

**EXPERIENCES OF HEARING PARENTS REGARDING THEIR CHILD'S
HEARING LOSS**

by

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**A full thesis for the fulfilment of the requirements for the Degree of
MASTERS IN SOCIAL WORK**

at the



**UNIVERSITY OF THE WESTERN CAPE
FACULTY OF COMMUNITY AND HEALTH SCIENCES
DEPARTMENT OF SOCIAL WORK**

*UNIVERSITY of the
WESTERN CAPE*

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NOVEMBER 2013

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DECLARATION

I hereby declare that this dissertation, **THE EXPERIENCES OF HEARING PARENTS REGARDING THEIR CHILD'S HEARING LOSS** is my own work and that all resources that were used or referred to by me during the research study is completely acknowledged by means of a complete reference and acknowledgement.

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Abstract

Overwhelming evidence suggests that 90% of children with a hearing loss are born to hearing parents. Research indicates that often these hearing parents are ill-informed about the cause and type of hearing loss their child has, leading the hearing parents to feelings of grief and disempowerment. Many hearing parents at the time of the diagnosis experience emotional turmoil as the diagnosis is often unexpected, resulting in a plethora of questions asked.

The research approach for the study was qualitative in nature as it set out to explore and describe the experiences of hearing parents of their child's hearing loss. A phenomenological strategy of design was employed to capture the lived experience from the hearing parents. Data was collected by means of unstructured individual in-depth interviews with 11 hearing parents. Volunteer and snowball sampling were implemented so as to access hearing parents whose children had been diagnosed with hearing loss. Data was analysed according to Creswell (2007) and Klenke (2008) and the trustworthiness of the qualitative study was evaluated against the criteria that Guba described in Krefting (1991). Ethical considerations, such as voluntary participation, informed consent, confidentiality, anonymity, no harm done and debriefing, were adhered to.

After the conclusion of the research analysis, the findings of the research were discussed and recommendations were made. The findings of the recommendations spoke to the better understanding of the emotions and challenges of hearing parents as well as putting forward suggestions for supportive coping mechanisms to be put in place to support hearing parents whose children have been diagnosed with a hearing loss.

KEYWORDS: Hearing parents, diagnosis, children with hearing loss

ACKNOWLEDGEMENT

I would like to thank the following people for the support and encouragement that they have shown towards me for the last three years in pursuing my MA degree. In these three years I have experienced my own personal journey of loss but without their help, patience and support, completing the degree would not have being possible.

Personally-

- My personal relationship in God in whom I trust and believe. Without my faith in Him this thesis would not have being completed;
- My University supervisor, Dr Mariana De Jager, a woman of strength, for all her guidance, support and most of all, her patience;
- To my husband, who encouraged me in the first place to do my MA degree, thank you for all the support and for believing in me;
- Thank you to my children for their patience and sacrificing some of their “going out time” in order for me to complete my thesis;
- Lastly to the Deaf Community of S.A., my second home. A big thank you to you for allowing me into your world.

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CHAPTER 1:

INTRODUCTION AND PROBLEM FORMULATION

1.1 Introduction

There is no doubt that any disability of a child has a profound impact on the parent and family system. The White Paper on the Integrated National Strategy on Disability (INDS, 2007:5), the overarching government policy framework on disability equity, states that “parents of children with disabilities have a special and specific role to play in the development of their children; mothers especially of children with disabilities often face ostracism from their partners, their families and their communities. This exclusion badly affects other non-disabled siblings, the survival of the family as a unit and the meaningful development of the disabled child.”

The present study points to available literature on hearing loss which provided for an understanding of each parent’s response to the diagnosis of their child’s hearing loss which Krywko (2012) describes as being unique, just as the needs of each child with a hearing loss are unique as pointed out by Ritter-Brinton & Stewart (1992) in Adams (1997).

To understand the impact of a child’s hearing loss on parents, it is argued that hearing parents need to understand the etiology of the child's hearing loss and in doing so empower themselves with informed choices. Understanding deafness or hearing loss for a hearing parent can however be a slow and sometimes painful and perplexing experience as evidence suggests that most hearing parents have never met a deaf person or somebody with profound hearing loss especially if one considers that more than 90% of deaf children are born to hearing parents as suggested by Higgins & Nash (1987) in Adams (1997).

Similarly there is no doubt that any disability has a profound impact on the family system but it should be borne in mind that there are different variables such as poverty, unemployment, income and so on which have a direct bearing on the understanding of the impact disability has on the family. The INDS (1997) states that 80% of black disabled children live in extreme poverty. In addition, the birth of a disabled child often places extra demands on families affecting their morale and pushing them deeper into poverty.

Therefore in an attempt to gain an understanding of this phenomenon, this research has explored and described the lived experiences of hearing parents regarding their child's hearing loss.

1.2 Literature review

1.2.1 Prevalence of deafness/hearing loss

It is estimated that 700 million people worldwide suffer from hearing loss (Toriello & Smith, 2013) and more than 900 million people worldwide will suffer from hearing loss by 2025 as estimated by the British MRC Institute of Hearing Research. The latest figures from the World Health Organisation (WHO, 2010) suggest that about 278 million people have moderate to profound hearing impairment worldwide, and that 80% of these live in low and middle-income countries. The lack of epidemiological data in most countries would suggest that the number of people with hearing loss around the world is much higher, and mentioned for example the lack of contact between mother, baby and the health system, as half of the babies are born at home especially in developing countries (WHO, 2010).

Swanepoel, Storbeck & Friedlander (2009) point out that every day almost 2000 babies are born with or acquire permanent infant hearing loss worldwide. It is estimated that 718 000 infants are either born with, or acquire early-onset permanent hearing loss every year. In America alone, more than 12,000 babies are born with a hearing loss (Centre for Disease Control and Prevention, 2010).

Interestingly enough, WHO (2010) presents some promising data on countries that provide early hearing detection programmes and the benefits of these programmes. Taylor (2011) points out that there is a rapid increase in newborn screening around the world. As reported by WHO (2010) and authors such as Olusanya, Luxon & Wirz (2006) and Yoshinago-Itano (2003) for example, most European countries implement an early hearing detection and intervention (EHDI) programme nationwide with the result that 80% of all births are screened.

By 2007 94% of all babies in the United Kingdom (UK) were screen for hearing loss, and although these tests were optional, around 99.8 % of parents had their baby's hearing tested. In America, the Centre for Disease Control (CDC), (2009) reported that 97% of newborn babies were tested for hearing loss at birth. These numbers are in stark contrast to countries in

the South East Asia block and Sub Saharan countries where very little is done regarding newborn and infant hearing screening programmes (WHO, 2010).

Closer to home, the 2010 General Household Survey (GHS), estimated that 981 000 people in South Africa were classified with a hearing loss, but this number did not take into account the number of children under the age of five years old. The Deaf Federation of South Africa (DeafSA) (2006) asserted that 10% of the total population have some kind of hearing loss stating that many hearing parents do not record their children as being deaf and that a large number of people with a hearing loss have never filled in a census form. Of the deaf population (S.A. Census, 2010) 68% live in informal settlements, 70% are unemployed, only 40% attend school while 66% are illiterate.

Apart from a single study reporting hearing loss prevalence in the private health sector, no other screening programmes in South Africa had being applied to determine the true prevalence of hearing loss in infants (Swanepoel et al., 2009). It was estimated that three in every 1000 babies born in the private sector may be diagnosed with a hearing loss and six in every 1000 babies in the public sector may be diagnosed with a hearing loss as tabulated by the South African Department of Treasury (2005). It is furthermore estimated by Swanepoel et al., (2009) that 6116 infants are annually born with or acquire permanent bilateral hearing loss in the first few weeks of life with approximately 92% born in the public health sector.

Thus a conclusion could be drawn that more than 90% of babies born in South Africa do not have the prospect of early detection of hearing loss despite a reasonably established health care infrastructure compared to other sub-Saharan African countries (Swanepoel, Ebrahim, Joseph & Friedlander, 2008). In 2007 the Professional Board for Speech, Language and Hearing Professions of the Health Professions Council of South Africa (HPCSA) issued a statement in which it proposed infant screening for high-risk infants with a family history of permanent childhood hearing impairment, or risk indicators such as in-utero infections such as CMV, rubella, Malaria, or HIV or postnatal infections to be tested.

A recent survey of 100 mothers in South Africa has also provided insight into maternal knowledge and attitudes on infant hearing loss. The attitudes of mothers regarding infant hearing screening were overwhelmingly positive with almost all (99%) indicating the desire to have their baby's hearing screened after birth. Fifty seven percent held at least one

superstitious cultural belief regarding a possible cause of infant hearing loss (Swanepoel & Almec, 2008).

In order to provide some insight on hearing loss, the following discussion will explain the anatomy of the ear.

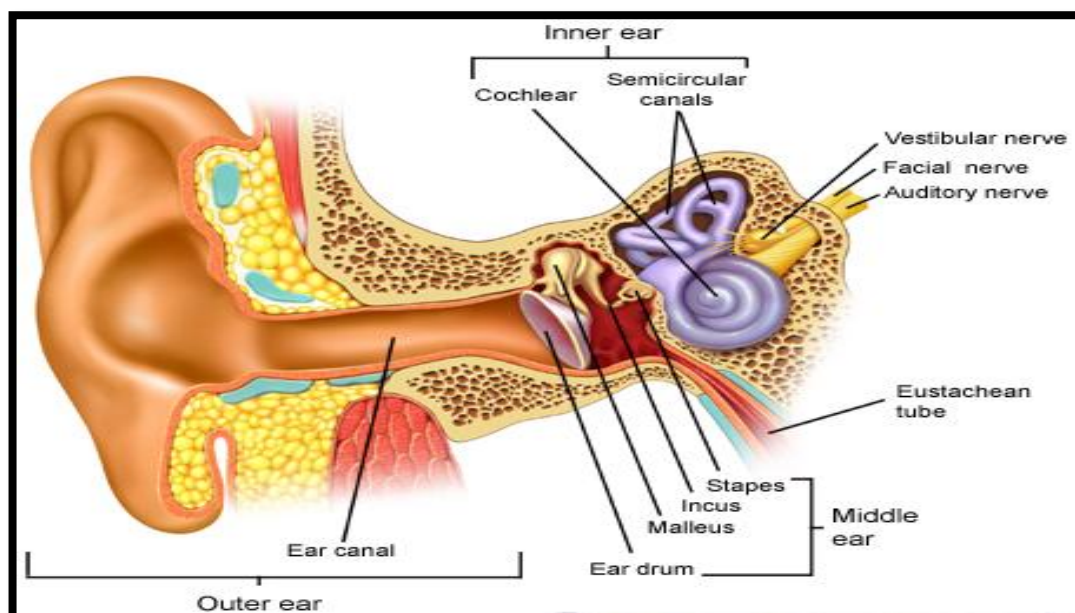
1.2.2 The anatomy of the ear and hearing loss

Paul & Whitelaw (2010) explain that hearing happens when sound waves travel through the external, middle, and inner ear before moving to the hearing mechanisms of the brain.

Hearing encompasses four parts of the ear, namely the outer ear (external), the ear canal, the middle ear and the inner ear. The external part of the ear is known as the pinna and is shaped in a way that captures sound waves. The sound moves through the ear canal and strikes the eardrum which separates the outer (external) and middle ear (Paul & Whitelaw, 2010). Sound waves cause the eardrum to vibrate, sending the bones in the middle ear (ossicles) into motion (Clark, 2003). In addition, the inner ear consists of the cochlea, which is important for hearing processes, and the vestibular system, which is important for balance. The cochlea is shaped like a snail shell and is filled with fluid and houses the organ of Corti which contains approximately 20,000 tiny hairs called cilia (Paul & Whitelaw, 2010). The vibrating motions from the middle ear cause the fluid inside the inner ear (cochlea) to move the tiny hairs called cilia. The movement of the cilia creates electric impulses upon hearing (auditory) and the impulses are sent into the brain and one hears sound.

Figure 1: The following figure portrays the workings of the inner ear

(Acknowledgement: Encyclopaedia Health of Diseases and Disorder)



1.2.3 Hearing loss

Hearing loss occurs when the channels of sound conduction are damaged so as to prevent sound waves from being conveyed to the inner ear. Thus hearing loss occurs primarily when the inner ear or auditory nerve is damaged or when sound waves cannot reach the inner ear (Paul & Whitelaw, 2010; Clark, 2003).

In order to get a better understand of what constitutes hearing loss, possible indicators, causes as well as the etiology of hearing loss will be discussed.

1.2.4 Indicators of hearing loss among children

The following indicators/symptoms amongst children may cause suspicion of hearing loss for parents:

- Notice that the child does not respond to sound or react to loud noises;
- Often ask for things to be repeated or often says: “What, say again, what did you say?”
- Noticeable delay in speech or their own speech is unclear, or wrong pronunciation of words;
- The volume is continuously being tuned louder for instance the television;
- Have a fever, have constant ear pain, constantly pulling and rubbing ears;
- Constantly irritable for no apparent reason.

In order to provide greater clarity and understanding of the above, it is recommended that indicators should be followed up by visiting an audiologist or medical specialist to determine whether there is a hearing loss.

1.2.5 Types of hearing loss

There is strong evidence to suggest that parents do not understand the nature of their child’s hearing loss. Northern & Downs (2002) emphasise the importance for parents to understand the etiology of their child’s hearing loss. For example, where does the hearing loss occurs in the ear, the type of hearing loss the child is being diagnosed with, the possible cause of the hearing loss, the degree and severity of the hearing loss and what does it all mean for the child (Krywko, 2012). Luteran, Kurtzer-White & Seewald (1999) strongly advocates the need for hearing parents to understand their child’s hearing loss in all forms in order to make

informed decisions and suggests that hearing parents upon hearing the words hearing loss tend to block out any other information and can be completely overwhelmed by all the new information they have to learn.

In an attempt to explain hearing loss and to provide a better understanding of the phenomenon, Krywko (2012); Storbeck (2005); Smith, Bale & White (2005); Northern & Downs (2002); explain the following types of hearing loss, namely: sensorineural (SNHL) hearing loss, conductive (major two) hearing loss and mixed hearing loss.

1.2.5.1 Sensorineural hearing loss (SNHL)

Sensorineural hearing loss occurs in the inner ear. Krywko (2012); Bale Jr., Bonkowsky, Filloux, Hedlund, Nielsen & Larson (2011); Storbeck (2005); Northern & Downs (2002) point out that usually hearing loss is associated with defects in the fine hair cells within the cochlea or along the nerve pathway from the inner ear to the brain. This type of hearing loss rarely responds to surgical intervention. Sensorineural losses are, by far, the most common type of hearing loss. It affects the nervous system, that is the spinal cord, brain, cochlea or the eighth cranial nerve. In adults, about 95% of hearing loss is sensorineural and is commonly referred to as “nerve damage” (Northern & Downs, 2002). Hearing aids or a cochlear implant are often appropriate for this type of hearing loss (Krywko, 2012).

A hearing aid can assist with SNHL. It consists of a tiny microphone, amplifier and speaker and uses small microphones to enhance soft sounds. The microphone receives the sound or the vibrations and converts it into electrical pulses or electrical signals that send the data to the speaker where sound is produced. The ear mould which is placed inside the ear transmits the sounds to the electrical unit that is placed behind the ear. There are settings on the microphone that can be adjusted to suit the person’s degree of hearing loss (Bale Jr., Bonkowsky, Filloux, Hedlund, Nielsen & Larson, 2011).

A cochlear implant works differently to hearing aids as it basically amplifies sound. Cochlear implants are also known as a bionic ear, therefore restoring hearing when the inner ear is damaged by a disease or injury (Clark, 2003). The cochlear implant bypasses the inner ear and transmits an electrical signal straight to the cochlea which the brain interprets as sound (Paul & Whitelaw, 2010; Bale, Bonkowsky, Filloux, Hedlund, Nielsen & Larson, 2011).

Various components of a cochlear implant are: a microphone (outer part), sound processor, headpiece, and an inner portion that receives the transmitted signal and sends it to the cochlea by way of electrodes (Paul & Whitelaw, 2010). A surgeon implants part of the cochlear device behind the ear under the skin and inside the inner ear. A coil is worn behind the ear and is magnetically attached to a part of the device under the skin. The coil is equipped with a microphone which captures the sound and transmits it to a speech processor. The speech processor converts the sound into electrical signals and sends them to the receiver or magnetic headpiece which is implanted under the skin behind one of the patient's ears. The magnetic headpiece sends the electrical signals to the electrodes which were implanted during the cochlear implant. The electrodes take the signals to the brain where they are interpreted as sound (Krywko, 2012).

Recipients of a cochlear implant are either completely deaf (profoundly deaf) or have a severe hearing loss and cannot benefit from wearing hearing aids (Krywko, 2012) and who suffer from sensorineural deafness (Paul & Whitelaw, 2011).

1.2.5.2 Conductive hearing loss

Conductive hearing loss affects portions of the inner ear that are responsible for transmitting sound to the nerves from the outer ear to the inner ear (Krywko, 2012 and Northern & Downs, 2002). Conductive hearing loss usually occurs when there are complications with the middle or outer ear, including the ear canal, ear drums, ossicles, and the middle ear cavity.

Both types of hearing loss can either be genetic, thus inheriting the gene from a family member, or non-genetic as well as environmental influences for example noise induction (Krywko, 2012; Smith, Bale Jr. & White, 2005).

1.2.5.3 Mixed hearing loss

A person can experience a combination of conductive and sensorineural hearing loss which means that there may be damage to both the outer and middle ear (Krywko, 2012). This means that the conductive part of the hearing loss is treatable whereas the sensorineural part of the hearing loss is permanent. Either a hearing aid or a cochlear implant may be used to correct this type of hearing loss (Krywko, 2012).

1.2.6 The onset of hearing loss

Two questions need to be answered when questioning the onset of hearing loss, namely: was hearing loss acquired after birth or was it present at birth? The onset of hearing loss relates to the structure of the ear that is the narrowing of the ear canal or the malfunction of the cochlear in the inner ear resulting in the interference of hearing (Krywko, 2012 and Gelfand, 2009). The onset of a hearing loss if **acquired** (acquired hearing loss), can be as a result of an illness such as meningitis, mumps, measles, non-polio viruses to mention but a few as well as injuries such as damage to the ear (Krywko, 2012 and Smith, Bale Jr., & White, 2005).

