms of sensory management, such as cochlear implants (CI) and frequency modulation (FM systems) (Makhoba & Joseph, 2016). This could have contributed to why audiologists do not provide options of alternate forms of sensory

management. In addition to sensory management, communication intervention was also absent from the data obtained. Some forms of alternate communication strategies were employed by the participant in terms of lip-reading and writing, but these methods were self-taught. Aside from the hearing aid orientation, no information related to Sign Language classes, auditory training, telephonic training or communication strategies was provided.

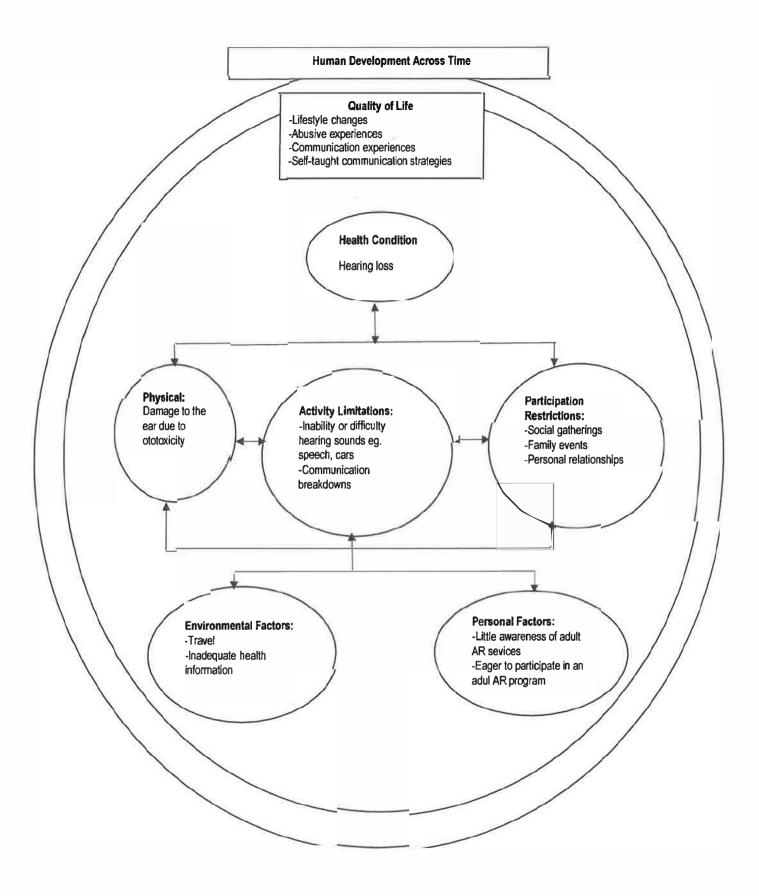
The exclusion of the audiologist from the ototoxic management multidisciplinary (MDT) could have been one of the contributing factors for the participant's general lack of awareness. The information obtained from the study also confirmed that participants with an acquired hearing loss post MDR-TB treatment were not accessing adult AR services. Although there was evidence of minimal AR service provision in the form of hearing aid orientation, the majority of the AR components were missing, such as counselling and auditory training (American Speech-Language-Hearing Association (ASHA), 2020), which forms an integral part of the hearing loss and AR process. Personal adjustment counselling, such as coping with changes in lifestyle and quality of life (QoL) as a result of a hearing loss were also absent. Furthermore, it was evident that the participant was unaware of the pernanency of her hearing impairment and the management options available for her, for example, the possibility of CI, which indicated a lack of informational counselling. The absence of these services post hearing aid fitting/hearing aid orientation could have contributed to participants' unawareness of the existence of AR services. Therefore, the results of the study concurred with the literature discussed about participants lack of awareness of AR services post MDR-TB treatment.

The ICF framework model provided a useful guide to understanding the factors that affect the perceptions of patients with an acquired hearing loss post MDR-TB treatment towards adult AR services, as well as the implications for their activities and participation, with resulting implications for their QoL.

The modified formal definitions components of ICF as they relate to participant X were as follows (adapted from the World Health Organization (WHO), 2002, p. 10):

- Body Functions of the ear were affected in terms of hearing due to the hearing loss
- Body Structures of the ear were affected due to ototoxicity as a result of MDR-TB treatment.
- Impairments were the problems in the body function or structure in terms of hearing loss.
- Activity allowed X to engage with her family, socialise and undertake routine activities e.g. go to the clinic, shopping
- Activity Limitations resulted in X using self-isolation as a coping method and having problems engaging productively with people.
- **Participation** was the involvement of X in her family and friends lives, and engage meaningfully with various service providers.
- Participation Restrictions resulted in X avoiding communication with others.
- Environmental Factors that affected her participation were inadequate AR services, intolerance of others of her hearing loss

The various components of the ICF framework, as they relate to participant X, are indicated in Figure 4 below:



# Figure 4. ICF framework adapted for hearing loss due to MDR-TB aminoglycoside medication (adapted from WHO, 2002, p. 9)

From Figure 4 above, it is clear that hearing loss has an effect on activity (limitation) and participation (restriction), as there is physical damage to the ear due to ototoxicity. QoL is affected in terms of lifestyle changes, abusive experiences, communication experiences and self-taught communication strategies. Activity limitations include inability or difficulty hearing sounds eg. speech, cars and communication breakdowns. Participation restrictions include social gatherings, family events and personal relationships. Contextual factors, ie. environmental and personal factors are also affected. Environmental factors include travel & inadequate health information. Personal factors include little awareness of adult AR services, eager to participate in an adult AR program and health.

## 6.3 Strengths

The study had the following strengths:

- A single case study using an in-depth, semi-structured interview schedule allowed for the gathering of rich data for the study.
- The use of three separate interview sessions with the participant allowed for accuracy in the information collected.
- The various methods to record data, i.e. audio recordings using a voice recorder and a cell phone as back up provided digital recordings of the interview for later transcription.
- The inclusion of the ICF framework and literature specific to the study's topic in deriving the interview schedule, member checking, back-translations and inter-rater reliability enhanced the reliability and validity of the study.

- The interpreter was fluent in isiZulu and English, which allowed him to communicate easily and efficiently with the researcher and participant as well as to provide clarity where required. The interpreter was familiar with the entirety of the study due to previous assistance with translations, information provided by researcher prior to the study and a keen interest in the field of audiology and MDR-TB. The interpreter also received training from the researcher prior to the interview session, which helped him to understand his role, familiarize himself with the interview process, gain clarity and ask questions. These attributes better equipped him in his role as an interpreter.
- The participant was referred to a cochlear implant unit during the interview process, which is both ethically correct and improves the management of the hearing loss, particularly for the participant. This reflected the 'Standard of Care' as discussed by Hall (2019), where the audiologists practice audiology in relation to clinical guidelines (Hall, 2019).
- Informational counselling for management of hearing loss was given to the participant, such as providing her with more information on adult AR services to create awareness and participation.

# **6.4 Limitations**

The study had the following limitations:

- Recruiting participants proved to be difficult, as some of the potential participants could not be contacted due to incorrect contact details on participant files.
- From the participants who fitted the inclusion criteria, many had passed away or were unable to participate in the study due to the recent outbreak of the Covid-19 pandemic and lockdown regulations. Other potential participants lived too far away and in remote areas that could not be located on a map. Of the four potential participants recruited for

the study, two participants had to be excluded due to the researcher not being able to make contact with them via telephone or SMS.

- Due to the logistics of the study, only one MDR-TB hospital was selected for the site, therefore the results of the study could not be generalized to all MDR-TB institutions.
- Due to the introduction of bedaquiline (BDQ) in 2018, the aminoglycoside treatment regime for MDR-TB was most probably completed in in 2016. As a result of the time lapse, the likelihood of memory recall bias was highly possible. Recall bias can be defined as a systemic error due to participants being unable to remember occurrences or events that took place with accuracy, and includes the omission of details (Spencer, Brassey and Mahtani, 2017). However, recall bias was overcome by adopting some of the methods outlined by Glen (2017), such as devising questionnaires of high quality and allowing the participant sufficient time to recall adequate memories that are long term. This was also supplemented by reading the participant's hospital file to note if any reference was made to AR services being provided, referrals to counselling and confirming the sequence of events with the participant to identify any differences.

#### 6.5 Implications of the study

The study has the following implications:

- The importance of including audiologists in the ototoxic management team for participants with MDR-TB was highlighted, their role being to ensure early detection and intervention of hearing loss and the provision of AR services.
- The improvement of service delivery beyond the hearing aid fitting
- Providing new knowledge in terms of AR and AR service provision
- Implementing health promotion and health awareness in terms of AR
- System improvements, such as audiologists being part of the MDT

• Treatment/engagement to include AR as part of these processes

# 6.6 Recommendations for further research

The following recommendations are made for research:

- Undertake further research using a bigger sample size to establish the provision of AR services across all public health sector facilities in KwaZulu-Natal (KZN).
- Investigate the audiologists role within a MDT working with participants on treatment for MDR-TB to enable this to be included as part of required AR services.
- Explore factors that contribute to the exclusion of audiologists within a MDT working/managing participants on treatment for MDR-TB in public sector health facilities in KZN.
- Explore the audiologists perspectives regarding their role within the MDT managing participants with an acquired hearing loss post MDR-TB in the public sector, and how this can be formalised.
- Explore the current practices of audiologists dealing with hearing loss patients for various reasons, not only MDR-TB, at public sector hospitals to establish if AR services are provided to some extent as routine for affected patients.
- Compare the degree of the acquired hearing loss between participants who used BDQ verses aminoglycosides and the need for AR services.

# 6.7 Summary

Although some intervention in the form of hearing aids is provided to participants with an acquired hearing loss post MDR-TB **w**eatment in KZN public sector health facilities, it should be a starting point rather than the end of the AR process. The quality of life of patients with an acquired hearing loss post MDR-TB treatment considering that their hearing loss is caused by medication provided by the Department of Health, there needs to be some accountability to making sure that they also do what they can to restore their hearing, to warn patients of the consequences and prevent them from having a poor quality of life, as this is a widespread problem in KZN and the South African (SA) context. A way forward would be to analyze the university curricula in terms of equipping student audiologists with the knowledge and tools to provide AR, so that when they are in the real world, they can understand the importance of providing AR services and utilize what they have learnt in order to provide optimal service delivery in the future.

"I hope someday I will be able to hear again."

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# Appendix A

## Ethics Evaluation Certificate

TRIMEE	Zertifika Certificat	Certificate
Certificat de formation - Training Certificate Ce document atteste que - this document certifies that		
Navishka Brijlal		
a completé avec succès - has successfully completed		
<b>Research Ethics Evaluation</b>		
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## Appendix B

### Letter to Medical Manager - King Dinuzulu Hospital Complex

# Perceptions of adult aural rehabilitation services for a patient with acquired hearing loss post multidrug-resistant tuberculosis (MDR-TB) treatment: A case study

Dear Sir/Madam

### RE: Request for permission to conduct a study: King Dinuzulu Hospital Complex

My name is Navishka Brijlal. I am currently studying towards my Masters degree in Audiology at the University of KwaZulu-Natal (Westville Campus). I am interested in investigating the perceptions of a patient who has an acquired hearing loss post multidrug-resistant tuberculosis (MDR-TB) treatment towards adult aural rehabilitation.

The aim of the study is to determine the perceptions of a patient who has an acquired hearing loss post MDR-TB treatment towards adult aural rehabilitation. The title of the study is "Perceptions of adult aural rehabilitation services for a patient with acquired hearing loss post multidrug-resistant tuberculosis (MDR-TB) treatment: A case study".

Postal Address: P/Bag X54001, Durban, 4000, South Africa Discipline of Audiology Telephone: +27 (0) 31 2608771 Email: blosez@ukzn.ac.za Website: www.ukzn.ac.za Founding Campuses: Edgewood — Howard College — Medical School — Pletermaritzburg — Westville INSPIRING GREATNESS



King Dinuzulu Hospital Complex is being requested to allow access to patient files at the Department of Audiology. The participants in this study will be selected based on the following inclusion and exclusion criteria:

## (a)Inclusion criteria

- Participants who are 18 years and older
- Participants who have completed ototoxic MDR-TB treatment
- Participants who have completed ototoxic MDR-TB treatment 6 months' prior
- Participants who have a confirmed hearing loss as a result of MDR-TB treatment
- Participants who have received/are currently receiving audiological management at King Dinuzulu Hospital Complex between 2018 and 2019

### (b)Exclusion criteria

- Participants who are  $\geq 65$  years old
- Participants who are currently on MDR-TB medication
- Participants who are currently on or post Bedaquiline medication
- Participants who are currently on or post tuberculosis (TB) treatment
- Participants who are currently on or post extensively drug-resistant tuberculosis (XDR-TB) treatment
- Participants who are too ill to participate in the study
- Participants who have normal hearing bilaterally

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Founding Campuses:	📻 Edgewood 🔚 Howard College 📥 Medical School 🛑 Pletermarlizburg 💻 Westville
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The researcher will obtain permission from the hospital CEO prior to contacting the audiologist to request permission to access the patient files. The researcher will then contact the audiologist at the hospital to arrange a convenient time to access and view the patient files. The study is expected to enrol 1 participant for the pilot study and 1-5 participants for the main study. It will involve the following procedures:

- (a) Signed informed consent
- (b) Interview schedule (including audio recordings, field notes, presence of interpreter and participant's significant other/family member/friend)

The duration of participation is expected to be approximately 60 minutes per participant. Semistructured interviews in the form of a case study will be conducted. This study has been ethically reviewed and approved by the University of KwaZulu-Natal Human and Social Sciences Research Ethics Committee (HSSREC) (Protocol Reference Number: HSSREC/00000676/2019).

"Most ethical issues in research fall into one of four categories: protection from harm, informed consent, right to privacy, and honesty with professional colleagues" (Leedy & Ormrod, 2005, p.111).

Ethical considerations for the study will follow the World Medical Association Declaration of Helsinki (JAMA, 2013) principles.



The following ethical and legal considerations will be adhered to as described by Beauchamp and Childress in 1979: beneficence, autonomy, justice and nonmaleficence (Jahn, 2011).

The current study will acknowledge the following legal and ethical considerations:

- Respect for participants: All participants in the study will be respectfully treated. This
  respect will be reflected by how the researcher addresses participants eg. referring to
  participants instead of "subjects". The researcher will also take into consideration the
  cultural diversity of all participants and respect their right to privacy and confidentiality
  (Wilson & MacLead, 2011).
- Physical harm: The researcher accepts their duty of caring for participants who take their time to participate in the study. The researcher will ensure that all participants will be protected from undue risks that can result from participation in this study.
- Psychological stress: The researcher will consider the potential risk of emotional and psychological distress and counselling or referrals will be made as required.
- Privacy and confidentiality: The researcher will guarantee that the privacy of participants is respected. Data obtained from the study will be coded and kept in a locked and secure place for a period of 5 years and thereafter will be destroyed. The researcher will maintain confidentiality, as participants' responses will be entirely anonymous. Data will be carefully coded and stored. No names will be recorded on the data collection instruments and codes will be used in the place of names. The researcher

#### WAZULU-NATALI WWZULU-NATALI WYUVESI YAKWAZULU-NATALI

will explain the research procedure prior to participants' participation in the study to eliminate any questions with regard to confidentiality.

- All participants will have to provide informed consent to participate in the study. The
  researcher will provide all participants with detailed information about the study. This
  will allow participants to make an informed decision regarding their willingness to
  participate in the study. The information provided to participants will be detailed
  enough and consist of information that may contribute to participants withdrawing their
  participation, e.g. the use of audio recordings.
- Participants will be informed about the procedures, purpose and duration of the study. Participants will be informed that they are allowed to withdraw from the study at any point, without providing an explanation for their withdrawal. Risks, potential discomfort or adverse effects as a result of participation in the study, possible benefits, confidentiality limits, incentives and contact details that participants can use to address any queries or issues that may arise will be provided to all participants.

Data will be collected from site, i.e. King Dinuzulu Complex Hospital. Data will then be carefully stored in a locked and secure cabinet at the Department of Audiology at the University of KwaZulu-Natal (Westville Campus). Data will be destroyed after a maximum period of 5 years. The researcher, interpreter (if required) and research supervisor will have access to the raw data. Data (audio recordings and transcriptions) will be saved on a USB stick with an access code/pin code to gain access to the data. Data will

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#### **INSPIRING GREATNESS**



be coded to ensure privacy of the institution and participants and to maintain confidentiality and anonymity.

You may contact the following people should you have any queries:

Miss Navishka Brijlal (Student) on 083 403 4577 or navishka.brijlal@gmail.com

Mrs. Zandile Shezi (Supervisor) on 031 260 8771 or blosez@ulan.ac.za

#### **HSSREC Research Office**

Tel: 031 260 8350

Email: hssrec@ukzn.ac.za

Miss N. Brijlal

Researcher

Mrs. Z. Shezi

**Research Supervisor** 

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#### Appendix C

#### Letter to Audiologist - King Dinuzulu Hospital Complex

# Perceptions of adult aural rehabilitation services for a patient with acquired hearing loss post multi-drug resistant tuberculosis (MDR-TB) treatment: A case study

Dear Sir/Madam

#### RE: Request for permission to conduct a study; King Dinuzulu Hospital Complex

My name is Navishka Brijlal. I am currently studying towards my Masters degree in Audiology at the University of KwaZulu-Natal (Westville Campus). I am interested in investigating the perceptions of a patient who has an acquired hearing loss post multidrug-resistant tuberculosis (MDR-TB) treatment towards adult aural rehabilitation.

The aim of the study is to determine the perceptions of a patient who has an acquired hearing loss post MDR-TB treatment towards adult aural rehabilitation. The title of the study is "Perceptions of adult aural rehabilitation services for a patient with an acquired hearing loss post multidrug-resistant tuberculosis (MDR-TB) treatment: A case study".