On the other hand, idiopathic hearing loss may occur and is referred to when there is no specific reason why a hearing loss is suffered and making its onset difficult to understand especially when there is no history of hearing loss in the family (Krywko, 2012).

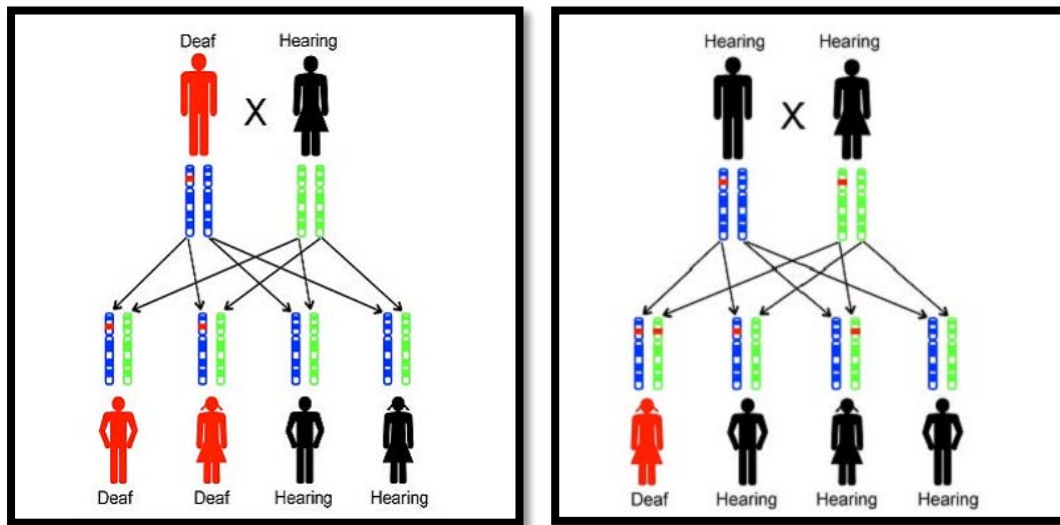
Otitis Media, another major cause of hearing loss, is when inflammation occurs in the middle ear which may cause temporary hearing loss due to the fluid build-up in the middle ear (Bluestone & Klein, 2007). Although the infection can be treated with antibiotics, neglect as well as repeated bouts of otitis media, can cause permanent hearing loss.

Genetic hearing loss on the other hand, relates to the history of hearing loss in the family. It relates to the “mutation (see Figure 2) in the genes encoding the gap junction protein connexin 26 (GJB2/DFNB1)” and those associated with syndromic disorders (Bale, Bonkowsky, Filloux, Hedlund, Nielsen, & Larson, 2011:112). The following figures provide an illustration of how genetic hearing loss can occur resulting in syndromic hearing loss.

Figure 2: Genetic hearing loss

Inheritance of a dominant mutation

Inheritance of a recessive mutation



Common forms of syndromic hearing loss (Bale, Bonkowsky, Hedlund, Filloux, Nielsen & Larson, 2011)

Syndrome	Main Features besides hearing loss
Alport	Kidney problems
Branchio-oto-renal	Neck cysts and kidney problems
Jervel and Lange_Nielsen	Heart problems
Neurofibromatosis type 2	Tumor of the hearing and balance nerve
Pendred	Thyroid enlargement
Stickler	Unusual facial features, eye problems, arthritis
Usher syndrome	Progressive blindness
Waardenburg syndrome	Skin pigmentation

A child who displays a syndromic hearing loss could suggest that the hearing loss is hereditary (Van de Water & Staecker, 2006). The syndromic hearing loss is accompanied by another illness that is Branchio-oto-renal, the hearing loss is often mixed and the syndromic features are kidney problems, bronchial cleft cysts and so on (Van de Water & Staecker, 2006). Approximately 400 syndromes are associated with deafness (Bale, Bonkowsky, Filloux, Hedlund, Nielsen, & Larson, 2011).

The following section discusses the degrees and severity of the hearing loss, the amount of hearing the person being affected can or cannot hear by using the terms “mild”, “moderate”, “severe” and “profound” hearing loss.

1.2.7 Degrees of hearing loss

1.2.7.1 Normal hearing (0-25dB)

Smith, Bale Jr. & White, (2005) point out that a hearing person is able to hear sounds clearly within this category. A child’s hearing acuity will be classified as normal within this threshold. A child with a hearing loss will not be able to hear within this threshold.

1.2.7.2 Mild hearing loss/hard of hearing (25-40dB)

A person in this category is classified as having a mild hearing loss. Words beginning and ending with “ch”, “sh” are hard to pronounce and hard to differentiate. People with mild hearing loss may find it hard to follow speech, particularly in noisy situations and tend to cope better in a quiet setting, but their conversation is limited and it should be familiar to them (Schirmer, 2001). Hearing will become more difficult if speech is distant for example in a class room at school, therefore a hearing aid would be beneficial. This person with mild hearing loss would depend on lip-reading and will need some accommodation to assist with functioning such as sitting in front of a classroom or facing the presenter. Northern & Downs (2002) argues that a child with a mild hearing loss who has little support from parents or educationalist, is likely to lag behind at least one grade. Evidence suggests that children who are hard of hearing will find it much more difficult than children who have normal hearing to learn vocabulary, grammar, word order, idiomatic expressions, and other aspects of verbal communication (National Dissemination Centre for Children with Disabilities, 2004). It is obvious that a person with this type of hearing loss is faced with significant challenges and is in need of support to reach his/her optimum potential.

1.2.7.3 Moderate hearing loss (41 – 55dB)

Almost no speech sound at normal conversational level can be heard on this threshold. After 40 decibels, a hearing aid would be definitely required in order to improve functionality as class teaching would be challenging (Schirmer, 2001). Communication becomes difficult with conversational speech only being heard at close proximity. Speech sounds are inaudible without the assistance of a hearing aid(s). Early and continuous intervention must take place

at this point of time with the involvement of the family. It is argued that learners with a moderate hearing loss who have not received appropriate early intervention are likely to fall behind by at least two grades by fourth grade (Flexer, 1994).

1.2.7.4 Severe hearing loss (70-90dB)

From 70 decibels to 90 decibels, a person would definitely be considered deaf. No speech sound at conversation level can be heard, with severe speech problems. When the hearing loss is severe, early intervention is suggested to assist with language acquisition. According to the American Speech-Language-Hearing Association (ASHA), children with severe to profound hearing loss usually achieve skills no higher than the third- or fourth-grade level. Therefore the appropriate educational intervention for example special education and the support on the part of the family is without a doubt a crucial aspect of the child's development (ASHA) especially for the child to go beyond the fourth grade.

1.2.7.5 Profound hearing loss (90dB +)

With a loss of 90 decibels or more, most environmental sounds are lost as well as everything else. Possible sounds that can be heard are the sound of an aeroplane when standing next to it. It is questionable, however, whether a child with a profound hearing loss would benefit from a hearing aid. The Individual Disabilities Act (IDEA) argues that very little benefit is gained from spoken communication and the profoundly deaf person must **rely on other means** of understanding and being understood for example learning sign language, use of sign language interpreters (Waldman & Roush, 2005).

Sign language is made up of words expressed through hands, facial and body expressions (Kent, 2012). Duke (2009) explains that sign language is a visual language conveying information and conversation visually using hand shapes and movement, head and body movement and facial expression to communicate ideas, humour and feelings.

A South African Sign Language Interpreter (SASLI) acts as a “conduit” (Wadensjö, Dimitrova & Nitsson, 2007:182) who converts spoken language into sign language.

Table 1: The following table illustrates the different degrees of hearing loss and can serve as a tool to assist hearing parents with intervention strategies (Northern & Downs, 2002).

Table 1: Summary: Effects of hearing loss in Children					
Average hearing level (500-2000Hz)	Description	Possible condition	What can be heard without amplifications	Effects of hearing loss	Possible needs
0-15db	Normal range	CHL	All speech and sounds	None	None
15-25db	Slight hearing loss	CHL, some SHL	Vowel sounds heard clearly, may miss unvoiced consonants sounds	Mild auditory dysfunction in language learning	Possible hearing aid, speech reading, auditory training, speech therapy
25-30db	Mild hearing loss	CHL and SHL	Only some speech sounds, louder voice sounds	Auditory learning dysfunction, mild language retardation, mild speech problems, inattentiveness	Hearing aids, speech reading, auditory training, speech therapy
30-50db	Moderate hearing loss	Conductive hearing loss from chronic middle ear disorder, SHL	Almost no speech sound at normal conversational level	Speech problems, language retardation, learning dysfunctional	All of the above and possible speech classes
50-70db	Severe hearing loss	SHL, mixed losses, middle ear disease and sensorineural involvement	No speech sound at conversation level	Severe speech problems, as above	All of the above
70+db	Profound hearing loss	SHL or mixed losses, combination of middle ear disease and SHL involvement	No speech and other sound	As above	As above

*CHL- Conductive hearing loss

* SHL- Sensorineural hearing loss

The above table unpacks the different categories of hearing loss, limitations, effect of hearing loss and possible intervention. Knowledge of the degree of hearing loss can assist hearing parents with some understanding of the nature of hearing loss, and in making the appropriate decisions regarding their deaf child's learning and development (Northern & Down, 2002) especially in the last two categories of hearing loss as they present more challenges for hearing parents for example the choice of education and medium of instruction that is sign language verses oral communication.

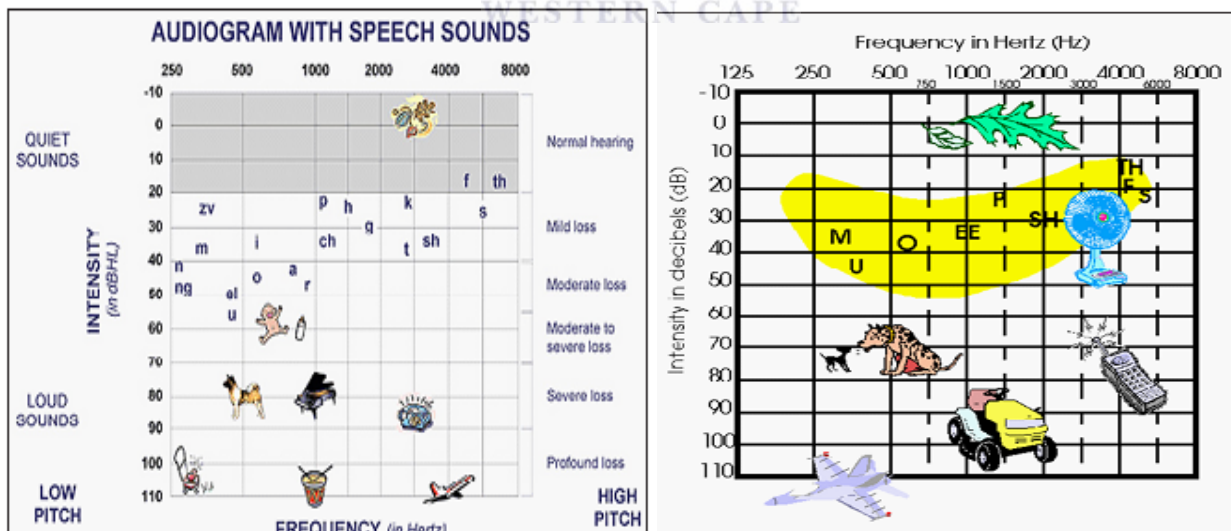
The following discussion explores the need for hearing parents to understand their child's audiogram as argued by Kurtzer-White, Seewald & Luterman (1999) in Northern & Downs

(2002:28) who suggest that hearing parents of a child with hearing loss need to be informed of what an audiogram means, what the child can and cannot hear, a description of the type of hearing loss and the possible medical intervention as well as family support to help reduce the stress on the parents. Northern & Downs (2002) further suggest that if hearing loss is not detected and treated at an early stage of a child's development, it can result in a delay in speech and language development, emotional and social problems as well as academic failure. The audiogram is therefore a useful tool for assessment and intervention strategies.

1.2.8 The role of an audiogram in the diagnosis of hearing loss

Knowledge of the degrees of hearing loss depicted on the audiogram can assist with a better understanding of the nature of hearing loss, which in turn can minimise parents' fears and anxiety, and in so doing assists hearing parents in making the appropriate decisions regarding the learning and developmental needs of a child with hearing loss. Krywko (2012) refers to an audiogram as a personalised chart/picture that shows an individual's hearing test results. It indicates where the different levels of sound are depicted as well as the level of volume (loudness or softness) the person is able to hear (Waldon & Roush, 2005).

Figure 3: The Audiogram



In order to read/understand an audiogram, it is important to know that the vertical lines on an audiogram represent pitch or frequency. The pitch is measured in frequency of sound vibrating per second. A deep voice has a low pitch and frequency, whereas a child's voice has a high pitch and frequency. The left line indicates the lowest tones and the right line indicates

the highest tones as well as the degrees of hearing loss. The crescent “banana speech” indicates the range of conversational speech (Smith, Bale Jr., & White, 2005; Storbeck 2005; and Northern & Downs 2002). The majority of speech sounds fall within the dark area referred to as the “speech banana”. If the threshold (level of hearing) is above the speech banana then a person can hear all sounds. If the threshold is below the speech banana the person is unable to hear the necessary sounds required for speech. If the threshold is somewhere along the edges of the speech banana then the indication is that the person can only hear certain sounds (Krywko, 2012).

The horizontal lines on the other hand represent loudness or intensity, the top line being the softest, and the bottom line being the loudest. The loudness of sound is measured in decibels and helps the audiologist to identify the softest sound the child can hear (Krywko, 2012; Smith, Bale Jr., & White, 2005).

In conclusion, the audiogram presents a picture of a person’s hearing and can provide vital information that is needed for the appropriate intervention strategies in the event that hearing loss is detected (Stobek, 2005). For hearing parents it presents a visual picture of what their child can and cannot hear. Blume, (2010); Northern and Downs, (2002) state that an audiogram is crucial in providing hearing parents with a greater understanding the causes of the hearing loss, type of hearing loss, the degree and severity of the hearing so as to assist parents to make informed choices and take an active role in their child's hearing loss management.

1.2.9 Hearing loss as a disability

The question of hearing loss as a disability is important to understand especially the impact hearing loss has on the family and the need for early intervention strategies (Marcsharf & Spencer, 2003). Owing to the diverse opinions and ongoing debates as to whether hearing loss is a disability or a minority linguistic/cultural group, for the purpose of this research hearing loss was defined as a disability as it was located grief within a disability framework. For instance some deaf people define themselves as culturally Deaf with an uppercase “D” and do not see their deafness as a problem but rather perceive themselves as a minority group with a sense of pride, self-worth and identity (Mindess, 2006; Devlieger, Rucsh & Pfeffier, 2007 and Marschark, 1997). Their cultural Deafness has been formed by common traditions

and strengths due to the use of a common visual language for example American Sign Language (Smith, Bale Jr., & White, 2005).

Inherent to the understanding of deafness as a disability, two models of disability, gave context to ones understanding of disability namely the medical and social model of disability. Larkin (2009) and Mindess (2006) maintain that the medical model defines disability in terms of individual pathology and view people with a disability as mere patients. In addition, Larkin (2009) suggests that the medical model of disability assumed that people with a disability were the problem and what was needed was care or a cure. In the case of hearing loss, the medical definition of hearing loss is defined by the degrees of hearing loss. Tanner (2007) is of the opinion that the medical model restricts the disabled person's ability to perform as a normal person. The medical model also known as the "individual model" puts emphasis on the person and therefore defines the person by the disability or illness.

However, inherent to the medical model, some argue that this model does have its benefits in that it provides medical relief to those in pain and opportunities to access housing, social grants and employment (Devlieger et al., 2003).

More recently there has been more focus centred on the strength, resilience and health in people and less focus on the personal weakness of the person. The concept of empowerment is based on the ability of self-reliance, self-representation and full participation (Hintermair, 2006; Bodner-Johnson & Sass-Lehrer, 2003) not only for the person with a hearing loss but also for the hearing parent. This change in perspective has also become extremely important for issues pertaining to the development of children with a hearing loss and the promotion of human rights for all disabled people in general.

Therefore due to the promotion of human rights through various United Nations initiatives and activism by disabled people, an alternative approach to the medical model has emerged with the emphasises on the rights of people with disabilities. The social model of disability implies that society must reconstruct and develop so as to make reasonable accommodation with the intent to address the developmental needs of disabled people in an inclusive society (INDS, 2007). The INDS (2007) further defines reasonable accommodation as removing the societal barriers in order for disabled people to have the same opportunities as everyone else thereby determining their own life styles. Larkin (2009) equally emphasises the move to an

inclusive society as promoted by the social model and that the disability is not the problem of the individual but rather the attitudinal and physical constraints that oppress disabled people. According to Mindess (2006:78) "It is not the extent of hearing loss that defines a deaf person, but the individual's own sense of identity and resultant actions." Disabled People South Africa, (2000) believes that it is the right of the disabled individual to decide whether he or she wants to be defined as disabled or not. The notion is based on the idea that no one is forced to be defined by others except by themselves, thus the statement "Nothing about us without us" leading to the expression of self-determination.

However, hearing parents would be forgiven for leaning towards the medical model as many hearing parents' first contact was with the medical fraternity when confronted with the diagnosis of their child's hearing loss. For many hearing parents the decision making and intervention processes are too often left in the hands of the medical profession because they fear the unknown or fear to make things worse for their child (Marscharck, 2007). Hence the following discussion which centres on the reaction of hearing parents to the diagnosis of their child's hearing loss and their experiences of facing such a loss.