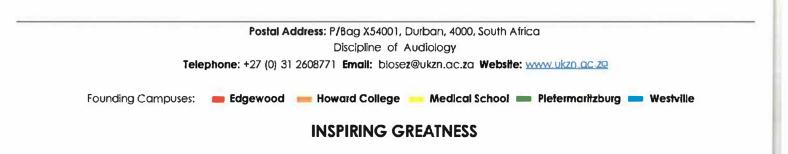
King Dinuzulu Hospital Complex is being requested to allow access to patient files at the Department of Audiology. The participants in this study will be selected based on the following inclusion and exclusion criteria:

#### (a)Inclusion criteria

- Participants who are 18 years and older
- Participants who have completed ototoxic MDR-TB treatment
- Participants who have completed ototoxic MDR-TB treatment 6 months' prior
- Participants who have a confirmed hearing loss as a result of MDR-TB treatment
- Participants who have received/are currently receiving audiological management at King Dinuzulu Hospital Complex between 2018 and 2019

# (b)Exclusion criteria

- Participants who are  $\geq 65$  years old
- Participants who are currently on MDR-TB medication
- Participants who are currently on or post Bedaquiline medication
- Participants who are currently on or post tuberculosis (TB) treatment
- Participants who are currently on or post extensively drug- resistant tuberculosis (XDR-TB) treatment
- Participants who are too ill to participate in the study
- Participants who have normal hearing bilaterally





The researcher will obtain permission from the hospital CEO prior to contacting the audiologist to request permission to access the patient files. The researcher will then contact the audiologist at the hospital to arrange a convenient time to access and view the patient files. The study is expected to enrol 1 participant for the pilot study and 1-5 participants for the main study. It will involve the following procedures:

- (a) Signed informed consent
- (b) Interview schedule (including audio recordings, field notes, presence of interpreter and participant's significant other/family member/friend)

The duration of participation is expected to be approximately 60 minutes per participant. Semistructured interviews in the form of a case study will be conducted. This study has been ethically reviewed and approved by the University of KwaZulu-Natal Human and Social Sciences Research Ethics Committee (HSSREC) (Protocol Reference Number: HSSREC/00000676/2019).

"Most ethical issues in research fall into one of four categories: protection from harm, informed consent, right to privacy, and honesty with professional colleagues" (Leedy & Ormrod, 2005, p.111).

Ethical considerations for the study will follow the World Medical Association Declaration of Helsinki (JAMA, 2013) principles.



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The following ethical and legal considerations will be adhered to as described by Beauchamp & Childress in 1979: beneficence, autonomy, justice and nonmaleficence (Jahn, 2011).

The current study will acknowledge the following legal and ethical considerations:

- Respect for participants: All participants in the study will be respectfully treated. This
  respect will be reflected by how the researcher addresses participants eg. referring to
  participants instead of "subjects". The researcher will also take into consideration the
  cultural diversity of all participants and respect their right to privacy and confidentiality
  (Wilson & MacLead, 2011).
- Physical harm: The researcher accepts their duty of caring for participants who take their time to participate in the study. The researcher will ensure that all participants will be protected from undue risks that can result from participation in this study.
- Psychological stress: The researcher will consider the potential risk of emotional and psychological distress and counselling or referrals will be made as required.
- Privacy and confidentiality: The researcher will guarantee that the privacy of participants is respected. Data obtained from the study will be coded and kept in a locked and secure place for a period of 5 years and thereafter will be destroyed. The researcher will maintain confidentiality, as participants' responses will be entirely anonymous. Data will be carefully coded and stored. No names will be recorded on the data collection instruments and codes will be used in the place of names. The researcher

#### UNIVERSITY OF **COLLEGE OF** INVUVESI VAKWAZULU-NATALI HEALTH SCIENCES

will explain the research procedure prior to participants' participation in the study to eliminate any questions with regard to confidentiality.

- All participants will have to provide informed consent to participate in the study. The researcher will provide all participants with detailed information about the study. This will allow participants to make an informed decision regarding their willingness to participate in the study. The information provided to participants will be detailed enough and consist of information that may contribute to participants withdrawing their participation, e.g. the use of audio recordings.
- Participants will be informed about the procedures, purpose and duration of the study. Participants will be informed that they are allowed to withdraw from the study at any point, without providing an explanation for their withdrawal. Risks, potential discomfort or adverse effects as a result of participation in the study, possible benefits, confidentiality limits, incentives and contact details that participants can use to address any gueries or issues that may arise will be provided to all participants.

Data will be collected from site, i.e. King Dinuzulu Complex Hospital. Data will then be carefully stored in a locked and secure cabinet at the Department of Audiology at the University of KwaZulu-Natal (Westville Campus). Data will be destroyed after a maximum period of 5 years. The researcher, interpreter (if required) and research supervisor will have access to the raw data. Data (audio recordings and transcriptions) will be saved on a USB stick with an access code/pin code to gain access to the data. Data will

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be coded to ensure privacy of the institution and participants and to maintain confidentiality and anonymity.

You may contact the following people should you have any queries:

Miss Navishka Brijlal (Student) on 083 403 4577 or navishka.brijlal@gmail.com

Mrs. Zandile Shezi (Supervisor) on 031 260 8771 or blosez@ukzn.ac.za

# **HSSREC** Research Office

Tel: 031 260 8350

Email: <u>hssrec@ukzn.ac.za</u>

Miss N. Brijlal

Researcher

Mrs. Z. Shezi

**Research Supervisor** 

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#### Appendix D

#### Letter from Medical Manager at King Dinuzulu Hospital Complex



DIRECTORATE: King Dinuzulu Hospital Complex

Enquires: Dr S.B. Maharaj Date: 28 November 2019

Dear Miss Brijlal

#### RE: PERMISSION TO CONDUCT RESEARCH "PERCEPTIONS OF ADULT AURAL REHABILITATION SERVICES FOR PATIENTS WITH ACQUIRED HEARING LOSS POST MULTI-DRUG RESISTANT TUBERCULOSIS (MDR – TB) TREATMENT"

I have pleasure in informing you that permission to conduct the above study has been granted to you by King Dinuzulu Hospital Complex.

Please note the following:

- 1. Please ensure that you adhere to all policies, procedures, protocols and guidelines of the Department of Health with regards to this research.
- 2. Please ensure that this office is informed before you commence your research.
- 3. Neither the District Office nor KDHC will provide any resources for this research.
- Your attention is drawn to the maintenance of confidentiality with respect to staff records/files and may not be removed from this Institution.
- 5. You will be expected to provide feedback on your findings to KDHC.

Yours sincerely

Sknol DR S. B. Maharaj MEDICAL MANAGER KDHC

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Appendix E

#### Letter to Department of Health

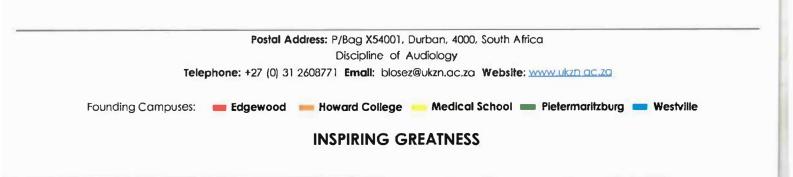
Perceptions of adult aural rehabilitation services for a patient with acquired hearing loss post multidrug-resistant tuberculosis (MDR-TB) treatment: A case study

Dear Sir/Madam

#### RE: Request for permission to conduct a study: King Dinuzulu Hospital Complex

My name is Navishka Brijlal. I am currently studying towards my Masters degree in Audiology at the University of KwaZulu-Natal (Westville Campus). I am interested in conducting a case study that investigates the perceptions of adult aural rehabilitation services for a patient with acquired hearing loss post multidrug-resistant tuberculosis (MDR-TB) treatment.

The aim of the study is to determine the perceptions of a patient, who has an acquired hearing loss post MDR-TB treatment, towards adult aural rehabilitation. The title of the study is "Perceptions of adult aural rehabilitation services for a patient with acquired hearing loss post multidrug-resistant tuberculosis (MDR-TB) treatment: A case study".





King Dinuzulu Hospital Complex is being requested to allow access to patient files at the Department of Audiology. The participants in this study will be selected based on the following inclusion and exclusion criteria:

# (a) Inclusion criteria

- Participants who are 18 years and older
- Participants who have completed ototoxic MDR-TB treatment
- Participants who have completed ototoxic MDR-TB treatment 6 months' prior
- Participants who have a confirmed hearing loss as a result of MDR-TB treatment
- Participants who have received/are currently receiving audiological management at King Dinuzulu Hospital Complex between 2018 and 2019

# (b) Exclusion criteria

- Participants who are  $\geq 65$  years old
- Participants who are currently on MDR- TB medication
- Participants who are currently on or post Bedaquiline medication
- Patients who are currently on or post tuberculosis (TB) treatment
- Patients who are currently on or post extensively drug-resistant tuberculosis (XDR-TB) treatment
- Participants who are too ill to participate in the study
- Participants who have normal hearing bilaterally

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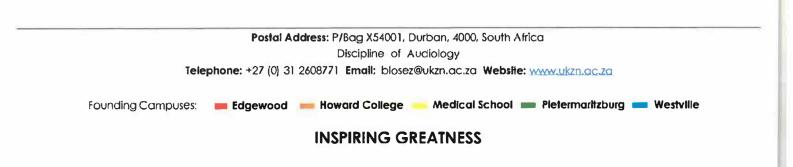


The researcher will obtain permission from the hospital CEO prior to contacting the audiologist to request permission to access the patient files. The researcher will then contact the audiologist at the hospital to arrange a convenient time to access and view the patient files. The study is expected to enrol 1 participant for the pilot study and 1-5 participants for the main study. It will involve the following procedures:

- (a) Signed informed consent
- (b) Interview schedule (including audio recordings, field notes, presence of interpreter and participant's significant other/family member/friend)

The duration of participation is expected to be approximately 60 minutes per participant. Semistructured interviews in the form of a case study will be conducted. This study has obtained provisional ethical clearance (approved by the University of KwaZulu-Natal Human and Social Sciences Research Ethics Committee (HSSREC), Protocol Reference Number: HSSREC/00000676/2019) pending gatekeeper permission from the hospital CEO and the Department of Health (Provincial).

"Most ethical issues in research fall into one of four categories: protection from harm, informed consent, right to privacy, and honesty with professional colleagues" (Leedy & Ormrod, 2005, p.111). Ethical considerations for the study will follow the World Medical Association Declaration of Helsinki (JAMA, 2013) principles.

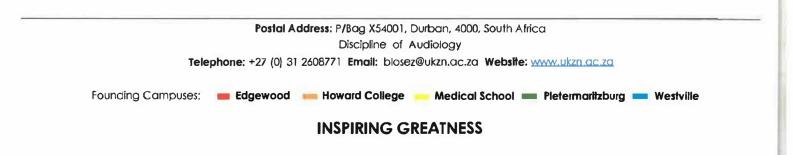




The following ethical and legal considerations will be adhered to as described by Beauchamp and Childress in 1979: beneficence, autonomy, justice and nonmaleficence (Jahn, 2011).

The current study will acknowledge the following legal and ethical considerations:

- Respect for participants: All participants in the study will be respectfully treated. This respect will be reflected by how the researcher addresses participants eg. referring to participants instead of "subjects". The researcher will also take into consideration the cultural diversity of all participants and respect their right to privacy and confidentiality (Wilson & MacLead, 2011).
- Physical harm: The researcher accepts their duty of caring for participants who take their time to participate in the study. The researcher will ensure that all participants will be protected from undue risks that can result from participation in this study.
- Psychological stress: The researcher will consider the potential risk of emotional and psychological distress and counselling or referrals will be made as required.
- Privacy and confidentiality: The researcher will guarantee that the privacy of participants is respected. Data obtained from the study will be coded and kept in a locked and secure place for a period of 5 years and thereafter will be destroyed. The researcher will maintain confidentiality, as participants' responses will be entirely anonymous. Data will be carefully coded and stored. No names will be recorded on the data collection instruments and codes will be used in the place of names. The researcher





will explain the research procedure prior to participants' participation in the study to eliminate any questions with regard to confidentiality.

- All participants will have to provide informed consent to participate in the study. The researcher will provide all participants with detailed information about the study. The information provided to participants will be detailed enough and consist of information that may contribute to participants withdrawing their participation, e.g. the use of audio recordings.
- Participants will be informed about the procedures, purpose and duration of the study. Participants will be informed that they are allowed to withdraw from the study at any point, without providing an explanation for their withdrawal. Risks, potential discomfort or adverse effects as a result of participation in the study, possible benefits, confidentiality limits, incentives and contact details that participants can use to address any queries or issues that may arise will be provided to all participants.

Data will be collected from site, i.e. King Dinuzulu Complex Hospital. Data will then be carefully stored in a locked and secure cabinet at the Department of Audiology at the University of KwaZulu-Natal (Westville Campus). Data will be destroyed after a maximum period of 5 years. The researcher, interpreter (if required) and research and research and transcriptions) will have access to the raw data. Data (audio recordings and transcriptions) will be asved on a USB stick with an access code/ pin code to gain access to the data. Data will be avel on a USB stick with an access code/ pin code to gain access to the data. Data will be access to the data. Data will be avel on a USB stick with an access code/ pin code to gain access to the data. Data will

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be coded to ensure privacy of the institution and participants and to maintain confidentiality and anonymity.

You may contact the following people should you have any queries:

Miss Navishka Brijlal (Student) on 083 403 4577 or navishka.brijlal@gmail.com

Mrs. Zandile Shezi (Supervisor) on 031 260 8771 or blosez@ukzn.ac.za

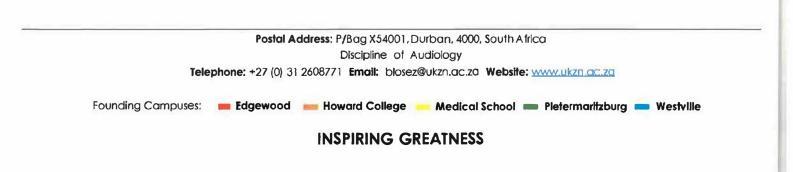
#### **HSSREC Research Office**

Tel: 031 260 8350

Email: <u>hssrec@ukzn.ac.za</u>

Miss N. Brijlal Researcher Mrs. Z. Shezi

**Research Supervisor** 



#### Appendix F

#### Letter from Department of Health



DALECTORATE:

Health Research & Knowledge Matagement

NHRD Ref: KZ\_202002\_020

Dear Ms N. Brijlal UKZN

Approval of research

1. The research proposal tilled 'Perceptions of adult aurel rehabilitation services for patients with acquired hearing loss post multi- drug resistant tuberculosis (MDR- TB) treatment: A case study' was reviewed by the KwaZulu-Natal Department of Health.

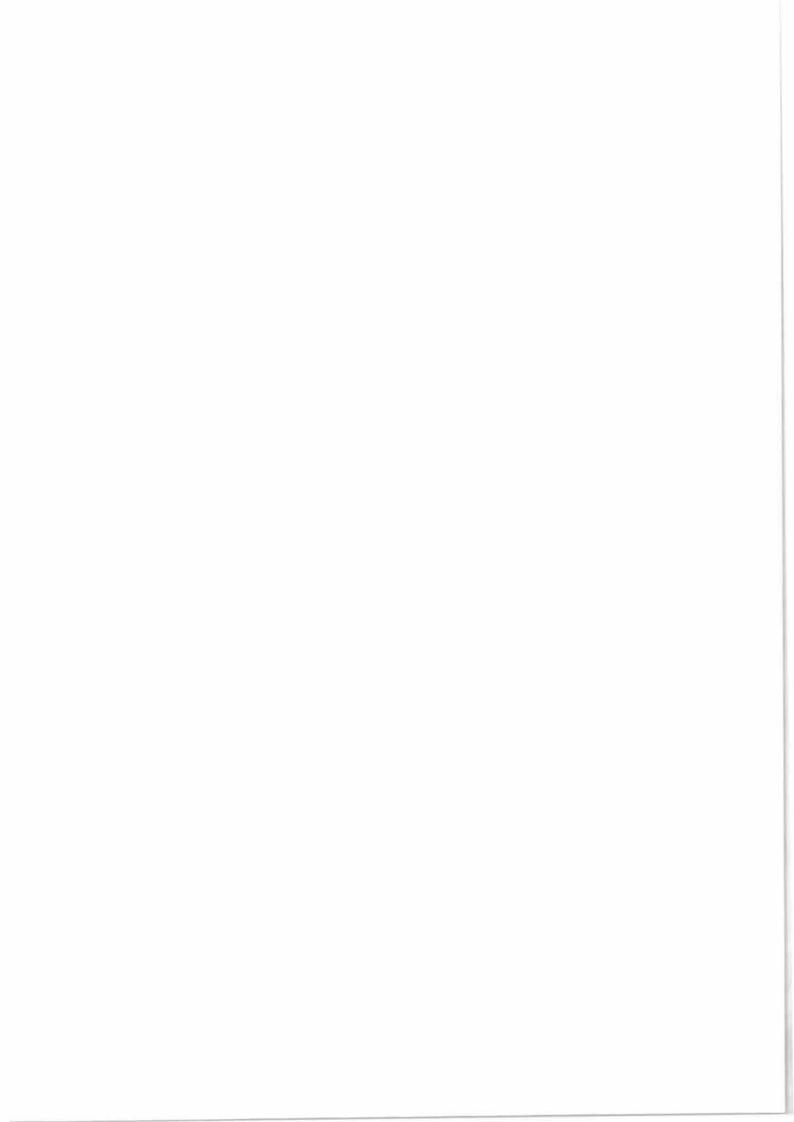
The proposal is hereby **approved** for research to be undertaken at King Dinuzulu Hospital Complex.

- 2. You are requested to take note of the following:
  - a Kindly fiaise with the facility manager BEFORE your research begins in order to ensure that conditions in the facility are conducive to the conduct of your research. These include, but are not limited to, an assurance that the numbers of patients attending the facility are sufficient to support your sample size requirements, and that the space and physical infrastructure of the facility can accommodate the research team and any additional equipment required for the research.
  - b. Please ensure that you provide your letter of ethics re-certification to this unit, when the current approval expires.
  - c. Provide an interim progress report and final report (electronic and hard copies) when your research is complete to HEALTH RESEARCH AND KNOWLEDGE MANAGEMENT, 10-102, PRIVATE BAG X9051, PIETERMARITZBURG, 3200 and e-mail an electronic copy to hrkm@kznhealth.gov.za
  - d. Please note that the Department of Health shall not be held liable for any injury that occurs as a result of this study.

For any additional information please contact Mr X. Xaba on 033-395 2805.