1.2.10 Hearing parents' reaction to the diagnosis of their child's hearing loss

There is evidence to suggest that 90% of children with a hearing loss are born to hearing parents who often know nothing about hearing loss and deafness (Krywko, 2012; Mitchell, Estabrooks (2004) in Estabrooks, 2012; Jackson & Turnbull, 2004 in Leigh 2009 and Northern & Downs, 2002). The response to the diagnosis of their child's hearing loss largely depends on the parents' perceptions, knowledge and experience of disability. Kutzer-White & Luterman (2003) warn that the kind of response from parents when hearing the diagnosis may impact negatively or positively on the bonding between the parent and the child with hearing loss.

Simer & Estabrooks (in Estabrooks, 2012) state that the way in which parents respond to the diagnosis of their child's hearing loss, can often lead to a disruption in the relationship between the parent and child. Similarly Dare & O'Donovan (2003:240) postulate that the sudden experience of having a baby with a special need can be upsetting and isolating, and hearing parents will inevitably need "time to understand, adapt and accept". Often an

unexpected diagnosis crushes a hearing parent's hopes and dreams for their child (Simer & Estabrooks in Estabrooks, 2012 and Kutzer-White & Luterman, 2003).

The realisation of the child's hearing loss can therefore put enormous stress and strain on hearing parents and their family, resulting in hearing parents having to weigh up information such as communication options, education, and rehabilitation at a time when they are dealing with a myriad of emotions (Simer, in Estabrooks, 2012; Kutzer-White & Luterman, (2003) in Marschark & Spenser, 2003). Jackson & Turnbull in Leigh (2009), on the other hand, mentions that family stress is also heightened when important choices need to be made for example the medium of communication or educational needs of the child with the hearing loss.

Boydell (2005) explains that as a result of all the stress and emotions being experienced, grief often sets in as a result of fearing the unknown, which can in turn lead to sadness, anger, denial and blame as a response to their child's hearing loss.

Perhaps the best model to explain the stages of grief stems from the pioneering work of Kubler-Ross (1969). She identified 5 stages of grieving specifically to death and dying: denial, anger, bargaining, depression and acceptance. However contrary to the stages identified by Kubler-Ross (1969), Kutzer-White & Luterman (2003) describe parent grief as chronic or indefinite sorrow, and suggest that hearing parents do not only experience grief at the time of the diagnosis, but rather throughout the lifespan of the child. Similarly Krywko (2012) wishes to highlight that grief is not experienced in a linear fashion meaning proceeding from one stage to another, but takes hearing parents back and forth through different stages of their grief at different times.

In similar vein Medwid & Chapman Weston (1995:12) is of the opinion that "parents need the opportunity to express their grief and expectations at each stage" and that "throughout a deaf child's life, hearing parents will probably have to cope with many difficult feelings; feelings that recede and emerge again at different developmental stages in the child's life". Finally Hintermair (2006) asserts that it is important for parents to get to the stage of acceptance of the reality that their child has a hearing loss, as it could assist them with the developmental needs of their deaf child.

A few theories on disability-related grief will be further unpacked in Chapter 2 underscoring the theory that will underpin this research.

1.3 Problem formulation

Overwhelming evidence suggests that when hearing parents hear the diagnosis of their child's hearing loss it often results in a significant life-changing event for both the parent and the child. Unresolved shock and grief can lead to stress and strain on the parent-child relationships while parents are forced to deal with a range of emotions such as anger, blame, frustration and loss of control. Hearing parents are often bombarded with information about education choices and language choices for example, but are not given the opportunity to express their pain and hurt about the diagnosis of their child's hearing loss. They are thrown into an unknown world where their questions are left unanswered and must travel this journey on their own.

In an attempt to understand hearing parents' experience of their child's hearing loss, a qualitative study was conducted to explore and describe their experiences.

1.4 Research Question

The research question is a central question being examined in the research. It attempts to describe feelings and emotions experienced by hearing parents. It is a general question so as not to limit the response/enquiry, (Creswell 2003).

The research question for this study was: **What are the experiences of hearing parents regarding their child's hearing loss?**

1.5 Research goal and objectives

1.5.1 Goal

The goal of the present study was to enhance the knowledge base of social work in healthcare by exploring and describing the experiences of hearing parents regarding the diagnosis of and caring for a child with hearing loss.

1.5.2 The objectives of the research were threefold:

- To explore the experiences and reactions of hearing parents upon the diagnosis of their child's hearing loss
- To explore and describe the experiences hearing parents have of caring for their child with hearing loss
- To explore the needs of hearing parents regarding the way forward.

1.6 Research Approach

The research study follows a qualitative approach as the researcher was interested in the experiences of hearing parents of their child's hearing loss. Creswell (2003) explains that a qualitative researcher builds a holistic picture by analysing words, reports detailed views of the interviewee and conducts the study in a natural setting.

1.7 Research Design

The research design for this study is phenomenological in nature and is broadly defined "as the study of a phenomenon" (Klenke, 2008: 222) and is underpinned by the following:

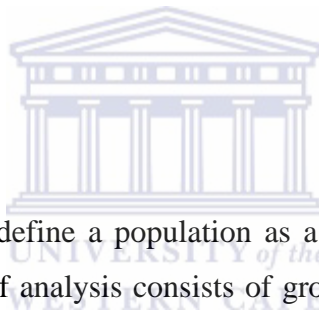
- Understand the common experiences of individuals that share the same phenomenon;
- The research topic is a phenomenon of interest to study;
- The researcher will at all times be objective in the research;
- Data is collected from individuals who have experienced this phenomenon;
- One broad general open-ended question is asked that is: what are the experiences regarding the phenomenon? Creswell (2003).

De Vos, Strydom, Fouché & Delport (2002) explain that phenomenological design aims to understand and interpret the meaning people give to their everyday experience. Moustakas (1994) states that phenomenological research explores lived experiences and aims to get a deeper and better understanding of the meaning attached to everyday human experiences. Similarly Klenke (2008: 223) states that "the intent of phenomenological research is to understand the phenomenon.....to provide a credible description of human experience as it is experienced by the individual (Benz & Shapiro: 96) in Klenke (2008) and allow for the essence of that experience to emerge (Cameron, Schaffer & Hyeon-Ae, 2001) in Klenke (2008).

Therefore the research is explorative in the sense that it was borne “out of a lack of basic information on a new area of interest in order to become acquainted with a situation so as to formulate a question or develop a hypothesis” (De Vos et al., 2002:109). It is descriptive in the sense that it describes the parents’ feelings and emotions (De Vos et al., 2002). The study describes the lived experience of individuals with a common phenomenon that is experienced by all participants as pointed out by Creswell (2003:190-191) and allows the researcher to enter into the “life world or life setting” of the hearing parent.

Leedy (in De Vos et al., 2002) states that the final result of phenomenological research is a general description of the phenomenon (disability in this case), as seen through the eyes of the people who have experienced it at first hand. Moustaka in Creswell (2003) talks about the “What?” and the “How?” experience. In short: what did these participants feel and how was their experience?

1.8 Research Methodology



1.8.1 Population

Durrheim & Painter (2006:133) define a population as a sample taken from a larger pool. Often in social science the unit of analysis consists of groups, individuals and organisations as reported by Babbie (in Durrheim, 2006:41).

The population or unit of analysis that participated in the research was hearing parents with children who had a hearing loss between the ages 0 – 10 years.

1.8.2 Sampling

According to Arkava & Lane (in De Vos et al., 2005: 194), sampling can be “viewed as a subset of measurements drawn from a population in which we are interested”. Hence data was drawn from a subset of individuals and was used to make inferences about the whole population.

To gain access to the participants, the researcher approached a local organisation of the deaf, namely the Deaf Community of Cape Town, which offers bi-monthly sign language classes for hearing parents with deaf children.

The hearing parents' participation was voluntary. Volunteer sampling consists of participants becoming part of a study because they volunteer when asked to respond to the research question at hand (De Vos et al. 2002). In addition, the snowballing technique extended the sample to other hearing parents who became aware of the research study. The process of snowball sampling as described by Castillo (2009) is much like asking the participants to nominate another person with the same experience. A sample of eleven hearing parents was included in the study when data saturation had taken place. The number of participants as pointed out by Pitney & Parker (2009) determined when data saturation was reached. Kumar (2011:248) explains that data saturation occurs when additional data is not required when existing data has already served the purpose of the research.

The sampling criteria for this study were: hearing parents with children between the ages of 0-10 years old and who were diagnosed with hearing loss.

The following criteria were identified for this study:

Merriam (2009) suggests that a list of attributes be compiled by the researcher before commencing with the study. This list should reflect the purpose of the study and in so doing assist in identifying rich information that can add to the validity of the research.

Firstly, central to the criteria selection was that participants had to have experienced the central phenomenon under investigation (Creswell, 2003). Therefore the participants had to be hearing parents of children who were diagnosed with a hearing loss between the ages 0-10 years.

Secondly the selection of participants was done with the assistance and permission of a local Deaf organisation (Deaf Community of Cape Town) in identifying potential participants. This organisation provides sign language classes to hearing parents with deaf children, and therefore presented the researcher with a unique opportunity to engage with parents. The organisation was briefed, and a letter of intent was given to the organisation about the research as well as explaining the aims and objectives of the research (Appendix C).

Thirdly, the hearing parents were also given a letter of intent regarding the research, explaining confidentiality and making a request to parents to volunteer to be interviewed (Appendix A) and give consent to be interviewed (Appendix B). There was a positive

response to the request and parents recommended others whom they knew and had a relationship with.

Fourthly, participants could be both male and female of all racial groups who lived in the proximity of Cape Town.

1.8.3 Data Collection

Information was gathered directly from participants by means of individual in-depth interviews, a technique suitable to phenomenological research (Klenke, 2008). The interview itself was unstructured, which De Vos et al. (2002) refer to as “a conversation with a purpose”, namely telling stories. The stories provided rich data that Denzin (in Creswell, 2007: 194) terms “thick description” and “going beyond mere facts and surface experiences”.

This method of qualitative data collection assisted the researcher to elicit information from the participants for better understanding. Grbich (2012:95) states that when following the process of phenomenological reduction with the use of observation and listening skills, a visible picture of the phenomenon is built up over time.

The “What?” and “How?” questioning technique led to descriptions of feelings and experiences that provided an understanding of the experiences of the participants (Creswell 2003). The interviews were audio taped after the researcher gained the permission of the participants, and field notes were used to capture the non-verbal communication of participants. Sacks (in Denzin & Lincoln, 2003: 354) recommends the use of the audio tape to record interviews as it is impossible to remember every detail such as “pauses, overlaps, and in breaths”.

The participants were asked one general open-ended question to elicit as much data as possible. Question: Your child has been diagnosed with a hearing loss. Please tell me your story?

Apart from the abovementioned question, the researcher utilised interview skills and communication techniques such as probing, active listening, reflecting, paraphrasing, summarising and asking questions for clarity (Wosket, 2006).

1.8.4 Pilot Study:

The researcher conducted a pilot study to help establish the foundation for the main study. Bless & Higson-Smith, (2006) state that the pilot study involves the testing of the actual study on a small sample from the population. A pilot study with one participant was conducted to ensure that the required data was generated with the proposed data collection method.

1.8.5 Data analysis

Data analysis is the process of bringing order, structure and meaning to the mass of data collected, De Vos et al. (2002). Creswell (2005:27) in Finch (2008:69) states that “qualitative data analysis consists of describing and developing themes”. The data analysis involves the process of making sense of all the data gathered (Creswell, 2007).

The following data analysis took place according to Creswell (2007:183-190) and Klenke (2008: 231).

Firstly the researcher organised and prepared the data for analysis. This included typing up all the transcripts. Secondly phenomenological research involved the researcher becoming immersed in the data, reading and re-reading through all the transcripts, getting a sense of what the participants said and reflecting on written notes. Thirdly, the process of coding took place in which data was grouped into themes so as to give a description to participant’s experiences of the phenomenon. This entailed searching for themes that can be “validated by the re-emerging and repetition of specific ideas” (Klenke, 2008: 231). Fourthly, the themes were tabulated into thematic clusters and then sorted into subthemes or higher order clusters so as to give a descriptive representation of the phenomenon.

1.8.6 Trustworthiness

In phenomenological studies the goal is to describe accurately the experience of the phenomenon under study, not to generalise, as pointed out by Field & Morse (1985) in Krefting (1991). Furthermore Klenke (2008:238) states that rigor is demonstrated by focusing on the participant’s perspective by faithfully recording and transcribing their experiences. Similarly Nagy, Hess-Biber & Leavy, (2011) asserts that the most important issue in evaluating the rigour in qualitative data is trustworthiness. Trustworthiness is seen as the backbone or strength of the qualitative analysis (Creswell, 2008). According to Marshall & Rossman (2011) all research must meet the criteria against which the trustworthiness

of the project can be evaluated. Lincoln & Guba (1985:290) in Rossman & Rallis (2011:59) state that the aim of the research is to produce findings that are “worth paying attention to, worth taking account of”.

The readers must be able to trust in the integrity and credibility of the study, in order for it to be used by other researchers and scholars (Rossman & Rallis, 2011). Lincoln & Guba (1981) in Krefting (1991) propose such a model for assessing the trustworthiness of qualitative data, namely through truth value, applicability, dependability/consistency, and neutrality. The study had to reflect the accuracy of information that was provided by participants and these accounts needed to be trusted and be seen as credible as suggested by Creswell, & Plano Clark (2011).

Lincoln & Guba (1985) in De Vos et al., (2002) add that the researcher should establish confidence in the truth of the findings. The study must establish how confident the researcher was with the truth of the findings based on the research design, informants and context. The research should capture the human experiences as they are lived and perceived by informants. One way of validating the analysis is to check with participants if they were reflecting certain emotions and feelings for example: “Is it true to say that you feel angry, disappointed, etc.?” This in essence speaks to the conformability / accuracy of the data as the findings describe the words of the participants (Polit, Beck in Hall & Roussel, 2012).

The **applicability** of research refers to the degree to which the findings of the research can be applied in other contexts. Data collected should be able to be tested against the literature, referring back to the theoretical framework that underpins the research ensuring **transferability**. Another way of validating and checking the accuracy of the analysis is through peer debriefing (Rubin & Babbie, 2009: 232; Creswell, 2009). **The dependability or “consistency”** (Lincoln & Denzin, 2003:172) of the information was ascertained with assistance from peer assessments done with the research supervisor. Peer briefing allowed the researcher to speak to her supervisor and reflect her methods deployed, discuss her potential biases, her emotions, feelings, thoughts and modify decisions (Rossman & Rallis, 2011; Babbie, 2010). Peer debriefing happened mostly during the first stage of the research as the researcher was passionate about the research but was guided by her supervisor to be objective and neutral to enhance the credibility of the study.

The **neutrality** of the study speaks to the conformability of data and its interpretation. An independent coder was appointed to audit the findings of the research. The independent coder assisted with the observations in transcripts to check for validity, a method identified by Creswell (2007) as member checking, which is cited by Lincoln and Guba (1985) in Krefting (1991) to ascertain the accuracy of the data, themes and interpretations. Thus the neutrality of the study speaks to the conformability of data and its interpretation.

Krefting (1991) puts forward the notion of reflexive analysis acknowledging that the researcher's own biases may influence the findings and suggests that the researcher should use data and documentation collected to support the findings and allay such claims of bias therefore ensuring the neutrality of the research, in that the findings are solely that of the participants.

1.9 Ethical Considerations

De Vos et al., (2002:63) defines ethics as “a set of moral principles that are suggested by an individual or group, are subsequently widely accepted, and offers rules and behavioural expectations about the most correct conduct towards others”. William, Tutty & Grinell 1995: 30 (in De Vos et al., 2002:62) states that “data should never be obtained at the expense of human beings”.

Ethical considerations were taken into account with the view that qualitative research is done with real people who live with their experience every day (Rossman & Rallis, 2011). It was important that all aspects of the research adhered to the ethical considerations in research starting from the research question, data collection, and sample selection, conducting the research and conveying the findings as recommended by Northway (2002) in Flick (2009).

According to Wassenaar (2006) and Terre Blanche & Durheim (1999) nonmaleficence, beneficence and justice are three ethical considerations pertaining to the autonomy of participants in this study. In addition, Flick (2009) reflects on 3 aspects that reflect the ethical soundness of qualitative research namely scientific inquiry, welfare of participants and respect for the dignity and rights of participants. The ethical considerations that were adhered to during the study are the following:

- **Autonomy** refers to the adherence of respecting the rights and dignity of participants in that their voluntary consent (Allmark in Flick, 2009) and voluntary participation were discussed and obtained before the commencement of the research. At the initial contact with the participants, participants were informed of the intended question to be investigated, the reasons for the research and the researcher's competence to do the research. The participants were made to understand that their participation was **voluntary** and that they had the right to ask questions about the research.
- Autonomy was also guaranteed through **confidentiality** where not only the identities of participants would be concealed by pseudonyms whereby it would be impossible for a reader to identify or match information and the identity of the participant (Rossman & Rallis, 2011 and Flick, 2009) but also taking into account privacy and sensitivity of information (Henning, 2004). Participants were also informed that they had the **right to withdraw** at any time from the research (Rossman & Rallis, 2011 and Flick, 2009) without any explanations. Permission was also sought from participants beforehand to audio tape the interviews.
- Confidentiality was also guaranteed with the compilations of the study as ethical considerations must be kept in mind when using small samples, where quotes are used verbatim making it easy for people to identify their own information (Flick, 2009).
- The principle of nonmaleficence or welfare of participants meant that the research would pose **no harm** to the participants. During the course of the research the researcher had to assess whether the research question would pose any weigh the risk and harm against the benefits, welfare and rights of the participants as pointed out by Punch in Nagy, Hess-Biber, & Leavy, (2011) and Denzin & Lincoln, (2003).
- The researcher was required to consider potential risks, such as emotional harm as the research question could evoke feelings of pain, guilt, sadness and guilt when collecting data. The researcher had to gauge whether it was ethical correct to risk a participants for the sake of the research. One of the participants became extremely emotional when speaking about her experience and the researcher made the decision to terminate the interview in light of causing any emotional harm to the participant.

- The principle of beneficence or scientific quality required that the researcher not duplicate existing research but design her own research that would be of benefit to other researchers as mentioned by Flick, (2009); Rossman & Rallis, (2011). The research study must be seen as contributing to the existing knowledge of the phenomenon.
- At the end of each interview the researcher requested the participants who took part in the study to discuss their feelings. Participants who seemed very emotional were referred to a social worker for **debriefing**.
- Permission from UWC Ethics Committee as well as the Deaf community of Cape Town was obtained before the commencement of the research.

In conclusion, the reader must walk away with the feeling of “I understand better what it is like for someone who experiences that” (Creswell, 2007 p.62).

1.10 Conclusion

Chapter 1 introduces the reader to the research at hand. It outlines the literature reviewed which brings together a greater understanding of what hearing loss entails. It speaks to the prevalence of hearing loss worldwide and nationally, the anatomy of the ear and the etiology of hearing loss which leads to a better understanding of hearing parents' experiences when confronted with the diagnosis of their children's hearing loss. Chapter 1 furthermore explained the planned processes of implementing the research by introducing the research question and the goal and objectives as well as the research design. It also described the research methodology to be implemented which includes the research population, sampling, data collection, data analysis and trustworthiness. Pertinent ethical considerations were also discussed so as to ensure the respect and autonomy of all participants.

Chapter 2 sets the stage for further literature to be explored so as to provide a better understanding of the experiences of hearing parents whose children have been diagnosed with a hearing loss.

CHAPTER 2

LITERATURE REVIEW

2.1 Introduction

Chapter 1 focused on the orientation and planning phase of the research process. An introduction to the study, the problem formulation, a theoretical assumption, the goal and objectives, the research approach and the design of the study as well as the research methodology were briefly mapped out. Measures to ensure trustworthiness of the study as well as ethical considerations to be adhered to were also addressed in the chapter.

In Chapter 2 attention will be given to a comprehensive literature study, to the different theories underpinning grief and loss, parents' response to the diagnosis of their children's hearing loss, and the role of professionals during and after the diagnosis. Emphasis on stress as a major contributor to the relationship between hearing parents and their children and the impact the diagnosis has on other siblings in the household will be included.

The ultimate focus of this chapter is to provide a literature review on the experiences of hearing parents raising children with hearing loss, describing grief and loss as an emotional response and the consequences it has on the family.

The following discussion provides a theoretical understanding of how parents over decades have responded to the news of their child's disability.

2.2 Grief and Loss

Upon hearing the diagnosis that their child has a hearing loss, the majority of hearing parents will experience feelings of loss and grief. Hooyman & Kramer (2008: 100) define "loss" as a perceived reaction to a negative event that results in long-term adjustments being made, and they emphasise that grief is the natural reaction to loss. What should be kept in mind however is that each parent's response to loss is unique and each parent will progress through their own personal journey of grief in their own way and in their own time.

Therefore in order to provide some understanding of how humans process grief and loss, the following discussion centres on how loss and grief can be applied in a disability-related grief framework.

2.2.1 Defining disability grief amongst hearing parents

Grieving is synonymous with death but unlike death that is final, disability-related grief tries to make sense of that which is loss, losing hopes and dreams as envisioned by parents whose child has been diagnosed with a disability (Kandel & Merrick, 2007). The aforementioned author together with Worden (2011), Foley (2006); Kandel & Merrick (2007) and Heiman (2002) described disability-related grief as an intense sadness, numbness, disbelief, anxiety, fear, anger, denial, disappointment, frustration, guilt, shame, and confusion, avoidance, shock, blame, disorientation, longing, depression, aggression, helplessness and acceptance. Furthermore Hooyman & Kramer (2008:6) state that parents with disabled children in particular, face long-term grief, referred to as "chronic sorrow" which indicates that they have to face constant adjustments throughout their life and that the feelings of grief can re-emerge at each milestone of their child's life, for example entering school and attending public events.

The following discussion reviews the literature from 1950 to 2010 on the perceptions of parental responses to disability in relation to grief and loss. These perceptions are linked to the concepts of disability, death, grief and loss, and examine the influence of Kübler-Ross's stage theory (1969) in shaping the traditional approach regarding parental response to disability, and secondly discussing an alternate paradigm that is positive for framing parental response to disability.

2.2.2 Theoretical perspectives on grief

2.2.2.1 The period stemming from 1948 – 1968: Task Based Theory

Ferguson (2002) in (Alfred & Hancock, 2012) explained that from the period 1920 to 1980 parental responsiveness to disabilities was in relation to the medical model, given impetus by the traditional approach to parental response to disability. Task based theory, as defined by Walter & McCoyd (2009:7), focused on what **task** parents needed to complete in order for them to heal. Lindermann (1994) in Walter & McCoyd (2009:6) was of the opinion that 8 to 10 sessions were enough time for parents to heal or manage their grief.

Task base theories characterised parental response to grief as follows: (1) the neurotic parent (2) the dysfunctional parent (3) the suffering parent who feels sorry for him/herself and sees the disability as a burden and (4) a powerless parent.

Olshansky (1962) and Solnit & Stark (1961) in Alfred & Hancock (2012) similarly, introduced the concepts of mourning and chronic sorrow as common parental responses to disability. These concepts presume that the hearing parents experience the death of a perfect child and thus grieve for the child hoped and planned for, when they learn that their child has a disability.

"Ventilation" of mourning is encouraged as part of a healing process to loss, in the same way as weeping. However, Carr, Nesse & Wortman (2006) in Walter & McCoyd (2009), Stroebe & Stroebe (1991) and Wortman & Silver (1989, 2001) in Walter, McCoyd (2009:7) warn against pressure on parents to ventilate if they are not ready, as this could make matters worse, thus leading to the assumption that the task based theory might not be suited in assisting parents who were grieving for the loss of the "perfect child" that they had anticipated.

In critiquing the task based theory, one would say that it is oversimplified as it leads to the assumption that the completion of a task at each stage leads to the completion of grief (Walter & McCoyd, 2009:7). Simos (1979:41) in Walter & McCoyd (2009:6) was of the opinion that the task based theory was too limiting in its approach and that professionals themselves became the "deterrent" or obstacle which prevented parents from grieving properly, especially in the case when parents took much longer than two months to grieve. Often parents who did not grieve within the prescribed time were referred to as "emotionally disturbed" or "maladjusted" by professionals. Therefore in summary the period between 1950s and 1960s, was characterised by the view that parents' response to their child's disability was one of pathology. The child's disability was viewed as a tragedy, and therefore the response was one of suffering and powerlessness on the part of the parents, similar to the approach advocated by the medical model on disability.

Following the period of 1948-1968 the stage theory was introduced as a parental response to grief.

2.2.2.2. The period stemming from 1969-1989: Stage Based Theory

This period was synonymous with the pioneering work conducted by Kubler-Ross (1969) and others like Rando (1993); Frontier & Wanlass (1984); Bowlby (1980/1981); Bowlby &

Parkes (1970); and Rosen (1954) authors in Walter, McCoyd (2009) reinforced the stage theory of parental response to grief. Stage based theories were also referred to as time-bound or linear models of grief and loss. It is understood that the stage based theory has a start and an end, the end being the point of acceptance. The timeframe within each stage is dependent on the parents' own coping and understanding of the problem, as some individuals will learn to cope with the loss more easily than others. This theory thus suggests a one-way journey, namely moving from one stage to another during the process of grief and loss, particularly denial, anger, bargaining, depression and acceptance (Kubler-Ross, 1969).

Bowlby (1980, 1981) in Walter, McCoyd (2009:100) on the other hand postulates the following stages in relation to grief and loss:

- **numbness**; described as shock and/or feeling stunned;
- **separation anxiety**; described as despair, denial and anger;
- **despair and disorganisation**; described as an attempt to recognise loss and develop a new “normal” and acquisition of new roles and reorganisation.

Rando (1993) identifies the “R” processes of grief as react, recollect, re-experience, relinquish, re-adjust and re-invent.



Livneh (1986) in Chan, Da Silva Cardoso & Chronister (2004) compares 40 stage models and uses the information to develop a more unified model of adaption. They identify the following five broad categories pertaining to the stage model:

- The initial impact: this involves feelings of shock, as the initial reaction to the diagnosis, and anxiety where the parent is stricken with panic;
- Defence mobilisation: involving bargaining and denial;
- Initial realisation: parents experience great emotional turmoil and need time to process the event (in this event, hearing loss). As parents internalise feelings of anger, bitterness and self-blame, mourning is perceived as a short-term response, and depression is viewed as a long-term response to the diagnosis;
- Retaliation/Rebellion: the anger and bitterness of the parent manifest themselves outwardly, and he/she becomes uncooperative and does not accept the disability of their child;

- Reintegration: the final stage that is characterised by acknowledgement by the parent and their acceptance of the disability.

In critiquing the stage based theory, Chan, Da Silva, Cardoso & Chronister (2004) are of the opinion that hearing parents' reactions are not universal, and they can therefore experience feelings of grief and loss at different stages throughout the life of their child with a hearing loss. Furthermore Walter & McCoyd (2009) are of the opinion that it is a fallacy to suggest that progressive movement through these stages does not allow for back-and-forth movement. Dale (1996) warns that some parents will go through more than one stage at a time or will go back and forth between the different stages. Furthermore Bruce & Schultz (2004) and Davis (1987) in Power & Dell Orto (2004) view grief as a chronic or recurring cyclic sadness which is not confined to time, with the result that the grieving process is never completed (Weisman 1973 in Power & Dell Orto, 2004). Walter & McCoyd (2009) also argue that not all parents go through all the stages, and warn against professionals labelling these families as dysfunctional and pathological in their final conclusion should each stage not be met.

Accordingly Walter & McCoyd (2009) believe that there is no pre-set path of grief and loss, and describe grief as similar to the waves of the ocean in that any emotions can resurface at any time/stage during their child's life; for example, when a child enters school parents can face sadness and sorrow as they become aware of their child's limitations. Similarly Luterman (1987) emphasises that there is no clear demarcation between one stage and another during the process of grieving. The author maintains that disability will persist or get worse during the lifetime of the parents, placing new demands on them as the child grows older, and therefore feelings of grief can resurface at any given time, as pointed out by Murgatoyd & Woolfe (1993) in Brown (2012). Medwid & Chapman Weston (1995) suggest that often these feelings recede and emerge again at different developmental times in the child's life thus emphasising the importance of hearing parents to express their expectations at each stage. Kearney & Griffin (2001 in Carpenito Moyet, 2008:636) call these experiences joy and sorrow, which may be felt at any recurring moments during the development of the child with hearing loss.

The stage theory period was followed by the transformative model that developed during the late nineties.

2.2.2.3 The period stemming from 1990-2010: Transformative theory

During the period 1990-2010 there has been growing dissonance among some researchers regarding the stage based theory of parental responses to disability, which is attributed to attitudinal changes in society regarding disability at the time. Several authors such as Scorgie, (2005) in Alfred & Hancock (2012); Scorgie, Wilgosh, & Sobsey, (2004) in Alfred & Hancock (2012); Scorgie, Wilgosh, & McDonald, (1996) in Alfred & Hancock (2012) have conducted both qualitative and quantitative research on parental responses to disability and have come up with a transformation theory which suggests that parenting styles are changing (transforming) to become more adaptive, evolving and supportive as parents have become more aware, adapting and understanding of their child's disability. This new wave of thinking further suggests that through better understanding and through more awareness regarding disability, parents' management of disability in the family has improved (Alfred & Hancock, 2012).

Contrary to the stage based theory, the transformative theory promotes the idea that parents are more accepting and adapting of the child's disability, and have more options on how to respond to their child's disability (Alfred & Hancock, 2012).

Since 2010 the postmodern grief theory has gained more recognition and is favoured in our attempt to understand grief and loss.

2.2.2.4 The Postmodern grief theory:

Another prevailing approach/theory for conceptualisation is the one supported by Neimeyer, (2001) in Walter & McCoyd (2009) who supports the postmodern grief theory. The postmodern grief theory is premised on the idea that human beings construct **their** truths and **they** make meaning of **their** loss by processing the grief the way **they** experience it. The author's view of understanding grief and loss speaks to elements of respect and listening to the stories of grief as told by those experiencing it. By opening up, Neimeyer (2001) in Walter & McCoyd (2009) believes individuals make sense of their pain themselves, and cautions professionals only to provide assistance from a view of filling in the gaps.

To further the debate on postmodern theory, Rappaport, (1987) in Hintermair (2006) encourages the empowerment of the individual, namely encouraging people to take control of their own affairs, to discover their own powers and capabilities, while at the same time

learning to appreciate the value of solutions that they have worked out for themselves. Hintermair (2006) is also of the opinion that empowerment of people with hearing loss and even deafness, begins with the empowering of the families into which they are born. The same author believes that empowerment of the family in which the person with hearing loss was born, starts with information (Hintermair, 2006). The importance of information for parents of a newly diagnosed baby has been well documented by authors such as Luterman, Kurtzer-White & Seewald (1999), Meadow-Orlans, Mertens & Sass-Lehrer (2003). Zaidman-Zait & Jamieson (2007) supports the view of previous authors by pointing out that the process of information gathering undertaken by parents can affect both parental coping and the decision-making process. Putz (2012) reiterates that parents should not be hasty in making decisions at the time of the diagnosis, but should take their time to gather enough information and meet with other (hearing) parents with children with a hearing loss in order to share experiences with them.

In contrast to the task and stage theories, the postmodern theories by implication advocates for grieving parents not to follow a set of predetermine tasks or stages after the diagnosis of their child's disability. This theory allows parents to tell their own story of their experiences in order for them to construct meaning from their experience (White & Epston, 1980 in Walter & McCoyd (2009)).

In conclusion, all of the theories except the postmodern theory seem to lend themselves to the medical and social models as discussed and defined in Chapter 1 in section 1.2.9. It moves from a pathological view where medical practitioners had a greater influence by determining the outcome of the grieving process by assigning labels should a parent not be able to complete a task or a stage at a pre-determined time, to a phase where parents have more control and understanding in their experience to parental grief and loss in relation to the disability, thereby reinforcing the postmodern theory. The shift has been from the professionals defining the parent to the parent defining their own responses to the situation they find themselves in. This approach basically transcends the medical model and alludes to the strength and a positive approach brought about by the social model of disability. It is further suggested that hearing parents empower themselves with information that will not only benefit them but also their child with a hearing loss. In line with this thinking, this study is underpinned by the postmodern theory which allows hearing parents to construct and give meaning to **their** truths and loss in the way they experience this phenomenon, the hearing

loss of their child. However it is not all parents with a disabled child who will find themselves in the postmodern theory position, as many parents still depend on the advice of professionals and feel that professionals know better than they do. Many parents may lack the ability to construct their own meaning about what they are experiencing, magnifying their “cant’s” and minimising their “cans”.

2.3 Hearing parents' reactions to the diagnosis of their child's hearing loss

Luterman (1979) and Mindel & Vernon (1974); were some of the earliest authors to write on the topic of the deaf child and his/her family. They were the first authors to focus on the initial responses and experiences of hearing parents in discussing hearing parents' reactions to the discovery of their child's hearing loss, as the stages of mourning, namely denial, rationalisation, shock, guilt, anger, helplessness, and acceptance as responses to their shock. Feher-Prout (1996) reports that prior to the 1970s, very little was understood about the family's adjustment and adaptation to the unique needs of a child with hearing loss. Only in recent decades has attention been paid to understanding the impact that a child with hearing loss has on a family, while at the same time being aware of the diversity and complexities in family responses to deafness (Krywko, 2012 and Feher-Prout, 1996).

Turnbull & Turnbull, (2001) point out that the birth of a child with a hearing loss into a hearing family can have a drastic impact on the family as well as on the development of the young child. Similarly upon receipt of such traumatic news, hearing parents may grieve for the loss of their healthy child as they often see their children as an extension of themselves. The diagnosis is often unexpected, and hopes and dreams of parents for their child are shattered (Simer & Estabrooks, 2012; Power & Dell Orto, 2004). At the time of the diagnosis, negative thoughts conjure up negative images in hearing parents' minds, resulting in parents probing and posing questions in an attempt to obtain answers (Putz, 2012) and how possible signs before the diagnosis could have being missed by the parents (Krywko, 2012; Lane, Hoffmeister & Bahan, 1996). The “Why?” and “How did this happen?”; “What is it?”; “Will she/he be able to hear at all or be able to talk?”; “What will others think of my child?”; “How will other children treat my child”, are all overwhelming negative thoughts that present themselves at the time of the diagnosis.

While these questions and feelings are all valid, Krywko, (2012) and Mindel & Vernon, (1974) points out that answers to these questions will ultimately be determined by the

parent's resilience to the problem, as feelings towards the child with hearing loss can influence all future decisions of the family. Family resilience speaks to the family's ability to adjust successfully to their adverse situations such as the diagnosis of their child's hearing loss (Marini, Glove-Graf & Millington, 2012).

At the same time Simer (2001 in Estabrooks, 2012) notes that a myriad of emotions may emerge for hearing parents at the time of their child's diagnosis. The latter often results in hearing parents feeling ill-equipped to help their child with the hearing loss. Hearing parents are thrown into a world of the unknown and fear, as many hearing parents have little or no contact or awareness of hearing loss, especially when taking into account that 90% of children with hearing loss are born to hearing parents (Krywko, 2012; Mitchel & Karchmer, 2004 in Estabrooks, 2012; DeafHear., 2011; Jackson & Turnbull, 2004; Marscharck, 1997, 2001 and Northern & Downs, 2002).

Power & Dell Orto (2004) furthermore point out that parents are put at an emotional risk when they are not emotionally, physically, interpersonally or financially adequately prepared for the journey ahead. Very often the demands of the disabled child are too hard for the parents to handle, especially in an attempt to sustain quality of life for the child (Brown, 2012).

Kutzer-White & Luterman (2003) similarly raise concerns about a diagnosis of a new-born baby which could negatively impact parent-child bonding during this vulnerable and critical time. Simer & Estabrooks (2012) in Estabrooks (2012) comment that the diagnosis of a child's hearing loss can disrupt the natural interaction between child and parent, with the result that enormous strain is introduced into the parent-child bond. Hearing parents are invariably upset after the diagnosis and thus the affection issue could also become an acute one for the child with a hearing loss at the time. Luterman (1987) explains that at the time of the diagnosis, parents could become angry with the child for being deaf, which may interfere with the process of bonding and the parent/child relationship. Simer & Estabrooks (2012), explain that the development and growth of the child largely depends on how children with a hearing loss are supported and nurtured by their hearing parents.