Yours Sincerely

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UNIVERSITY OF Letter from HSSREC - Approval Notification - Expedited Approval

04 March 2020

Miss Navishka Brijlal (209500588) School of Health Sciences Westville Campus

Dear Miss Brijlal,

Protocol reference number: HSSREC/00000676/2019 Project title: Perceptions of adult aural rehabilitation services for patients with acquired hearing loss post multidrug resistant tuberculosis (MDR- TB) treatment: A case study Degree: Masters

# **Approval Notification – Expedited Application**

This letter serves to notify you that your application received on 16 October 2019 in connection with the above, was reviewed by the Humanities and Social Sciences Research Ethics Committee (HSSREC) and the protocol has been granted FULL APPROVAL.

Any alteration/s to the approved research protocol i.e. Questionnaire/Interview Schedule, Informed Consent Form, Title of the Project, Location of the Study, Research Approach and Methods must be reviewed and approved through the amendment/modification prior to its implementation. In case you have further queries, please quote the above reference number. PLEASE NOTE: Research data should be securely stored in the discipline/department for a period of 5 years.

#### This approval is valid until 04 March 2021,

To ensure uninterrupted approval of this study beyond the approval expiry date, a progress report must be submitted to the Research Office on the appropriate form 2 - 3 months before the expiry date. A close-out report to be submitted when study is finished.

HSSREC is registered with the South African National Research Ethics Council (REC-040414-040).

Yours sincerely,



Professor Urmilla Bob University Dean of Research

/ms

Humanities & Social Sciences Research Ethics Committee UKZN Research Ethics Office Westville Campus, Govan Mbeki Building Postal Address: Private Bag X54001, Durban 4000 Tel: +27 31 260 6350 / 4557 / 3587 Website: <u>http://research.ukzn.ac.ze/Research-Ethics/</u> Founding Campuses: Edaewood Howard College Medical School Pielermatizburg Wertville INSPIRING GREATNESS



# Appendix H

#### Information Sheet for Participants of the Study (English)

#### **INFORMATION SHEET**

Dear Sir/Madam

# RE: Request for permission to participate in a study: King Dinuzulu Hospital Complex

My name is Navishka Brijlal. I am currently studying towards my Masters in Audiology at the University of KwaZulu-Natal (Westville Campus). I am interested in investigating the perceptions of a patient who has an acquired hearing loss post multidrug-resistant tuberculosis (MDR-TB) treatment towards adult aural rehabilitation.

The aim of the study is to determine the perceptions of a patient who has an acquired hearing loss post MDR-TB treatment towards adult aural rehabilitation. The title of the study is "Perceptions of adult aural rehabilitation services for a patient with acquired hearing loss post multidrug-resistant tuberculosis (MDR-TB) treatment: A case study".



The participants in this study will be selected based on the following inclusion and exclusion criteria:

# (a) Inclusion criteria

- Participants who are 18 years and older
- Participants who have completed ototoxic MDR-TB treatment
- Participants who have completed ototoxic MDR-TB treatment 6 months' prior
- Participants who have a confirmed hearing loss as a result of MDR-TB treatment
- Participants who have received/are currently receiving audiological management at King Dinuzulu Hospital Complex between 2018 and 2019

#### (b) Exclusion criteria

- Participants who are  $\geq 65$  years old
- Participants who are currently on MDR-TB medication
- Participants who are currently on or post Bedaquiline medication
- Patients who are currently on or post tuberculosis (TB) treatment
- Patients who are currently on or post extensively drug-resistant tuberculosis (XDR-TB) treatment
- Participants who are too ill to participate in the study
- Participants who have normal hearing bilaterally



You are being invited to consider participating in a study that involves research on the perceptions of patients post multi-drug resistant tuberculosis (MDR-TB) treatment towards adult aural rehabilitation services.

The study will involve the following procedures:

- (a) Signed informed consent
- (b) Interview schedule (including audio recordings, field notes, presence of interpreter and participant's significant other/family member/friend)

The duration of your participation if you choose to enrol and remain in the study is expected to be approximately 60 minutes. Semi structured interviews in the form of a case study will be conducted. This study has been ethically reviewed and approved by the University of KwaZulu-Natal Human and Social Sciences Research Ethics Committee (HSSREC) (Protocol Reference Number: HSSREC/00000676/2019).

Your participation in the study is entirely voluntary. You may withdraw from the study at any point and for any reason. Should you not want to participate in the study, this will not put you at any disadvantage.

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The researcher will treat participants with respect and this will be evident in the manner in which they will be addressed. The researcher acknowledges their duty of caring for participants who take their time to participate in the study. The researcher will ensure that all participants will be protected from risks that are undue that can come up as a result of participating in this study. The researcher will take into consideration the potential risk of emotional and psychological distress. The researcher will ensure that the privacy of the institution and participants are maintained. The data obtained for the study will be carefully coded kept in a locked and secure place. The researcher will maintain confidentiality as participants' responses will be completely anonymous. The researcher will explain the research procedure to the participants to eliminate any questions regarding confidentiality. The place and time for the interview will be determined by the participant. The researcher will conduct the interview at the preferred venue and time of the participant. There will be a debriefing session prior to the interview, where the participant will be informed of the interview process and procedures. The participant will also have the opportunity to meet the interpreter. In the event of emotional distress, the interview will stop immediately and only commence again should the participant wish to continue. Once it is concluded that the participant is willing to participate in adult aural rehabilitation services, the client will be referred to aural rehabilitation clinics, such as the University of KwaZulu-Natal aural rehabilitation clinic and other institutions that offer aural rehabilitation services.

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It is hoped that this study will create awareness about adult aural rehabilitation services to patients and the need for audiologists to implement these services at institutions. If the participant is illiterate, the participant can be assisted by the researcher or interpreter, only if the participant provides his or her signature/ thumb print as consent and prove that the information recorded is true and accurate.

You may contact the following people should you have any queries: Miss Navishka Brijlal (Student) on 083 403 4577 or <u>navishka.brijlal@gmail.com</u> Mrs. Zandile Shezi (Supervisor) on 031 260 8771 or <u>blosez@ukzn.ac.za</u>

#### **HSSREC Research Office**

Tel: 031 260 8350

Email: <u>hssrec@ukzn.ac.za</u>



Miss N. Brijlal

Researcher

Mrs. Z. Shezi

Research Supervisor

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# Appendix I

# Consent Form for Participants of the Study (English)

# **CONSENT FORM**

I \_\_\_\_\_\_ (name and surname) understand my involvement in this research study and I voluntarily agree to participate in this study. I understand the purpose and procedures of the study.

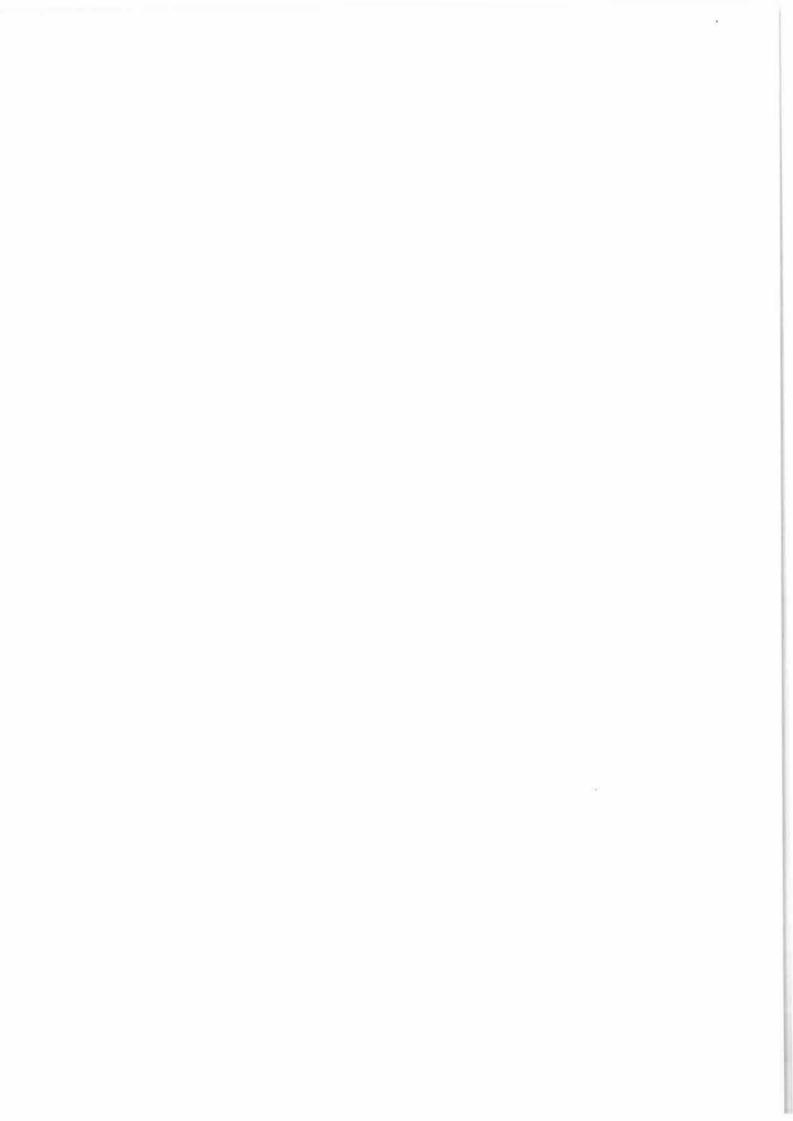
The researcher has requested for audio recordings to take place during the interview for the study. Therefore, I (the participant) agree to the use of audio recordings for the study as follows:

**AUDIO- RECORDING: YES / NO** 

Signature/ Thumb print of Participant

Date

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#### Appendix J

Information Sheet for Participants of the Study (isiZulu) Ikhasi lemininingwane yalabo abangenele ucwaningo

# IKHASI LEMINININGWANE

Othandekayo Mnumzane/Nkosazane

#### Isicelo semvume yokuba ingxenye vocwaningo: King Dinuzulu Hospital Complex

Igama lami ngiwu Navishka Brijlal. Ngenza iMasters yami emukhakheni we Audiology enyuvesi yaKwaZulu-Natal (Westville Campus). Nginentshisekelo ekwenzeni uphenyo ngemi cabango yeziguli ezingezwa emadlebeni eziphila ngemishanguzo yesifo sofuba esinenkani.

Inhloso nesizathu sokwenza lolucwaningo ukubona ukuthi iziguli ezingezwa noma okunzima ukuthi zizwe engasebenza yini ikhambi le adult aural rehabilitation. Isihloko sesifundo "Imibono yezinsizakalo zabantu abadala zokuhlunyeleliswa kwezimilo zesiguli esinokulahleka kokuzwa ngemuva kokwelashwa kwesifo sofuba esingazweli emishanguzweni (MDR-TB): isifundo secala" ucwaningo.



Abangenele lolucwaningo bazo khethwa ngokwehlukana kwabo:

# (a) Uhlu lwabafakiwe

- Abantu abangaphezulu kweminyaka eyishumi nesishagalombili
- Abantu abayiqedile imishanguzo yesifo sofuba esinenkani
- Abantu okwaqinisekiswa ukuthi abezwa
- Abantu asebathola noma abathola ukunakekelwa esibhedlela iKing Dinuzulu Hospital Complex

# (b) Uhlu labangafakwanga

- Abantu abadla imishanguzo yesifo sofuba esinenkani
- Abantu abadla imishanguzo yokuvikela isifo sofuba
- Abantu abadla imishanguzo yokuvikela isifo sofuba esinenkani
- Abantu abagula kakhulu ukuthi bangangenela lolucwaningo
- Abantu abezwa ngokugcwele emadlebeni

Uyamenywa ukuba ube yingxenye yocwaningo lwabantu abaphila ngokungezwa ezindlebeni.



Ucwaningo luzoba nalokhu okulandelayo:

- (a) Isivumelwano esisayindiwe
- (b) Uhlelo lwenkulumo eqo shiwe nesichazi magama kanye nelunga lomndeni walowo ongenele lolucwaningo

Uma ukhetha ukuba ingxenye yalolucwaningo kuzothatha cishe imizuzu engamashumi ayisithupa. Kuzoba nemibuzo ehleliwe kuqala. Lolucwaningo lubhekiwe kabanzi futhi lwavunyelwa ngabase enyuvesi yaKwaZulu-Natal Human and Social Sciences Research Ethics Committee (HSSREC) (Inombolo Yokuvunyelwa: HSSREC/00000676/2019).

Ukungenela kwakho akusiyo impoqo. Ungahoxa noma kunini noma ngabe esiphi.

Umcwaningi uzoziphatha ngenhlonipho iziguli nangendlela akhuluma ngayo. Umcwaningi uzokuphatha ngenhlonipho ngendlela azobe ekhuluma nawe ngayo. Umcwaningi uyayazi indlela ekumele anakekele ngayo iziguli ezithathe isikhathi sazo ukungenela lolucwaningo. Umcwaningi uzoqikelela ukuthi bonke abangenelile bazovikeleka kuzo zonke izingozi ezingaqhamuka kulolucwaningo. Umcwaningi uzokuqikelela nokuhlukumezeka ngokomphefumulo nomqondo okungavela. Umcwaningi uzokuqinisekisa ukuthi ucwaningo luyimfihlo. Imiphumela yocwaningo izovalelwa endaweni ephephile. Umcwaningi uzogcina imininingwane yesiguli iyimfihlo. Imiphumela izofakwa uphawu ivalelwe. Umcwaningi

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uzochaza kabanzi ngohlelo locwaningo ukuze kungabi nokudideka kulabo abangenelile. Indawo nesikhathi sokuhlangana sizoshiwo ilowo ongenelile. Umcwaningi uyena ozophatha uhlelo lwemibuzo endaweni ekhethwe ilowo ongenelile. Kuzoqala kube nokuchazelela okwandulela uhlelo lwemibuzo lapho ongenelile ezochazeleka ukuthi yini elindelekile kuye ongenelile uzobanethuba lokuhlangana nalowo ozomtolikela. Uma ehlukumezeka ngokomoya imibuzo izoma ngokushesha bese iyaqala futhi uma isiguli sifisa ukuqhubeka. Uma sekunesiqiniseko sokuthi isiguli siyafuna ukuba yingxenye yalolucwaningo sizobe sesidluliselwa enyuvesi yaKwaZulu-Natal aural rehabilitation clinic nakwezinye izindawo ezinikezela ngosizo olufanayo.

Sithemba ukuthi ucwaningo luzoshwaqisa labo abaphila ngokungezwa, isidigo sokuba nezikhungo, kanye ne audiologists ukuze bathole usizo. Uma lowo ongenelile engakwazi ukufunda uzosizwa umcwaningi noma utolika, uma ngabe isiguli siveza ubufakazi bokuthi siyavuma futhi yonke imininingwane eqoshiwe iliqiniso.



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# Appendix K

# Consent Form for Participants of the Study (isiZulu)

#### **ISIVUMELWANO**

Mina \_\_\_\_\_\_ (igama nesibongo) ngiyayiqonda indima engizoyidlala kulolucwaningo futhi ngiyavuma ukuba yingxenye yalo. Ngiyayiqondo inhloso nenqubo yalolucwaningo.

Umcwaningi unesicelo sokusebenzisa isiqophamazwi kusivivinyo salolucwaningo. Ngakhoke, mina (obandakanyekayo) ngiyavuma ukuthi sisetshenziswe kwisifundo:

ISIQOPHAMAZWI: YEBO / CHA

Isisayindo/ Noma isithupha sakho

Usuku

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#### Appendix L

Interview Schedule (English)

Perceptions of adult aural rehabilitation services for a patient with an acquired hearing loss post multidrug-resistant tuberculosis (MDR-TB) treatment: A case study

#### SECTION A - Background information & medical history

- 1. Name and sumame:
- 2. Date of birth (DD/MM/YY): \_\_\_\_\_
- 3. Gender:
- 4. When was treatment for multi drug- resistant tuberculosis (MDR-TB) completed?
- 5. Do you have:
  - (a) Family history of hearing loss
  - (b) Previous or recurrent middle ear infections
- 6. What medication are you currently taking?
- 7. Discuss the side effects (if any) you have experienced as a result of the MDR-TB medication?
- 8. Besides the hearing loss, what other problems have you experienced following the use of MDR-TB medication?
- 9. When did you first notice that you had a hearing problem?
- 10. Was the hearing loss sudden or gradual?



- 11. Discuss the treatment options you received following the diagnosis of a profound permanent hearing loss?
- 12. Discuss how these treatment options for your hearing loss have helped you?
- 13. Discuss how these treatment options have not helped you?
- 14. Discuss the difficulties you have experienced as a result of the hearing loss?
- 15. Discuss how these difficulties have impacted on your quality of life/lifestyle?
- 16. Discuss how you have addressed these difficulties or how do you plan to address these difficulties?
- 17. Describe the counselling you received following the diagnosis of a hearing loss?

# SECTION B - Perceptions and feelings towards the availability and accessibility of aural rehabilitation (AR) services and influencing factors

- 1. Describe how you felt when you were diagnosed with a hearing loss?
- 2. Describe how you currently feel with regards to having a hearing loss?
- 3. Describe how you manage your feelings of having a hearing loss?
- 4. Describe the expectations you have in the long run with regards to the hearing loss?
- 5. Describe what is your perception about hearing impairment/hearing loss?
- 6. Describe how your communication partners communicate with you?
- 7. Describe how your communication partners respond to you having a hearing loss?
- 8. Describe your lifestyle, eg. work, studies, hobbies, socializing with others?





- 9. In terms of your lifestyle, in which situation/s would you have the most difficulty as a result of your hearing loss?
- 10. How do you improve your communication and listening skills in challenging environments?

#### SECTION C - Impact or effect on quality of life - Hearing Handicap Inventory for Adults

(HHIA), The Flannagan Quality of Life Scales (QOLS), Tinnitus Handicap Inventory

#### (THI), Dizziness Handicap Inventory (DHI)

- What do you feel is the biggest problem you are faced with as a result of your hearing loss?
- 2. In which environment is it most difficult to communicate?
- 3. How do you communicate with other people?
- 4. What makes it easier for you to communicate?
- 5. What makes it difficult for you to communicate?
- 6. Describe the different communication methods you use to communicate?
- 7. Discuss how the hearing loss has affected your communication interactions with others?
- 8. Discuss what strategies you use when a communication breakdown occurs?



#### SECTION D - Awareness of aural rehabilitation (AR) services

- 1. Following your diagnosis, what information were you provided regarding your hearing loss?
- 2. What treatment or intervention plan were you provided with?
- 3. Are you aware of adult aural rehabilitation as a service?