However, nurturing and support are not enough to sustain the development of a child. As argued by Pipp-Siegel, Sedey, & Yoshinaga-Itano (2002); Pipp-Siegel et al., (2002);

Lederberg and Golbach (2001); Calderon and Greenberg (2002); Mapp and Hudson (1997); Feher-Prout (1996); Luterman (1991); Quittner, Glueckauf & Jackson (1990) in Hintermair (2006) states that variables such as the degree of hearing loss, status in the community, race, culture, age, ethnic background and personal support may have a direct bearing on how parents react to nurturing and supporting their child with a hearing loss. Mcleod, Shanahan (1996) and Yau and Li'Tsang (1999) in Marini, Glover-Graf & Millington (2012), find that families with a higher income tend to have more options and resources available to them, and have more time in supporting their child with a disability. Most mothers from a low socio-economic background experience fewer working hours than mothers who do not have a disabled child (Needy, Barnes & Dia, 2008) in Marni, Glover-Graf & Millington (2012).

Furthering the debate on variables, the question of age at the onset of hearing loss is further examined and it is argued that the age of the child when the diagnosis takes place can also influence parents' response to the diagnosis. Graungaard & Skov (2006) maintain that the time of diagnosis is crucial as lengthy periods of uncertainty result in parents becoming more stressed and anxious as the time goes by. A study conducted by Young & Tattersall (2007) observed that some parents were happy to receive an early diagnosis of their child's hearing loss as this prepared them early enough to make plans and decisions concerning the child's future. Yoshinaga-Itano (2001, 2003) suggests that early identification benefits both the parent and child allowing for a quicker response to grief, improved bonding, and decrease in parental stress. An early diagnosis can therefore facilitate early intervention, providing parents with more time to gather information and options around their child's hearing loss. However if the diagnosis takes place at a later stage, parents may be under pressure to make hasty decisions to make up for lost time and to make provision for the maximum development of their child.

Contrary to this view however Fitzpatrick, Graham, Durieux-Smith, Angus & Coyle (2007) assert that some hearing parents do not see the urgency to have their child's hearing loss diagnosed at birth as they would prefer to have time to bond with the child and not feel sorry and frustrated. The following section of the discussion will point to the emotional reactions of hearing parents after their child is diagnosed with hearing loss.

2.3.1 Emotional reactions

Grief is expressed as an overall response to the diagnosis of a child with hearing loss and can manifest itself in shock, denial, anger, frustration, fear and ultimately acceptance. Often the initial response of the hearing parent to the diagnosis is shock, which Hornby, (2000) translates into feelings of confusion, numbness and helplessness. Sometimes hearing parents may express their shock reaction with crying or even inappropriate laughter (Healey, 1997).

Still, Krywko (2012); Ross, Storbeck, & Wemmer (2004) and Wall (2003) points out that often hearing parents become suspicious that their child might have hearing loss but admitting to it is one of the hardest parts of parenting. Although there might be a suspicion of hearing loss, the diagnosis might still come as a shock to parents as it confirms their suspicions (Krywko, 2012).

Hornby (2000) describes denial as a typical reaction after the response to shock, and postulates that denying the existence of hearing loss could result in parents seeking different professional help/opinions hoping for a favourable outcome that satisfies them. They often believe that a mistake was made by professionals who made the diagnosis and therefore “start shopping around” for another opinion (Hornby, 2000:101). Healey (1997) suggests that hearing parents may become dejected and continuously deny the reality of the hearing loss of their child and in some way try to bargain for a different reality. They often believe that the child will grow out of the hearing loss (Dare & Donovan, 2002 and Dale, 1996) and thus seek a different professional opinion or look for a cure. Wall (2003) and Luterman (1987) suggest that denial is often used as a coping mechanism or a self-protecting mechanism, denying that the child has a permanent disability.

Krywko (2012) contends that often denial leads to anger, which is a difficult feeling to deal with as it can act as a barrier during the process of helping a parent and/or a child. Luterman (1987) describes anger as stemming from a violation of the expectations of the parent for a healthy child with a new reality that the child will not be normal and will not be able to hear. Luterman, (1987) and Boydell, (2005) emphasise that anger is a threatening emotion and can be equated to a loss of love. Furthermore the authors suggest that suppressed anger can lead to depression, frustration and stress, which in turn can turn to regret and guilt in later years and thus often become a barrier to dealing with loss (Luterman, 1987 and Boydell 2005). Moreover Power & Dell Orto (2004) comments that some parents may feel the need to inhibit

feelings of anger as this may not be the appropriate manner for them to react. This inhibition of anger by parents can however result in unresolved anger developing into rage, fear, frustrations and resentment if not properly vented, as suggested by Boydell (2005).

Putz (2012) also states that there is no joy at seeing hearing parents being confused with anger and overwhelmed by feelings of resentment. Power & Dell Orto (2004) refer to resentment in terms of loss, such as loss of an envisaged parenthood, losing control as hearing parents and entering into a world without forewarning (Krywko, 2012). Marini, Glover-Graf, Millington (2012) add that a loss of income occurs when parents may not be able to consider a promotion at a place that is too far from a special school for children with hearing loss, or when the family has to move to another area to be closer to the special school, or loss of an additional income if one of the parents is unable to work. Changing jobs is another factor that may cause resentment. Unresolved feelings of resentment and anger in hearing parents, can lead to an overwhelming feeling of sadness, in terms of losing a healthy child and the ambitions, dreams, hopes and opportunities that their child will not be able to fulfil (Hornby, 2000).

Mindel & Vernon, (1974) in Feher-Prout (1996) underscore the importance of parents resolving their feelings of grief, anger, guilt, and helplessness, so as to prevent them from remaining arrested in the earliest stages of their psychological reactions to the child's hearing loss. Power & Dell Orto (2004) and Hornby (2000), recognise that family demands are often so overwhelming that parents are not allowed to grieve at the time of the diagnosis, thus suppressing their emotions, which can lead to self-blame and guilt. Luterman, (1987) and Bowlby (1980) argue that venting anger and crying is a necessary response to the diagnosis and could lead to the recognition that the loss is final. The authors advocate for the expression of emotions of parents that can assist in the healing process and the final recognition and acceptance of their child's hearing loss. Hence Worden (2011) is of the opinion that grief can also be expressed physically and emotionally with occasional anger outbursts and even uncontrollable crying which can assist with the acceptance of the child's hearing loss.

Kandel & Merrick (2007) outline four characteristics of acceptance during the process of grief, based on the work of Dunst & Trivette (1986, 1981) in Kandel & Merrick (2007), namely:

- having a reasonable perception of the child's skills, weaknesses and limitations;
- having a realistic view of the child's disability with an appreciation of the complications created in the family by not being overwhelmed by guilt and self-pity;
- being engaged in a logical search for professional help and not a magical solution;
- being able to love the child without feelings of overprotection and rejection at the expense of the rest of the family.

Power & Dell Orto (2004) argue that some parents may suppress emotions because the demands on the family, such as seeing to the needs of the disabled child, are so huge. These demands could lead to parental stress causing further strain on family relations. Thus the following discussion explores family and parental stress in order to gain a better understanding of the enormous strain on the hearing parents and their family resulting from the diagnosis of a child with hearing loss.

2.3.2 Family and parental stress:

Marini, Glover-Graf & Millington (2012:171) states that stress sets in when the demands placed on any individual or system goes beyond their coping capacities. The author's furthermore states that disability in a family can result in stress in a family causing the family to struggle and break down or it could cause a family to become closer and stronger.

Hodapp & Krasner (1995); Taanila, Surjala, Kokkonen & Jarvelin (2000); Wallander & Noojn (1995) in Marini, Glover-Graf and Millington (2012:171) state that families with a disabled child experience more stress than one with normal children. Lavin (2001) in Marini, Glover-Graf, Millington (2012) point to a number of challenges that a family with a disabled child face, for example the repeated medical costs, difficult scheduling, societal isolation, educational placement and marital discord. Jackson & Turnbull (2004) and Mindel & Vernon, (1987) underscore the importance of fully understanding the extent to which the realisation of the child's hearing loss can add stress and strain on the family.

In recent years there has being extensive research undertaken by Hintermair, (2006); Meadow-Orlans, Spencer and Koester, (2004), Pipp-Siegel, Sedey and Yoshinaga-Itano, (2002); in Marshark, Spencer (2011) who focused on stress on parents who have deaf or hard-of-hearing children. Hintermair (2006: 493–513) suggests that understanding parental

stress is an important factor regarding the development of the child with hearing loss because hearing parents, with heightened stress tend to contribute to developmental problems exhibited by their children.

Pipp-Siegel et al., (2002) notes that it would be beneficial for the development of a disabled child if parental stress factors were identified and addressed. Scorgie, Wilgosh & McDonald (1998) in Gargiulo (2010) examined 25 studies conducted on stress and coping mechanisms of families with children with different disabilities. The authors found that social economic status, cohesion, hardiness, problem-solving skills/creativity, roles and responsibilities, and composition, quality of marital relationship, maternal locus of control, appraisal, and time/schedule concerns, degree of disability, age, gender, and temperament, stigmatising social attitudes, social network supports, and collaboration with professionals were all contributing factors leading to stress in the families. Pipp-Siegel, Sedey, & Yoshinaga-Itano, (2002), in a study where 184 mothers of deaf and hard-of-hearing children participated, identified the following factors that contributed to stress: age, gender, presence of additional abilities, factors related to the child's hearing loss, degree of hearing loss, age of identification, language ability, mode of communication using oral only or sign language, and characteristics and perceptions of the mother meaning maternal education, social support, and daily hassles. Numerous empirical studies done by Meadow Orlands, Spencer & Koester, (2004) and Pipp-Siegel et al., (2002) in Hintermair (2006) concluded that factors such as the parents' hearing status, the child's communicative competence, and additional handicaps in the children added to parental stress.

Leigh (2009) mentions that the family interaction may also be affected by stress caused by the choices that need to be made on behalf of the child with hearing loss, such as the medium of communication and/or educational needs. Therefore anxiety filters through and questions are posed as to “whether, I as a parent will cope with my child”; “What school do I put my child in and / or what education system do I follow?”; “What mode of communication must we follow?”; “Will my child be able to study further and get a good job?” Leigh (2009: 71).

Toth (2000) in Heiterman (2006) have explored parents’ perceived barriers to communicating and solving problems with their children who have a hearing loss as one of the major contributing stress factors, and conclude that frustration and shame set in when the child cannot receive or produce the language of the parent, thus making social interaction difficult.

Communication, whether signed or oral, played a leading factor in the stress levels experienced by parents. Parents expressed the need to communicate with their child with hearing loss but did not know how, leading to frustration and confusion on both sides. The child with hearing loss can also become frustrated for not being understood or for not understanding while the parents can become angry, impatient, and dismissive in his /her body language towards the child with hearing loss, simply out of sheer frustration of repeating things and not being understood. There is evidence to suggest that hearing parents who adapt their communication style to that of the child with hearing loss, experience less stress.

Pipp-Siegel et al., (2002:1-17) also suggest that early identification of hearing loss can reduce stress in the family as it could lead to early intervention strategies to the advantage of both parent and child. Evidence seems to suggest that parents experience more stress when there is a late diagnosis and the etiology of the hearing loss is unknown or if the hearing loss is diagnosed as severe profound deafness. The latter therefore argues that gathering information at an early diagnosis of a child with hearing loss can assist hearing parents with some form of coping mechanism.

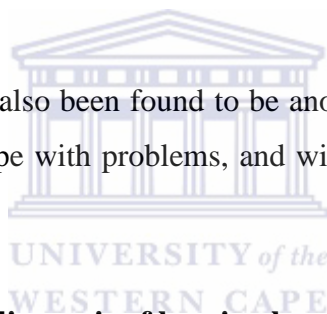
Calderon & Greenberg (2003) were able to demonstrate the significant role that mothers play in acquiring coping skills from the time of the early diagnosis of a child with hearing loss and thereby positively influencing the socio-emotional development of the child. They showed that the child displayed a higher cognitive flexibility and better social competence because of the early diagnosis and the involvement of the mother.

Olsson & Hwang, (2006) in Olsson (2008) notes that mothers experience more stress than fathers, seeing that many fathers continue their professional careers. Olsson and Hwang (2001), Salisbury (1987) and Beckman (1983) in Olsson (2008) reflects that single mothers irrespective of their children being disabled or not, experience more stress than those whose partners are present. In addition, Olsson, (2008) notes that often mothers are described as having high levels of stress, resulting in avoidance of emotions, and that the additional demand of a child's disability may add to symptoms of depression experienced especially by mothers (Singer 2006 in Olsson, 2008). However Wyngaarden Krauss, (1993) in Olsson, (2008) and Dyson, (1991) assert that both mothers and fathers experience the same amount of stress when bringing up a child with a disability.

Fisman, Wolf, & Noh, 1989 in Olsson (2008) reflect higher levels of parental conflict among parents with disabled children as a result of parental stress. Harwood, McLean, & Durkin, (2007) in Olsson, (2008) find that parents who are already experiencing a negative relationship before the diagnosis, can experience a further decline in the marriage afterwards. A study conducted by Taanila, Kokkonen and Javelin (1996) in Marini, Glover-Graf and Millington (2012) on the effects of disability on marital discord, find that 25% of parents feel that their child's disability has had a direct impact on their marital discord and identify unequal division of daily tasks, labour, daily care and supervision and insufficient time for relaxation as contributing factors to their marital discord.

However not all parents experienced stress as a negative factor Molly (2004), describes this adversity as a challenge that needs to be conquered. In similar vein, Singer and Farkas (1989) in Marini, Glover-Graf and Millington (2012) find that families with children with disabilities often report closer relationships.

The support of professionals has also been found to be another important contributing factor to stress in helping parents to cope with problems, and will be discussed under sub heading 2.4.



2.3.3. Siblings' reactions to the diagnosis of hearing loss

In section 2.3 the researcher discussed the experiences of hearing parents and their reaction to the diagnosis of their child's hearing loss. Edward and Crocker (2008) however indicate that there is very little research done regarding the relationship and the experiences of hearing siblings growing up with a deaf sibling. Stoneman (2008) in Edward & Crocker (2008) points out that there is some evidence to suggest that a disability has an adverse effect on another sibling, and identifies family cohesion, family hardiness, family problem-solving, sibling's own understanding of the disability and sibling's coping mechanisms as factors that have a direct or an indirect effect on sibling relationships. Furthermore the authors propose that proper information about hearing loss and the causes of hearing loss be provided to the hearing sibling so as to avoid misunderstanding and unnecessary anxiety (Stoneman, 2008 in Edward & Crocker 2008).

Giallo & Gavidia, (2006) in Edward & Crocker (2008) conclude that parents' behaviour to their child with a hearing loss can indicate that they are different, thus leading to strong

feelings of rivalry as hearing siblings can experience that they are less loved and getting less attention from their parents. Malcolm (1990) in Adams (1997) postulates that hearing siblings often feel detached from their families, unimportant and overlooked, because all the attention of the parents is devoted to the sibling with a hearing loss.

A study undertaken by Woolfe, Want & Siegel (2003) among deaf children with hearing siblings reveals that deaf siblings experienced frustrations and jealousy when they realised that they were different to their hearing siblings, especially in communication competencies and speech skills. The study also indicated that deaf children often experience low self-esteem, anxiety and hostile feelings and some felt that they were an embarrassment to their siblings. According to Adams (1997), deaf children shared their wish to be treated fairly and equally to their hearing siblings when they were young.

To suggest that deafness does affect sibling relationships would largely depend on the family dynamics of each family and how each family deals with a child's hearing loss.

2.4 The role of professionals in the diagnosis of a child with hearing loss:

“Attitude is the worst barrier of all” (Waldron in Putz 2012: 73)

Of particular interest to this study is whether audiologists or health care professionals are aware of their great responsibility when presenting test/diagnostic results to families (Martin & Clark, 2003). Dare & O'Donovan (2002); Dale (1998) and Harvey (2004) report that the manner in which the diagnosis is conveyed by professionals to patients affects the way they adjust to the situation, especially when confronted with words like "deafness" or "profound deafness".

Kearney & Griffin (2001) stress the point that unnecessary grief can be avoided from practitioners or health care professionals who provoke feelings of hopelessness, and the belief that the disability is tragic. Their role should be one of assisting the parents to find meaning and understanding of the perplexing problem at hand rather than subscribing to pathological grief. Hearing parents have expressed feeling distressed, hurt and upset when, after learning of their child's hearing loss, they are treated in a manner that they deem insensitive (Corcoran, Stewart, Glynn, & Woodman, 2000) in Dillon (2012). Molly (2004), the mother

of a deaf child herself, asserts that the medical practitioner who diagnosed her child with hearing loss, lacked compassion and understanding of her feelings. She speaks of the awful rebuff of the doctor after his diagnosis and how it impacted negatively on her.

The question that therefore needs to be asked is “how” information such as diagnosis of their child’s hearing loss is imparted to hearing parents. Northern and Downs (2002) stress the importance of healthcare professionals and audiologists being sensitive to the needs and feelings of the family and the child with hearing loss. Newhoudt-Druchen (2012) fervently believes that factors such as poverty and income status have a direct bearing on the treatment received from audiologists. Parents from low economic background are often treated differently to parents from higher economic backgrounds. The latter can also be attributed to the fact that too often hearing parents leave the decision-making and intervention processes in the hands of the medical profession because of their fear of the unknown or the fear of making things worse for their child (Marscharck, 2007).

A study undertaken by Tattersall & Young (2006) revealed that parents felt that their encounters with professionals were marked by poor explanations, insensitivity, a lack of partnerships and honesty. Luterman & Kutzer-White, (1999) emphasised the need for hearing parents to be informed of the diagnosis of their child’s hearing loss by audiologists and health care workers who are not only skilled clinicians but also empathetic and supportive counsellors.