(NB. If participant is not aware of adult aural rehabilitation services, provide information)

- 4. If you have answered 'yes' above:
  - 4.1. How did you find out about the other hearing services offered?
  - 4.2.In your own words, what is your understanding of these services?
- 5. If you have answered 'no' above:
  - 5.1. Now that you are aware of these services, how does it make you feel?
- 6. What is your knowledge about adult aural rehabilitation?
- 7. What is your knowledge about:
  - 7.1. Hearing aid orientation?
  - 7.2. Auditory training?
  - 7.3.Telephonic training?
  - 7.4.Communication strategies eg. Sign Languge; lip-reading?
- 8. How has this information assisted you in improving your communication skills and quality of life?

(NB. Only if patient has some knowledge on intervention services then prompt Question

5)



#### SECTION E - Perceived impact towards adult aural rehabilitation (AR) as a service

1. Would you be willing to participate in these services? Please explain:

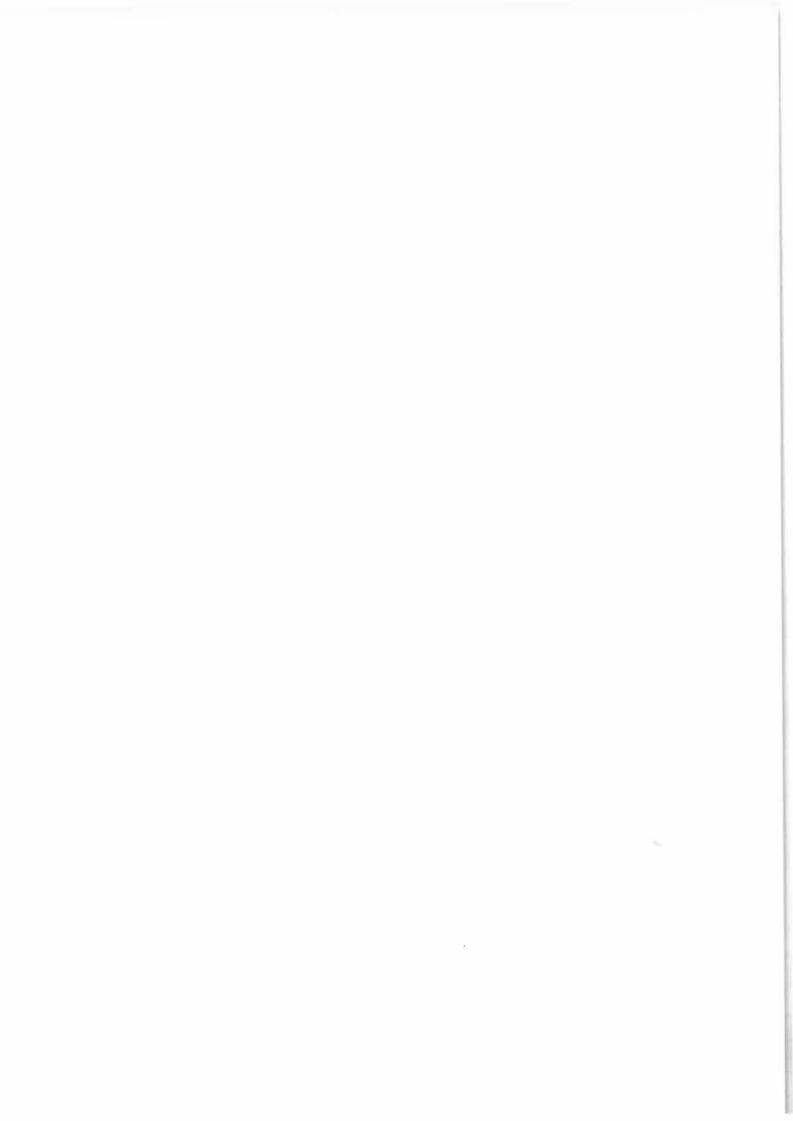
1.1.If yes, what would encourage you to participate in these services?

1.2. If no, what would discourage you in participating in these services?

- 2. Would you prefer working in a group or working individually during therapy? Please explain:
  - 2.1. Why you would prefer/ not prefer to work in a group?
  - 2.2. Why you would prefer/ not prefer to work individually?
- 3. Would your communication partners be willing to participate in these services?

#### **SECTION F - Other**

- 1. What would be the benefits for you if you choose to participate in these services?
- 2. What would be the challenges for you if you choose to participate in these services?
- 3. Is there anything that you would like to add?





#### Appendix M

#### Interview Schedule (isiZulu)

#### Uhelolwe Inthavyu

Imibono yezinsizakalo zabantu abadala zokuhlunyeleliswa kwezimilo zesiguli

esinokulahleka kokuzwa ngemuva kokwelashwa kwesifo sofuba esingazweli

emishanguzweni (MDR-TB): isifundo secala: Ucwaningo

INGXENYE YOKUQALA - Imininingwane yesiguli nokwelashwa kwaso

- 1. Igama nesibongo:
- 2. Usuku lokuzalwa (DD/MM/YY): \_\_\_\_\_
- 3. Ubulili:
- 4. Wayiqeda nini imishanguzo yesifo sofuba esinenkani?
- 5. Unalo:
  - (a) Ilunga lomndeni elingezwa emadlebeni?
  - (b) Wake noma unakho ukungezwa?
- 6. Iluphi uhlobo lwemishanguzo oluthathayo?
- Chaza ukungaphatheki kahle (uma kukhona) ohlangabezane nako ngokosebenzisa imishwanguzo yesifuba sofuba esinenkani (MDR-TB)?
- Ngaphandle kokungezwa, eziphi ezinye izinkinga zokugula oke wahlangabezana nazo ngemuva kokusebenzisa imishwanguzo yesifuba esinenkani (MDR- TB)?
- 9. Waqala nini ukuzibona ukuthi unenkinga yokungezwa?

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- 10. Into evele yenzeka noma ithathe isikhathi?
- 11. Chaza ngezindlela zokwelashwa ezahlukene ozitholile zokungezwa?
- 12. Chaza ukuthi zikusize kanjani lezindlela zokwelapha?
- 13. Chaza ukuthi azikusizanga kanjani lezindlela zokwelapha?
- 14. Chaza ubunzima osudlulekubona ngenxa yokungezwa?
- 15. Chaza ukuthi kunzima kangakanani ukuphila ngaloluhlobo?
- 16. Chaza osukwenzile ukuzama ukubhekana nalesisimo?
- 17. Chaza ngosizo olutholile lokwelulekwa ngemuva kokuthola ukuthi awuzwa?

# INGXENYE YESIBILI – Imibono nemizwa maqondana nokutholakala kanye nokufinyeleleka kwezinsizakalo zokuyuselelwa kwe-aural (AR) nezinto ezinomthelela

- 1. Chaza ngendlela owazizwa ngayo ngenkathi bekutshela ngokungezwa?
- 2. Chaza indlela ozizwa ngayo manje mayelana nokungezwa?
- 3. Chaza indlela omelana nayo ngemizwa yakho ngenxa yokungezwa?
- 4. Chaza okulindele esikhathini esizayo mayelana nokungezwa?
- 5. Chaza umbono wakho mayelana nokungezwa?
- 6. Chaza indlela abantu abaxhumana nawe ngayo?
- 7. Chaza indlela abantu abakuthatha ngayo ngenxa yokungezwa?
- 8. Chaza ndlela ophila ngayo, isibonelo, umusebenzi, izifundo, izinto ozithandayo, ukuxhumana nabanye?

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- 9. Chaza endleleni ophila ngayo esiphi isimo ongathi singakunika inkinga njengoba ungezwa?
- 10. Wenza kanjani ukuxhumana nokulalela kwakho kube ngcono?

## INGXENYE YESITHATHU - Umthelela noma umthelela kwikhwalithi yempilo - Ukuzwa

Ukukhubazeka Kwabantu Abadala (HHIA), I-Flannagan Quality of Life Scales (QOLS),

#### Tinnitus Handicap Inventory (THI), Isizungu Sokukhubazeka Inventory (DHI)

- 1. Yini ongathi iyinkinga kakhulu obhekene nayo njengoba ungezwa nje?
- 2. Ikuyiphi indawo lapho uzwa engathi kunzima ukuxhumana nabantu?
- 3. Uxhumana kanjani nabanye abantu?
- 4. Yini eyenza kube lula kuwe ukuxhumana?
- 5. Yini eyenza kube nzima kuwe ukuxhumana?
- 6. Chaza izindlela ezahlukene oxhumana ngazo nabantu?
- 7. Chaza ngendlela ukulahlekelwa ukuzwa okuhlukumeze ngayo indlela oxhumana ngayo nabanye?
- 8. Chaza izindlela ozisebenzisayo uma kunokulahlekelana kokuxhumana?

#### INGXENYE YESINE- Ukuqwashiswa kwezinsizakalo zokuvuselelwa kwezakhiwo (AR)

- 1. Ukulandela ukungezwa, eyiphi imininingwane abakunika yona mayelana nokungezwa?
- 2. Omuphi umshanguzo abakunika wona?
- 3. Uyazi yini ngohlelo olusiza abantu abadala?