Mcwhinney (2003) in English (2008) refers to the traditional clinical model that was established in the 1880s, in which the approach focused more on the problem/disease and very little on the patient’s needs. Patients viewed the clinical model as impersonal. Balint (1964) in English, 2008 then introduced a new model, namely a “patient-centred” model that was based on mutual understanding, where the clinicians came with their professional views/questions and the patients came with their experience.

Engel (1977) in English (2008) proposed the “biopsychosocial” approach which suggests that clinicians focus on the biological, psychological (reactions, coping strategies), and social existence of the patient. Another approach called the relationship-centred care approach was introduced by Tresolini (1994) in Nyberg (2011) that centred on the relationship between the clinician/audiologist and the patient, an approach much more favoured by patients. This kind

of relationship speaks to the good rapport between audiologist/healthcare professional and patient/parents. It suggests that the relationship can ease the stress/strain of hearing parents when receiving the diagnostic results of their child's hearing loss.

To support the notion of a good rapport between the patient and audiologist, the Audiologic Counselling Evaluation (ACE) tool was designed to assess the effectiveness of audiology treatment received, especially when counselling parents on the diagnosis of their child's hearing loss (English, Naeve-Velguth, Rall, Uyehara-Isono and Pittman, 2007 in Flasher & Fogle 2003: 332). The following is a summary of the ACE tool to be used by audiology students and patients to assess audiology services:

- Consultation should be privately conducted and be comfortable for the patient;
- The diagnostic information should be done in a compassionate and sensitive manner. The information of the diagnosis should be conveyed in lay terms, avoiding institutionalised jargon (Luterman, 2001). Healey (1997) argues that the manner in which the diagnosis is explained can have a prolonged direct effect on the parents' attitude towards their child with hearing loss, including the concerned child's development.
- Audiologists should gauge parents/patients' perceptions of the information given and find out the concerns of the parents. The consultation should also not be a monologue session (English, 2008).

English (2008) perpetuates the notion that audiologists are like teachers, and states that unbeknown to the audiologist, they assume the role of the teacher as they provide new and unfamiliar information to individuals who have taken on the role as learners. Thus it is evident that the audiologist as well as the healthcare worker plays an important role in providing information that is accurate and reliable, which then enables parents to make informed choices and take an active role in their child's development (DesGeorges, 2003; Luterman et al., 1999, Young et al., 2005).

Although the researcher discussed the role of an audiologist in providing information, it is inevitable that parents have to face the impact of the diagnosis of a child's hearing loss on the family, their parenthood and their own relationship with each other and their relationship with

the child. Their response to the diagnosis will also determine the outcome of their relationship with others and especially with their child with the hearing loss.

2.5 Conclusion

In this chapter, the researcher proposes a theoretical framework that guides understanding on hearing loss and the experiences of hearing parents upon regarding their child's hearing loss. Overwhelming evidence suggests that when hearing parents learn of the diagnosis of their child's hearing loss they experience shock and grief. Unresolved grief can lead to stress and strain on the parent-child relationship while parents are forced to deal with a range of emotions such as anger, blame, frustration and loss of control. Hearing parents are often bombarded with information such as choices about education and language, but are not given the opportunity to express their pain and hurt about the diagnosis of their child with hearing loss. They are often thrown into an unknown world where their questions are left unanswered.

In an attempt to understand what hearing parents experience, Chapter 3 will discuss the methodology employed to indicate how the research plan in Chapter 1 was executed, which included the research goal and objectives, the research approach and the design underpinning the approach.



CHAPTER 3

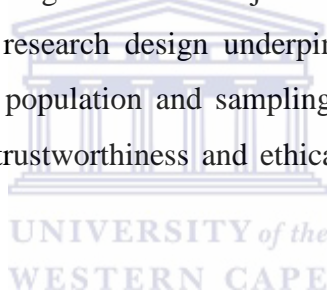
RESEARCH METHODOLOGY

3.1 Introduction

A brief overview of the research methodology was discussed in Chapter 1. It introduced the research problem, a worldwide and national perspective of the prevalence of hearing loss and defined hearing loss so as to ease the reader into a better understanding of what hearing loss is all about.

Chapter 2 put into context the literature underpinning the theoretical models of grief and loss in defining grief within the disability framework.

Chapter 3 will unpack the research methodology used, which includes: 1) the research question that defined the research goal and its objectives; 2) the nature of the research approach employed, and 3) the research design underpinning the approach. This will be followed by a discussion of the population and sampling strategies, data analysis and the limitations of the research. The trustworthiness and ethical considerations were thoroughly discussed in Chapter 1.



3.2 Research question

Denzin, Lincoln (2003) refers to a research question/problem as a concern that needs to be addressed. Babbie & Mouton (2007) elaborate that the research question guides the research design and can be described as a statement being examined during the research process. The research question for this study was general, so as not to limit the response/enquiry as suggested by Creswell (2003). In addition, Kumar (2011) points out that the research question identifies the destination the study attempts to reach. A research question is a comprehensive question that requires exploration of the essential experience or idea in a study. A qualitative research study starts with devising questions which will be answered in the collecting of data. The research question is general and abstract, and differs from the questions in an interview guide.

The research question for this study was: What are the experiences of hearing parents regarding their child's hearing loss?

3.3 Research goal

Durrheim (2006:44) states that a goal in research seeks to generate new information about a specific topic. The goal of the present study was to enhance the knowledge base of social work in healthcare by exploring and describing the experiences of hearing parents regarding the diagnosis of and caring for a child with hearing loss.

In order to reach the goal of the study, the following objectives were formulated.

3.3.1 Research objectives:

- To explore the experiences and reactions of hearing parents upon the diagnosis of their child's hearing loss
- To explore and describe the experiences hearing parents have of caring for their child with hearing loss
- To explore the needs of hearing parents regarding the way forward.

3.4 Research approach

Creswell (2003) postulates that there are certain factors that affect the choice or type of approach that is to be undertaken in a research study. These choices are firstly to be the choice of the research questions, secondly the personal experiences of the researcher, and lastly the audience for whom the research will be written. Creswell (2003) adds that often a certain type of social problem will define a specific research approach to be used.

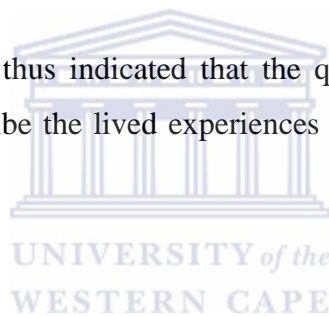
Flick (2009) maintains that qualitative research has a specific relevance to studies in the social sciences. In addition, Finlay (2011); Marshall & Rossman (2011) and Smith, Flowers & Larkin (2009) describe qualitative research as a human science because it allows for the understanding of human conditions. Creswell (2005: 45) refers to the “need to learn the details of the complexities of the phenomenon” and therefore suggests that a qualitative approach would best suited to explore and understand a phenomenon from the participants' perspective.

The present research was located within the qualitative approach as it sought to answer the research question by gathering descriptive qualitative data about a social phenomenon that was grounded in the lived experiences of people, as suggested by Tracy (2012) and Marshall

& Rossman (2011). The strength of this kind of approach lies within the descriptions of how and what the experiences are of the people under discussion. It allows for a story to be told that few know about, creating an opportunity to hear from those affected by a certain phenomenon, as suggested by Tracy (2012).

The motivation for selecting the qualitative approach also related to the fact that the approach allows the researcher to gain a first-hand holistic understanding of a humanistic phenomenon and how this phenomenon is lived out (Tracy 2012; Creswell 2007 and De Vos et al., 2005). A qualitative approach, as pointed out by Tracy (2012); Olson, Daggs, Ellevild & Rogers (2007) as cited by Tracy (2012) allows for the interpretation of participants' viewpoints and stories. It focusses on the lived experiences as told by them, as well as providing for important insights into interpersonal relationships such as friendships, support, bad relationships, conflict and abuse.

The abovementioned arguments thus indicated that the qualitative approach was the most appropriate to explore and describe the lived experiences of hearing parents regarding their child's hearing loss.



3.5 Research design

Creswell (2009 & 2007) and Creswell & Plano Clark (2007) describe a research design as a plan or “blueprint” of how a research study is to be conducted (Babbie & Mouton, 2007:74).

An explorative and descriptive design was implemented in this research study. It was **explorative** in nature, as discussed by Durrheim (2006); Nagy, Hess-Biber & Leavy (2011) as it sought to generate and investigate new information about an unknown phenomenon. It was **descriptive** as it provided for a deeper understanding of a phenomenon allowing detailed descriptions of participants' feelings and emotions (experiences) in order to achieve rich data that could possibly inform an accurate description of the phenomenon, as pointed out by Durrheim (2006); Babbie & Mouton, (2007) and Nagy, Hess-Biber & Leavy (2011). As Marshall & Rossman, (2011); Creswell (2007, 2009) state, it allows for the description and exploration of a phenomenon as described by the participants. In this research study, it allowed the researcher to explore and describe the experiences of hearing parents regarding their deaf child.

In qualitative research five strategies of research designs are identified, namely grounded theory, narrative, ethnography, case study and phenomenology (Creswell, 2007). The strategy of design best suited for this research as argued by Gilgun (2010); Donalek (2004) and Tattersal & Young (2006) was phenomenology as it dealt with lived experiences that were sensitive personal issues. Phenomenology, as described by Titchen & Hobson (2005) and Finlay (2011) is a study of the lived world, human phenomena in everyday social contexts, in which the phenomena occur from the perspective of those who experience them doing justice to their everyday experience. Grbich (2012:92) adds that phenomenology is an attempt to understand the “hidden meanings” and the “essence of an experience” together with the participants and how they make sense of these experiences. It is the study of a phenomenon on which there is little in-depth data (Grbich, 2012: 92). The research question in phenomenology is very general, which allows for an in-depth conversation to take place, for instance "**What** are the experiences of hearing parents?"

The data that was collected from hearing parents of children with hearing loss, in an attempt to gain an understanding of the participants' lived experiences and how they made sense of them, as pointed out by Moustakas in Creswell (2007) and Smith, Flowers & Larkin (2009). It generated a deeper understanding of a phenomenon as described and understood by them. It was an attempt to get a so-called insider's view of the experience of the phenomenon, with a focus on describing rather than explaining or making predictions, as suggested by Babbie & Mouton (2007) and Denzin & Lincoln (2011).

As stated earlier, this research finds itself within a **phenomenological strategy of design** as it seeks to describe and explore the experiences and feelings of hearing parents regarding their child's hearing loss. This strategy of design was also chosen as it allowed the hearing parents to become engaged in an open, deep and sensitive discussion about their experiences, allowing for a deep and rich understanding of their lived experiences.

3.6 Research methodology

The following discussion describes the research processes undertaken to obtain the necessary data in order to answer the research question. Mouton (2002) refers to research methodology as the total set of means that a researcher uses to attain the goal of their research.

The methodology used in gathering data allowed the researcher to gain entry into the participants' lives, allowing interaction with them, analysing and interpreting data which only added to the “thick description” (Hays, Singh 2011:225) of the research which went beyond the facts. The methodology employed allowed the researcher to gather data from people who had experienced the phenomenon (in this case, the experiences of parents) which led to a full description of all the participants' experiences (Moustakas in Creswell, 2007 and Fouché, 2005).

3.5.1 Population

Babbie & Mouton (2007) and Durrheim & Painter (2006) refer to a population as a larger group from which a sample is taken, from whom the researcher wants to draw a conclusion. Lapan, Quartaroli & Riemer (2011) refer to a population as the specific group of people under focus in relation to the research topic.

The population for this research study consisted of hearing parents (focus population) whose children between the ages of one and ten were diagnosed with a hearing loss (research topic).

3.5.2 Sampling

As this was a qualitative research study, only a sample of a population was selected, therefore there was no need to collect data from large numbers in the community to validate the findings. The idea behind sampling a small representative of the bigger population is to obtain a significant higher degree of probability of meaning, and a true reflection of the population being studied, as well as obtaining maximum accuracy for the study (Kumar, 2011).

The accuracy of the findings therefore depended on the way the sample was identified but bearing in mind that at the same time that the sample needed to adhere to the purpose of the qualitative study (Babbie & Mouton, 2007). Thus only a small sample of participants with a specific experience (Altmaier & Hansen, 2012) was interviewed, with the aim of revealing the experiences of each of the participants (Smith, Flowers & Larkin, 2009) keeping in mind that in phenomenological research the sample size is relatively small and ranges from 2 to 25 (Klenke, 2008:226). Data was collected from a sample of participants who were selected from a population of participants (Somekh & Lewin 2005) with similar experiences, and

bearing in mind that the objectives of the research determined which and how many people would be selected to participate in the research.

Non-probability (purposive) sampling was undertaken in this study as it purposely selected participants who assisted the researcher in discovering, understanding and gaining insight (Patton, 2002) into the research problem (Creswell, 2007). Klenke (2008:226) states that phenomenological research uses “purposive sampling in an effort to identify participants who can illuminate the phenomena of interest and can communicate their experiences”. Furthermore, Patton (2002) states that purposeful sampling is a process in which the participants are chosen with a specific purpose in mind – in this case, hearing parents' experiences of their child's hearing loss. Creswell (2001) and Patton (2002) identify different types of purposeful sampling, namely typical, unique, maximum, variation, convenience, snowball and chain sampling. Similarly Patton (2002) in Nagy, Hess-Biber & Leavy (2011) identifies 16 different types of purposive samples. However, for the purpose of this research, voluntary and snowball sampling were employed.

Rubin & Babbie (2009) state that snowballing occurs when the researcher asks the individuals participating in the study to provide information needed to locate other members with the same experiences.

The snowball technique was primarily used for explorative purposes (Babbie, 2010). Data was collected from participants who were difficult to locate or when they were not readily identifiable, as described by Rubin & Babbie (2009); Babbie (2010). Each participant interviewed suggested other possible participants to be interviewed who they knew had a similar experience to theirs (Babbie, 2010).

Pitney & Parker (2009) point out that the number of participants will determine when data saturation will be reached. By the ninth interview it became evident that there were recurring themes emerging from the data, suggesting that data saturation had been reached. Pitney & Parker (2009) also suggest that data saturation can be reached when similar quotes by participants are made, leading to the conclusion by Leavy (2011); Creswell (2002) in Pawlak (2011) that no collections of additional data would provide new information or insights to further the purpose of the research.

The following criteria were identified for the selection of participants:

Merriam (2009) suggests that a list of attributes be compiled by the researcher before commencing with the study. This list should reflect the purpose of the study and assist in identifying rich information that can add to the validity of the research (Merriam, 2009).

Firstly, central to the criteria selection was that participants had to have experienced the central phenomenon under investigation (Creswell, 2003). Therefore the participants had to be hearing parents of children who were diagnosed with a hearing loss between the ages 1 to 10 years.

Secondly, the selection of participants was done with the assistance and permission of a local Deaf organisation (Deaf Community of Cape Town). . This organisation provides sign language classes to hearing parents with children with a hearing loss and therefore presented the researcher with a unique opportunity to engage in meeting with these parents, where she introduced the research project. The organisation was also briefed; a letter of intent was given to the organisation about the research as well as explaining the aims and objectives of the research (Appendix A).

Thirdly, the hearing parents were informed and given a letter of intent of the research explaining confidentiality and making a request to parents to volunteer to be interviewed (Appendix B) and give consent to be interviewed (Appendix C). There was a positive response to the request as some hearing parents agreed to participate voluntarily and some recommended other parents whom they knew and had a relationship with, and who met the criteria of the study.

Fourthly, participants could be both male and female of all racial groups who lived in the proximity of Cape Town.

3.6.3 Data collection

Pawar (2004) highlights the point that data collection assists in answering the research question and assists in achieving the research goal and objectives. The quality of the data collected determines the quality of the research findings, and when further analysed leads to the understanding of the phenomenon under study, as reported by Pitney & Parker (2009).

Moustakas (1994) states that qualitative phenomenological data collection involves an interactive and informal process of interviewing where participants describe their feelings and experiences. Primarily the data was gathered directly from participants by means of individual in-depth interviews, a technique suitable to phenomenological research. The in-depth interviews were unstructured (open-ended interviews) so as to allow the freedom of participants to talk about their experiences in a natural conversation. De Vos, Strydom, Fouche & Delport (2002) refer to unstructured interviews as a conversation with a purpose of telling stories. Greeff (2005: 292) point out that in-depth interviewing is designed to get at the “deep information” and “thick descriptions” of parents’ subjective experiences.

These unstructured conversations with participants led to the provision of rich information of descriptions and exploration of the experiences of the parents. These interviews as explained by Creswell (2007) and Klenke (2008) provided the researcher with an opportunity of going beyond the surface of experiences, probing into the details of the participants’ emotions and the meaning that they attached to their child’s hearing loss.

The advantage of conducting one-on-one interviews was first that the researcher had the opportunity to probe complex issues and get a better understanding of something little known about and deeper understanding of the views and their emotions (Klenke, 2008). Second, the researcher had the opportunity to observe the body language and voice tones of the participants (Neuman, 2006). A challenge occurred when the participants steered away from the question at hand (the interview question) making it difficult for the researcher to redirect the interview/conversation. However, the richness of the stories told in the interviews could be reflected in the verbatim quotes from the parents which allowed the reader to judge the accuracy of the researcher’s interpretation of the stories told.

Research setting

A list of potential names was provided by the Deaf Community of Cape Town. The researcher met with the group to brief them about the proposed study and to request voluntary participation. In addition, participants referred the researcher to other hearing parents with children who had a hearing loss and who they thought would be interested in participating in the research, thus using the snowballing technique. Four parents volunteered to take part in the study after the researcher briefed them at the Deaf Community of Cape Town. Five of the participants were referred to the researcher by other parents by means of snowball sampling.

With the assistance of a social worker from the Deaf Community of Cape Town, the researcher identified two more participants who met the selection criteria. Each participant was contacted telephonically, informing them of the research, and after consenting verbally, the participants decided upon the time and venue for the proposed interview. All of the interviews took place at the homes of the participants with the exception of one which was held at an organisation for the deaf.