(Okubalulekile. Uma ngabe isiguli singazi ngaloluhlelo lokwelapha, sinike iminingwane)

- 4. Uma ngabe uphendule ngo 'yebo' ngaphezulu:
  - 4.1. Uthole kanjani ngaloluhlobo lokwelashwa?
  - 4.2. Ngamagama akho, yini oyizwayo ngaloluhlobo losizo?
- 5. Uma uphedule 'cha' ngaphezulu:
  - 5.1. Manje ngoba usuyazi ngalolusizo, uzizwa kanjani?
- 6. Yini oyaziyo nge Adult Aural Rehabilitation?
- 7. Yini oyaziyo ngalokhu:
  - 7.1. Usizo lokuzwa olufakelwayo?
  - 7.2. Ukuqeqeshwa ngokuphenywa?
  - 7.3.Ukuqeqeshwa ngocingo?
  - 7.4. Amasu okuxhumana, isibonelo, ukukhuluma ngophawu, ukufunda izindebe?
- 8. Lemininingwane isikusize kanjani ekwenzeni ngcono ukuxhumana nokwenza impilo yakho ibe ngcono?

(Okubalulekile. Uma ngabe isiguli sinolwazi ngezinsiza ezikhona bese ubuza umbuzo wesihlanu)

# INGXENYE YESIHLANU- Umthelela obonakalayo ekuvuseleleni abantu abadala ngokwemvelo (i-AR) njengensizakalo

- 1. Ungakwazi yini ukuba yingxenye yalezinsiza? Chaza:
  - 1.1. Uma uthi yebo, yini engakugqugquzela?

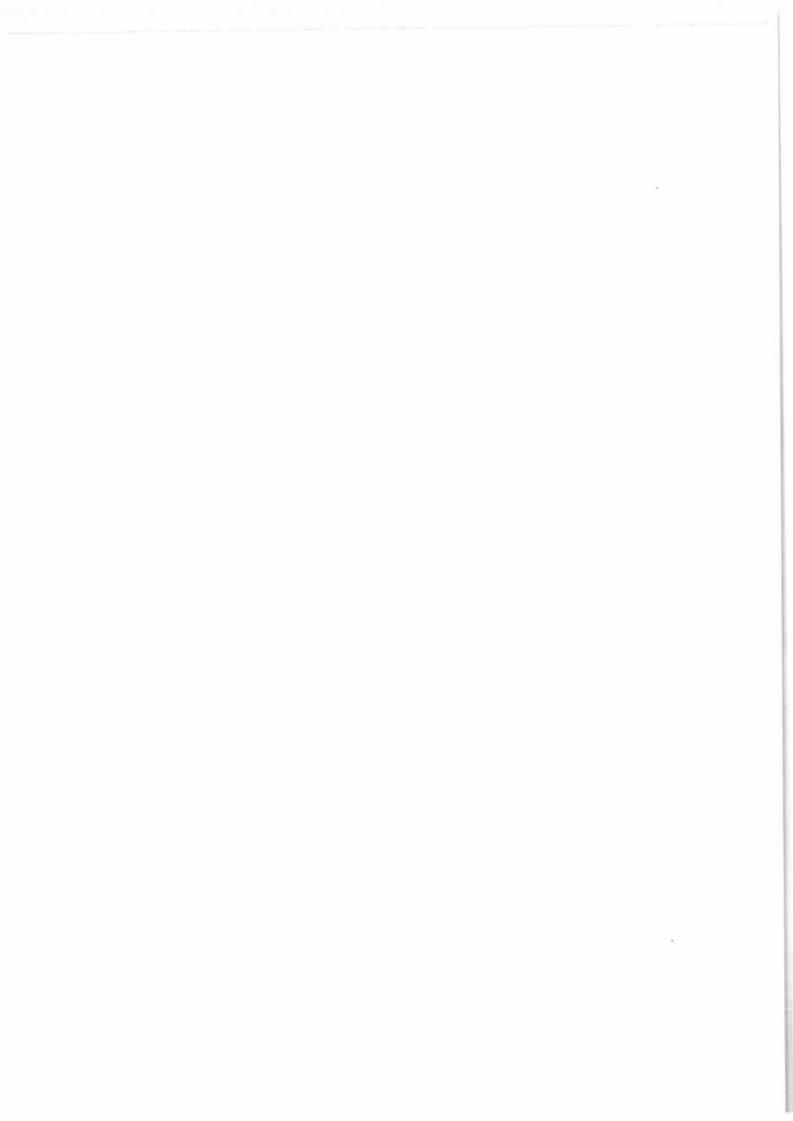
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- 1.2. Uma uthi cha, yini engakuqeda amandla ukuba ube yingxenye?
- 2. Ungathanda ukusebenza nibe yibandla noma wedwa? Sicela uchaze:
  - 2.1. Yini engakwenza ufune/noma ungafuni ukusebenza nebandla?
  - 2.2. Yini engakwenza ufune/noma ungafuni ukusebenza wedwa?
- 3. Bangavuma yini abantu oxhumana nabo ukungenela loluhlobo nocwaningo?

#### **INGXENYE YESITHUPHA - Okunye**

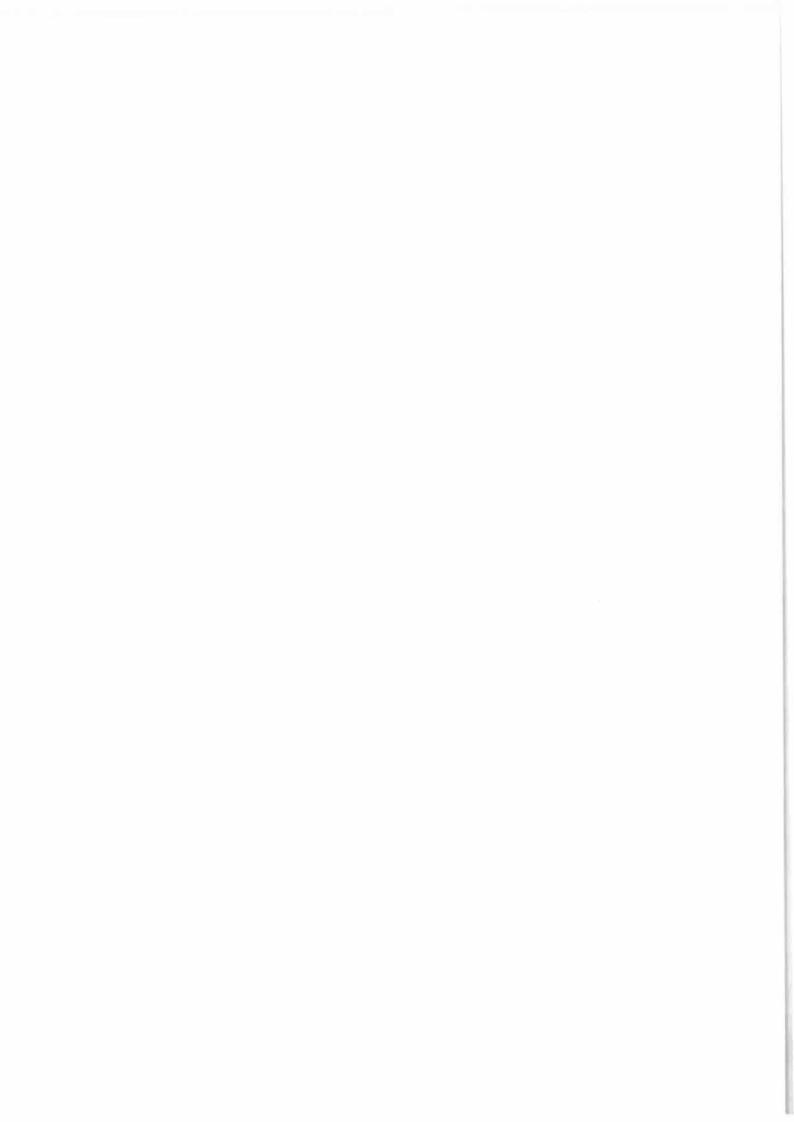
- 1. Yini ongayizuza uma ukhetha ukungenela loluhlobo losizo?
- 2. Yini engabanzima uma ukhetha ukungenela loluhlobo losizo?
- 3. Kukhona ongathanda ukukufaka?



## Appendix N

## Random selection of data for inter-rater reliability calculation

Participant	Interview session 1	Interview session 2	Interview session 3
X	Interview session 1 with researcher,	Interview session 2 with researcher,	Interview session 3 with researcher,
	interpreter and X. The audio recordings	interpreter and X. The audio recordings	interpreter and X. The audio recordings
	represented a random selection of data	represented a random selection data	represented a random selection data
	derived from the interview schedule and	derived from probe and follow up	derived from probe and follow up
	probe questions (Section A, Section B	questions from Interview session 1	questions from Interview session 2
	and Section C of interview schedule).	(Section D and Section E of interview	(Section F of interview schedule).
		schedule).	



### Appendix O

#### Inter-rater agreement scores for audio recordings

Participant X	Interview session 1	Interview session 2	Interview session 3	Inter-rater agreement
Section A	100/102	-	-	98%
Section B	212/212	-	-	100%
Section C	31/31	-	-	100%
Section D	-	42/42	-	100%
Section E	~	11/11	-	100%
Section F	-	-	19/19	100%
Section G	-	-	18/18	100%

Inter-rater = <u>Number of agreements</u> x100%

Number of disagreements

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<u>= 433</u> x100%

435

= 99.5%