In total nine females and three males participated in the research. The women tended to be more forthcoming with their emotions while the researcher had to probe male participants more to speak about their emotions. During the course of the research three men withdrew from the interview processes, citing no reasons for their withdrawal. However through the snowballing technique, another two male participants were identified by participants already participating in the research study and who they knew had a similar experience to theirs (Babbie, 2010).

The interview started with the researcher introducing herself, stating the research question and once more asking participants for their voluntary consent to participate in the research, which was granted for the pilot interview as well as the 10 interviews until data saturation occurred. A good rapport was immediately established between participants and researcher when the researcher indicated that she had prior knowledge of the Deaf community. This helped put parents at ease with the researcher, thereby encouraging a more open discussion to take place.

The duration of the interviews varied from 40 minutes to 60 minutes. The researcher made field notes of observations during the interviews, namely tone of voice, emotions and anger. Often the descriptions of people's experiences determined the mood of the interviews. The interviewing process was particularly challenging and emotional for one participant with the result that the researcher decided to terminate the interview as it had become too emotional for the parent. The researcher then referred the participant for debriefing to the social worker at the local Deaf community.

All parents expressed appreciation for the opportunity to share their experiences and said that this was the first time that they had been a chance to express their feelings and emotions and tell their side of the story.

Preparation of the participants

All the interviews except for one were conducted in the participants' homes, thus demonstrating that the setting for the interview was important to allow the participants to feel comfortable and be able to express themselves in their own territory. The researcher provided each participant with letters of intent explaining the purpose of the research and a letter from the University of the Western Cape granting permission for the research to be carried out, as well as the researcher's competence to carry out the research.

All the participants were informed that their participation was voluntary and that confidentiality would be ensured, protecting the privacy of the participants. Consent was also sought and obtained to gather data by means of an audio recorder to record actual events and field notes to facilitate data collection (Pawar, 2004). The audiotapes assisted in creating a written account of the interviews. This assisted enormously with details such as pauses, tone, and point of emphasis, thus enabling the researcher to focus on other details such as following up questions to certain points of interest. Field notes were also jotted down by the researcher during the course of the interviews which eventually assisted with identifying recurring themes in all the interviews, and assisted with the final data analysis.

The participants were asked one general open-ended question to elicit as much data as possible: **Your child has been diagnosed with a hearing loss. Please tell me your story?**

Klenke (2008) suggests that in phenomenological study questions like "How did you feel?" and "What were you thinking about?" will elicit more descriptive stories. Furthermore (Gadamer, 1989 in Klenke, 2008) states that phenomenology begins with reflections. Therefore these parents were asked to reflect and share their personal journey of their experiences when facing the diagnosis of their child's hearing loss. The open-ended question allowed participants to give an account of their experiences and perceptions in their own words and construct meaning to the way they understood how this phenomenon (hearing loss) affected them personally (Neuman, 2006; Fouché, Delport, 2005; Creswell, 2003; Denzin, Lincoln, 2003).

The establishment of a good rapport and empathy with the participants was of utmost importance in establishing trust with them. The researcher as suggested by Wosket (2006)

relied on her interviewing skills and communication techniques in order to extract information from participants during the interview process, especially when some of the participants found it difficult to express their emotions.

3.6.4 Pilot study

Bless, Higson–Smith (2006) states that a pilot study involves the testing of the actual study on a small sample from the population. Out of a sample of 11 interviews, one interview was piloted to ensure that the required data would be generated.

Conducting the pilot study enabled the researcher to see whether there were any trends that could be identified with future interviews, as suggested by Strydom & Delpont, (2005). The pilot study also provided an opportunity to make sure that the interview question allowed the researcher to gather rich data.

The following comments from the researcher's supervisor assisted in making the next few interviews more valid.

Supervisor comments in assisting the researcher to gather further rich data:

- The researcher needed to focus on the central question and not allow the participants to stray too far from the research question, allowing the participant to tell their story.
- Wait until participants are done with telling their story and then probe, as De Vos et al. (2005) state that 90% of the talking in the interview must be done by the participant.
- The researcher needed to avoid leading questions and focus on her interviewing techniques in order to probe for rich data. Probing as stated by De Vos et al. (2005) helped deepen the response to the question, as well assist with the richness of the data. It encouraged the participants to provide more information about their experiences.
- The researcher was encouraged to conclude the interview with the following phrase "Is there anything further that you feel you want to add?" (De Vos et al., 2005).
- The researcher was encouraged to only ask questions when she did not understand something (De Vos et al., 2005).

This guidance and advice assisted greatly as it put into context what the research was about, which was gaining an in-depth understanding of parents' grief and grief processes through one-on-one interviews and allowing the conversation to flow without interruptions from the researcher.

3.6.6 Reflexivity as a qualitative researcher:

Tracy (2012) and Gilgun (2010) state that qualitative research allows a researcher to make sense of a context and add to the richness or thick description of the research by interweaving empirical, theoretical data and adding their own professional and personal reflexivity. As a social worker, the researcher has been involved in the Deaf community for the past 20 years and as such has developed a personal interest in the phenomenon and formulated her own opinion on the research question. It was important that the researcher remain neutral and objective and keep in mind her role of researcher in an attempt to not alter the interpretation of the data.

What was applicable for the researcher when starting this research was the issue of self-reflexivity. The core to reflexivity is that the researcher becomes aware of her own influences on the research process, such as her role and feelings (Creswell, 2005) and the credibility of the research must be maintained at all times (Gilgun, 2010 and Tracy, 2012) taking into account that these influences could act as the researcher's own analytical resource (Tracy, 2012). The uniqueness of qualitative research is that self-reflexivity is acknowledged by the qualitative researcher by reflecting on her own feelings, thoughts and ideas (Finlay, 2011). Throughout the study the researcher stayed in contact with her supervisor who advised, mentored and assisted by checking the credibility of the interviews.

By applying interview and communication skills, the researcher listened to both the story being told by the hearing parents and the underlying meaning to things not being said. She posed questions for her own understanding, thereby checking out her own understanding and meaning. At the same time she made her own reflexive notes after each interview which assisted her to reflect on her own emotions and thoughts so as to avoid any biases that could affect the interpretation of the data, as suggested by (Rocco & Hatcher, 2011). After every interview she reflected on the mode of the interview. For instance after one of the interviews, the researcher felt an enormous sense of defeat and sadness as the participants had come

across as being totally disempowered by their experiences of their child's hearing loss, while in another interview, she came away feeling totally refreshed and excited about a parent who showed resilience despite her adversities .

3.6.7 Data analysis

Creswell (2007) refers to data analysis as the process of making sense out of the verbatim text taken from participants. It is the process described by Marshall & Rossman (1999) as bringing order, structure and interpretation to the mass of data collected. It takes into account the extensive and intensive process of rigorous thinking that takes place throughout the research process as reported by Altmaier & Hansen (2012). It provides understanding and brings meaning to the large amount of data that was gathered (Creswell, 2007).

The analysing of the data in this study gave a phenomenological description of the uniqueness of the experiences and captured the richness of information (Wilkinson & Birmingham, 2003) of those interviewed. Monette, Sullivan, & DeJong (2010); Creswell (2007) and Sarantakos (2005) are of the opinion that data collection and data analysis in qualitative research often occur at the same time, as the researcher writes down observations while participants respond to the research question. The audiotape was of immense help for back-up information when the researcher noted down other important information.

The following steps outline the phenomenological data analysis undertaken in the research study as suggested by Creswell (2007:183-190); Klenke (2008:231) as discussed in Chapter 1.

Firstly the researcher, according to Creswell (2007) organises and prepares the data for analysis. In this study the process started with first transcribing 11 interviews from the audiotape and field notes verbatim. The transcribing included observations and reflections from the researcher. Secondly, according to Creswell (2007) and Klenke (2008), the researcher read and re-read through the data in order to develop a better understanding of the lived experiences of participants and what they were saying, at the same time as evaluating whether the research question was answered. In so doing, the researcher got to understand the tone of the interview, and started to record similar ideas in the data (Sarantakos, 2005). Hycner (1999) in Klenke (2008:231) explain that phenomenology “involves being immersed in the data as a whole and the data in part – through extensive reading and re-reading,

reflections and writings”. Similarly the data was explored for common themes that were repeated in each interview and short comments/observational notes were written down in the margins of the transcripts. Key words or interesting issues were underlined or bracketed. Themes were highlighted that related to the central experiences of the participants (Devenish, 2002 in Klenke, 2008:96).

Thirdly the coding process began. Rossman & Rallis (2011) and Babbie, (2010) point out that coding is the process of organising the information into segments/groups before adding meaning to it. The data in this case was presented to an independent coder who assisted the researcher in analysing and interpreting it and recognising recurring themes which were highlighted with different colour pens. Fourthly the representation of the data took place. Klenke (2008:231) states that in phenomenology research the researcher identifies all the themes emanating from the interviews, then begins to sort them out according to thematic clusters, and then divides them into higher-order clusters. The data was then put into themes, categories and sub-categories, with significant statements from the data, searching for theme connections. These themes basically generated a description of what the participants’ experiences were, as well as describing what the settings or contexts were (Creswell, 2007). Fifthly the data was represented in a research report. The interpretation of the data analysis eventually became the findings of the research – it became the narrative account of the analytical interpretation as presented in full and supported by verbatim extracts from the research participants. Finally came the interpretation or meaning of the data. The researcher’s own personal interpretation from the data was that it had revealed that perhaps the research question was too broad and that perhaps a set of three or four questions should have been prepared. This issue is elaborated under 3.7.

3.7 Limitations of the study

The following limitations were identified during the course of the study:

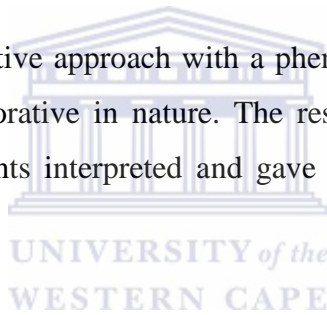
- Firstly the research sample included fewer men than women participants. Many of the female participants spoke about shouldering the responsibility of caring for their child with a hearing loss, and how at times they felt anger and resentment towards their spouse or towards the child’s biological father. Unfortunately three male participants withdrew from the study. Therefore, the research would have benefited in hearing from male participants, not leaving the reader to make assumptions or conclusions

about their experiences which could have been similar or completely different from those of the women.

- Secondly a few participants struggled to tell the stories of their deaf child. They expected to answer a set of prepared questions put to them and seemed to struggle to have a dialogue with the researcher. It could have been that they struggled to tell the story, sometimes being very emotional, or perhaps the interview guide could have provided more structure to their stories.
- Thirdly the research could have benefited from a wider ethnicity representation. The majority of participants were from a "Coloured" background; it would have benefited the research if equal representation was present such as four from each ethnic group.

3.8 Conclusion

The researcher selected a qualitative approach with a phenomenological strategy of enquiry which was descriptive and explorative in nature. The researcher herself was interested in understanding how hearing parents interpreted and gave meaning to their world and their child's hearing loss.



The research attempted to explore and describe a social reality with rich and thick descriptions of stories of individual experiences, translating it into a narrative that lends understanding and interest. Purposive sampling was undertaken in this qualitative research study as participants were purposely selected who assisted in the discovering, understanding and gaining insight into the research problem. The central criterion for the research was that the participants experience the same phenomenon. The data collection instrument was in-depth interviews which helped with a deep understanding of the phenomenon. Member checking assisted with data verification, checking for credibility, reliability and accuracy of data. Throughout the research, ethical considerations were adhered to, which included confidentiality, respect for autonomy and consent of participation.

The following chapter details the findings for the qualitative data that was obtained during data collection. It will be presented in themes and sub-themes and provides verbatim quotes of the participants to substantiate their experiences

CHAPTER 4

FINDINGS

4.1 Introduction

The overall purpose of Chapter 3 was to describe the research approach, research design and the research methodology that was implemented to collect and analyse the data resulting in the findings that will be discussed in this chapter. The data analysis assisted in categorising the data by extracting and formulating themes and sub-themes that structured the findings of the research study.

Chapter 4 firstly sets out the demographics of the participants interviewed and secondly discusses the findings in relation to the experiences of hearing parents regarding their child's hearing loss. The discussion is structured according to the themes and sub-themes that were identified during the process of data analysis. Verbatim quotes from the participants are inserted to verify the themes and sub-themes and to provide examples of the lived experiences of the participants.

In order to put the findings in context the researcher also reminds the reader of the research goal and objectives of the study. **The goal** of the study was to enhance the knowledge base of social work in healthcare by exploring and describing the experiences of hearing parents of the diagnosis of and caring for a child with hearing loss.

The objectives of the research were threefold:

- To explore and describe the feelings and reactions of hearing parents upon the diagnosis of their child's hearing loss;
- To explore and describe the experiences of caring for a child with hearing loss;
- To explore the needs of hearing parents regarding the way forward.

4.2 Demographic data of the participants

The following table reflects the demographic profile of the hearing parents regarding their experience of their child's hearing loss.

Table 2 Biographical details of the participants

Pseudo name	Gender:	Marital/ Status	Race	Employed /	Age of Deaf Child	Position of deaf child in family	Age of onset	Type of hearing loss	Cause of Deafness
X	Female	Single	C	Yes	10yrs	Only child	Unsure	Hard of hearing	Unknown
M	Female	Single	C	Yes	6yrs	Eldest of two	1yrs old	Hard of hearing	Unknown
C	Female	Married	C	Yes	10yrs	Youngest of two	Birth	Profoundly deaf	Rubella
D	Female	Married	C	No	9yrs	Eldest of two	Unsure	Hard of hearing	Unknown
E	Male	Married	C	Yes	9yrs	Eldest of two	Unsure	Hard of hearing	Unknown
F	Female	Married	W	Yes	10yrs	Youngest of two	Birth	Hard of hearing	Ear infection
J	Female	Separated	B	Yes	7yrs	Eldest of two	Unsure	Hard of hearing	Unknown
T	Female	Married	C	Yes	10yrs	Eldest of two	Unsure	Hard of hearing	Unknown
L	Female	Married	C	Yes	8yrs	Youngest of three	Unsure	Profoundly deaf	Unknown
A	Male	Married	C	Yes	10yrs	Youngest of three	Birth	Profoundly deaf	Unknown
N	Male	Married	C	Yes	10yrs	Youngest of two	3yrs old	Hard of hearing	Meningitis

The demographic details of the participant will be unpacked under the following headings.

a) Gender

Eight hearing mothers and only three fathers of a child with hearing loss were interviewed. It was a challenge for the researcher to get the cooperation of fathers. Hearing mothers were more readily available to agree to take part in the study than hearing fathers.

b) Age

Hearing parents who took part in this study were between the ages 20-50 years. Three of the participants were between the ages of 20-30 years, five parents between the ages 30-40 years and three between the ages 40-50 years.

c) Language

The first language of eight of the hearing parents who took part in the study was Afrikaans; however all of them were conversant in English. Three of the participants' home language was English. The languages predominately spoken during the interviews were English and Afrikaans. Fortunately the researcher is fluent in both languages thus accommodating an easy flow of conversation.

d) Education

Two of the hearing parents had attended university, while three parents had attended college. Two of the parents matriculated, and four had left school without passing matric.

4.3 Discussion of the findings

The participants in the study constituted a heterogeneous group in terms of age, household, relationships, educational and socio-economic profiles. However the group united around a common phenomenon of experiences relating to hearing loss of their children. Although there were some general experiences to having a child with hearing loss, there were also diverse experiences. The experiences of these hearing parents regarding their child's hearing loss will be presented in the following section of the research report.

The following table reflects the themes and sub-themes of the findings of the study and guided the discussion that follows. The researcher has included verbatim quotes to substantiate statements.

Table 3: Themes and sub-themes

Theme	Sub-Theme
<p>1. Shared/<u>general</u> initial emotional reactions during the time of the diagnosis</p> <p>2. <u>Specific</u> and individual behavioural and emotional reactions following the diagnosis of the child with hearing loss.</p> <p>3. General experiences of post diagnosis on the way forward “it’s a journey.”</p> <p>4. Specific experiences of the way forward for hearing parents with a child with hearing loss</p>	<p>1.1 Hearing parents' emotional reactions related to shock and grief</p> <ul style="list-style-type: none"> ○ Confusion and shock, -“what now” ○ Disbelief and denial ○ Extreme sadness <p>2.1 Hearing parents' emotions of blaming and anger</p> <ul style="list-style-type: none"> ○ Hearing parents’ anger ○ Hearing parents’ anger, guilt and self-blame ○ Hearing parents' anger and blame towards the biological father ○ Hearing parents' anger and blame towards a higher power ○ Hearing parents' anger and blame towards health-care workers ○ Hearing parents' anger at delayed diagnosis <p>2.2 Hearing parents' experiences with regard to their planned pregnancy</p> <ul style="list-style-type: none"> ○ Hearing parents’ shattered dreams ○ Hearing parents' immediate acceptance based on religion ○ The acceptance of a deaf father <p>3. “It’s a journey”</p> <ul style="list-style-type: none"> ○ Hearing parents' journey of decisions and practical arrangements ○ Hearing parents' journey of emotions and miscommunications ○ Hearing parents' journey of emotions and physical tiredness ○ Hearing parents' journey of discipline and supervision ○ Hearing parents' journey of schooling and independent living ○ Hearing parents' journey of family dynamics ○ Hearing parents journey of community perceptions <p>4. The way forward</p> <ul style="list-style-type: none"> ○ Hearing parents' general need for the way forward ○ Hearing parents' experience of self-empowerment versus. defeated acceptance ○ Hearing parents' need for support

4.3.1 Theme 1: Shared initial emotional reactions during time of diagnosis

Keeping in mind that this study defined hearing loss within the disability grief-related framework, most literature on disability confirms that parents’ initial emotional reaction to the news of a diagnosis of a disabled child is one of shock, denial, guilt, blame, fear, depression, anger, frustration, and acceptance (Ross & Deverell, 2004; Shovhov, 2004; Flasher & Fogle, 2003; Kandel & Merrick, 2003; Marschark, 1997; Feher-Prout, 1996; Worden, 2011).

The analysis of the data indicates that the majority of hearing parents shared some emotional reactions to the diagnosis of a child born with hearing loss. These include reactions such as confusion and shock; disbelief and denial; extreme sadness and loss; shattered dreams and plans for the future.

Northern & Downs (2002) emphasise the emotional trauma that parents and family members experience when their child is diagnosed with a hearing loss. Stroebe, Gergen, Gergen, & Stroebe, (1992) in Power & Dell Orto, (2004); describe these emotions as being debilitating, intense, consuming and all enduring.

The findings of this study support the interpretation of Romanoff (1993) in Power & Dell Orto, (2004) who state that the responses of the hearing parents are often a complex interplay of emotional, cognitive, spiritual, physiological and behavioural responses to the diagnosis of the child's hearing loss.

Hearing parents' emotional reactions related to shock and grief

- **Shock and confusion**

Shock is described as the initial response to grief especially when parents were expecting a healthy baby. Similarly Dare & O'Donovan (2003:240) state that confusion is the "inability to come to terms or fully comprehend what has happened".

Nine out of the eleven hearing parents who took part in the study reacted with complete shock after the diagnosis of their child's hearing loss. One participant described her reaction to the diagnosis as being dealt with a "heavy blow" after hearing the unexpected diagnosis of her child's hearing loss. Others describe their emotions of "despair" of not being prepared for a diagnosis of hearing loss in their child.

The following statements serve as evidence of the hearing parents' reactions of shock to the unexpected diagnosis of their child's hearing loss.

"...I was like what, is this man serious this was like a blow for me..."

“I was very emotional... I wasn't prepared.... I wasn't prepared, I really did not know what to expect....”

“...and I was thinking, like oh my word, my world is going to end, what's going to happen to this child?”

“I just thought to myself, where, what and how?”

“I was confused because I was thinking oh my word is this child disable? He won't be able to read and write, I don't know any deaf people so I thought deaf people are dumb, they can't read, they can't write they can't speak, how are they going to fit into society?”

“It was nerve wrecking to say the least”

These feelings amounted to the complete shock and confusion of hearing parents when receiving the diagnosis of their child's hearing loss. These reactions are similar to those revealed by Nielsen (2008); Hornby (2000) and Bowlby (1980, 1981) who associated parents' feelings of shock and confusion with numbness and helplessness as the initial reaction to the diagnosis. Meadow-Orlands, Sass-Lehrer & Mertens (2003:122, 183) also speak to the fact that parents will feel shocked and devastated when hearing that their child has hearing loss.

However these authors advocate that parents should try to acknowledge their shock and confusion and try to move on and focus on what is best for the child.

Similarly another participant concluded that when hearing about her daughter's diagnosis, she was so shocked and confused that she had to sit down in order for her to grasp the enormity of the problem and the challenges she was about to face. Hers was a planned pregnancy (future constructed around a normal child) and therefore the idea of a disability had never entered her mind:

“I was shocked; I just sat there for a little, confused...”

Drawing from the participants' responses, a conclusion can be made that the diagnosis of their child's hearing loss was traumatic for hearing parents. Their initial responses are supported in literature by Young (2002:7) who reports that hearing parents are not prepared for such a diagnosis and that "their whole world had just being turned upside down". Similarly Medwid (1995:12) states that when parents are confronted with the diagnosis of hearing loss of their child, they are "shocked and saddened"; they may feel "numb" and may feel completely "lost". Therefore according to Dare & O'Donovan (2003:240) parents should be given time to understand the diagnosis, as parents will inevitably go through different emotional stages and will therefore need time to grieve for the apparent "lost baby"

- **Disbelief and denial**

Hornby (2000:100) reports that denial or disbelief is the typical reaction that will follow shock, as parents find it difficult to accept that their child has a problem. Luterman (2008); Dare & O' Donovan (2003); Wall (2003); Dale (1996) indicate that denial can be referred to as a self-protecting mechanism, by denying that the child has a permanent disability. Putz (2012) states denial is a coping mechanism that is neatly packaged for hearing parents who are not ready to deal with their child's hearing loss. Northern & Downs (2002); Hornby (2000) and Brown (2012) state that hearing parents often find it difficult to believe the diagnosis and therefore go through a denial phase.

The following quotes indicate a participant's struggle to believe the diagnosis, and responded in the following manner:

"I didn't want to believe the diagnosis..."

"We were in complete denial– the psychology and the -whatever can tell you, you go through a state of absolute denial. How can it happen to our child? How can our child be deaf?"

".....and found that she was deaf, I couldn't believe it"

"My wife is at home and so she said that it is strange, a strange thing was happening to this child – she don't respond. I said 'nonsense'"

Struggling to believe the diagnosis of their child's hearing loss, some participants went in search of a second opinion. Braden (1994) and Seligman (2000) suggest that denying the existence of hearing loss of a child will often result in parents seeking different professional help or opinions hoping for a favourable outcome that will satisfy them. This denial phase is characterised by visits to various healthcare professionals in search of a better diagnosis or even a cure for the hearing loss. Nielsen (2008:9) states that in an attempt to change their reality, parents go to different professions in search of an easy solution. Kubler-Ross in Walter & McCoyd (2009:8) characterised the denial stage as "shopping around" for a second opinion in the hope that the diagnosis was incorrect.

One of the participants recalled her husband's reaction after she informed him that their child was deaf, and described his denial as follows:

"He was totally shocked, he asked me if the doctor was sure, ...we sought a second opinion"

Another participant remembers how devastated she felt when she heard the diagnosis. She was determined to seek a second opinion because she did not want to believe the diagnosis of her child's hearing loss.

"I was devastated if I can say that, but at the same time I didn't want to believe the diagnosis and I for sure wanted a second opinion..."

One participant's mother convinced her to seek another opinion because the doctor who had diagnosed her child's hearing loss was very old and thus could, according to her opinion, have made a wrong diagnosis.

"My mom said 'no... this is an old white man and he doesn't know he's old and maybe he didn't check right I'm taking him to Red Cross Hospital'..."

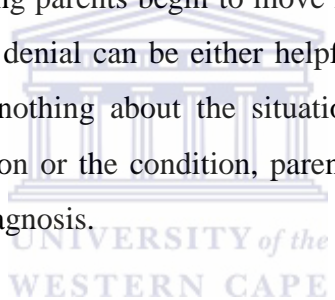
One of the participants admitted to not acknowledging (and thus denying) her suspicion of her son's hearing loss and attributed this to her sense of pride:

“I suspected something was not right ...but I think my pride got in the way. Parents don’t really want to acknowledge that there is something wrong with their kids.”

Another participant recounted how he tried to check whether his suspicion was right by carefully watching and waiting for his daughter’s response to loud sounds and to his whistles:

“I still remember that I went and put my finger to my mouth behind her and I would whistle and she did not hear”

The aforementioned findings show that although participants were in many instances suspicious of their child’s hearing loss, the confirmation of the loss was still very traumatic for them. Due to a false sense of shame or even sheer ignorance, these participants had secretly hoped that everything would be fine. Ross, Storbeck &Wemmer (2004) and Wall (2003) believe this is when hearing parents begin to move into a state of denial. In the same vein Adams (1997:8) warns that denial can be either helpful or destructive when there is a continuous avoidance of doing nothing about the situation. Adams (1997:8) furthermore states that by denying the situation or the condition, parents are denying their feelings and thus avoiding the reality of the diagnosis.



Overwhelmed with emotions of denial and disbelief, some participants initially tried to dissect the diagnosis. They searched for answers. They asked questions such as “what”, “how”, “why”. Their questions warranted their concern as they did not know what to do or what to expect. They dissected the diagnosis trying to make sense of it. Their anxiety and fears were displayed in the following quotations:

“I just thought to myself, where, what and how.....”

“He (my husband), was totally shocked; he asked me if I was sure and if the Dr was sure. He wanted answers; he wanted to know the how and the whys”

“How, did he have an ear infection? Maybe, did he fall when he was a baby?”

“(How) could we be so blind that we didn’t or could not see that R was Deaf?”

Dare & O'Donovan (2002:17) state that in an attempt to process and understand the diagnosis of their child's hearing loss, it is important for hearing parents to pose the "how" and the "why" questions. Adams (1997: 9) states that it is important for parents to understand the etiology of the hearing loss, and understanding its causes as there are numerous reasons why a child has hearing loss. Adams (1997) adds that not knowing the cause of the hearing loss can lead to a parent's feelings of anxiety and may sometimes lead to self-blame. According to Mindel & Vernon (1987) in Adams (1997:9) knowledge about the hearing loss will reduce the tendency for self-blame. Dare & O'Donovan (2002:19) state that suddenly having a child with a disability can be very upsetting, and supports the notion that parents should be given time to understand to adapt and to accept. This will not happen overnight.

- **Extreme sadness**

Hornby (2000) explains that sadness often kicks in when hearing parents start to grieve for that which they have lost. For many participants, sadness was synonymous with chronic sorrow. Sadness seems to be a recurring emotion that was revisited each time a child approached a developmental milestone (Flasher & Fogle (2003). According to Northern & Downs (2002), parents go through a mourning phase which is characterised by sadness and depression over the hearing loss of their child.

For one of the participants who took part in this study, recalling her experience led to immense sadness; her sorrow was chronic, with perpetual crying, which was an indication that she had not yet come to terms with her child's hearing loss. Steenkamp & Steenkamp (1992) in Ross & Deverell (2004:76) state that the emotion of shock may be accompanied by "tremendous feelings of sorrow" and constant weeping. Ross et al. (2004) believe that parents need to go through this mourning process, as the following participant expressed herself:

"I cried a lot..... I cried almost every time....."

Another participant describes how sad and heartbroken she was at the beginning when she found out that her daughter had a hearing loss.

"In the beginning it was hard, I was so sad, I was heartbroken, I cried for months..."

“I never expected my child to be deaf. I was oooo so heart sore”

One participant remembers her reaction to the diagnosis of her child’s hearing loss and described herself as follows:

“I had my quiet times or can I say my crying times of.....bitterness and sorrow. I remember going to the bathroom at times and just sitting there and just crying”

One of the hearing parents was forewarned about the possibility that the third child could have a hearing loss, but decided to continue with the pregnancy, and was extremely sad when her daughter was diagnosed with a hearing loss. She described her experience as follows:

“She was planned yes..... she was planned, and when she was born nothing was said about she being deaf so I was glad. Only at 9 months did they find out that there is something wrong ooo I was sad. I cried for months because when she was born there was nothing wrong.”

Wilmshurst & Brue (2005: 115) refer to sadness as the emotion that parents experience when they come to the realisation that the vision that they constructed about their child has suddenly being altered. Ross et al. (2004) furthermore point out that sorrow can result in perpetual weeping, which can be an outlet for parents for a short time. Hornby (2000) however, warns that parents who are unable to move beyond the stage of sadness can become depressed. Similarly, as pointed out by Ross et al. (2004:156) parents experiencing chronic sorrow will be in need of professional assistance over time.

It became obvious that the participants who took part in this study had accepted their children's hearing loss but that this acceptance co-existed with a lot of sadness and sorrow (Shohov, 2004; Kearney & Griffin, 2001).

The following theme centres around anger and blame, and seems to be a direct reaction flowing from the emotion of sadness that hearing parents experience after their child is diagnosed with hearing loss.

4.3.2 Theme 2: Specific/individual behavioural and emotional reactions following the diagnosis:

4.3.2.1 Hearing parents' emotions of blaming and anger

- **Anger, guilt and blaming**

After the first initial emotional reactions of shock, disbelief, denial and sadness, hearing parents reported specific emotional-behavioural responses of anger, guilt and blame after their child was diagnosed with hearing loss.

- **Hearing parents' anger**

Kriegsman & Palmer (2013) state that some parents may experience anger at the time of the diagnosis by displaying anger towards themselves, God, medical staff and even their spouse. Dale (1996) refers to anger as a feeling of bitterness. According to Dowling, Nicoll & Thomas (2013:46), anger is one of man's strongest emotions as it provides human beings with protection from emotional trauma. The same authors furthermore state that anger arises when one feels anxious, helpless and overwhelmed by a particular situation. Two participants in particular felt angry about getting themselves in this situation in the first place. The following quotes are illustrative of the participants' anger and helplessness:

"I was very angry..... I was young and wanted to go on with my life"

"I am at home all day...if I can say so, I can't work and that makes me cross as we have many problems.....he (father) wants to do this and I want to do that, he can't get his way all the time, what must I do, I am the one at home..... there are also things that I need or that I want"

"I also have dreams of my own, I am just here, and I feel as if I am trapped, I am here all week, all week in this place"

Hornby (2000) and Ricci & Kyle (2009) state that parents often move into a state of anger about loss, about lost opportunities, lost ambitions, feeling trapped in a life that they had never envisioned. Dare & O'Donovan (2003) state that especially teenage mothers will feel trapped if they lack support from family. Columbus & Shohov (2004:14) in Shohov (2004)

postulate that parents often feel bitter and cheated by life and fate for giving them a disabled child. Similarly Blass (2012) and Northern & Down (2002) state that parents often feel angry towards the deaf or disabled child because of all the time, effort, energies and attention they require.

According to Northern & Downs (2002) parents will experience feelings of anger and will want to lash out at clinicians and doctors, and try to place blame. The following quotation from one of the hearing parents bears evidence of this notion:

“I didn’t know who to lash out on to, not lash out... who to speak to.

The findings of this study reveal that as a result of having to deal with many issues pertaining to the child’s disability, parents may become angry, frustrated and bitter. Seemingly once these parents became aware of the challenges of raising a disabled child, they had to give up their own dreams. Dowling, Nicoll & Thomans (2013:46) state that some parents realise that they have to let go of ambitions, interest and relationships to focus on the needs of their disabled child, and therefore anger often sets in. Anger can be a dangerous emotion, according to Kriegsman & Palmer (2013) who assert that parents should be given the opportunity to vent their feelings about their child’s disability. Ross et al. (2004:76) define anger as a normal coping mechanism and suggest that “these embittered emotions” should be expressed.

- **Hearing parents’ anger, guilt and self-blame**

Ross et al. (2004) are of the opinion that guilt is a normal part of the grieving process, although Gascoigne (1995:13) warns that “guilt is the most damaging emotion of all” as it can lead to self-blame. Hornby (2000) refers to guilt as the underlying feeling of anger. Guilt arises from feeling somehow to blame or responsible for the child's deafness. For example Dowling, Nicoll & Thomas (2013) refer to mothers who will wonder whether they have done something wrong during the course of their pregnancy.

The following quotes are illustrative of this point as one two of the hearing parents expressed themselves:

“I blamed myself, I felt that maybe I did something wrong while I was pregnant?”

“I questioned myself.....I said I blamed myself, I was very emotional I couldn't understand how come my child is deaf”

Another participant went further and indicated her self-blame as follows:

‘I felt like a failure’

According to Roeser & Downs (2004) mothers in particular go over their pregnancy and try to figure out where they have gone wrong. Furthermore Luterman (1987:43) in Meadow-Orlands, Sass-Lehrer, Mertens (2003:48) postulates that mothers often feel that they may be responsible for their child's hearing loss, which can probably prolong their search for the cause of the hearing loss. In similar vein Hooyman & Kramer (2008) report that mothers in particular feel a sense of unfairness, guilt and anger at what they may have done to cause their child's hearing loss. Adams (1997:8) maintains that in some instances both parents may experience guilt as they feel responsible for the child's hearing loss. At the same time they feel sad as they recognise their child's limitations that come with the hearing loss.

On the other hand Luterman (1987:43) in Meadow-Orlands, Sass-Lehrer, Mertens (2003:48) cautions parents not to linger too long on apportioning blame and encouraging parents to make better use of their energies in managing the hearing loss.

- **Hearing parents' anger and blame towards the biological father**

Seligman (2000:82) refers to “projection” as the coping mechanism for blame. Basically it suggests that blame is projected onto oneself or another person in order to reduce anxiety that is being experienced. Blame could, for example, be projected onto one's spouse or doctor.

The following participant indicates how she did not only project blame onto herself but also towards her son's biological father in the following quotation:

“I felt angry, I blamed myself, and his dad was also not there, not supportive...”

Another participant recalls her anger towards her daughter's biological father when she was pregnant at the age of 16, when her partner had tried to convince her to have an abortion. She expressed herself as follows:

“I wanted to blame him, when I told him I was pregnant, I still remember there at the station, he then told me to do away with the baby. That curse is on that child, all those words, all those negative things and words put a curse on the child”

Simpson (1999) confirms that young vulnerable parents may feel angry for finding themselves in this situation; they may feel ashamed and guilty for getting pregnant in the first place and for considering an abortion.

The findings of this study are in agreement that with the birth of a disabled child a severe strain is introduced into the family, with the result that the parents may blame each other leading to irritability and arguments between parents (Dare & O'Donovan, 2003:24). Nielsen (2008) adds that parents can apportion blame to each other for the cause of the deafness, leading to accusations and additional stress in the family.

- **Hearing parents' anger and blame towards a higher power**

Seligman (2000:82) and Dowling, Nicoll & Thomas (2013: 60) state that blame can also be projected towards God as parents may pose the question “why me”? Kriegsman & Palmer (2013) are of the opinion that the question “why me” can be considered as a prayer from parents or a demand for better understanding on their side. Knight (2007) states that sometimes parents feel that they are being punished for something they have done wrong. Blass (2012:326) puts it as “being punished for the sins they have committed”. Furthermore Blass (2012:325) suggests that parents apportion anger to God for “visiting this injustice upon them and their baby”. Based on some religious beliefs, parents think that the birth of their disabled child is a “curse” and “retribution” by God for the sins they have committed (Alur & Bach, 2012:164).

The above findings were evident in a remark made by one young participant who viewed her daughter's hearing loss as curse from God and asked whether God was punishing her for falling pregnant at the age of 16. She expressed herself as follows:

“I asked God if he was cursing me now for falling pregnant at such a young age”

- **Hearing parents’ anger and blame towards healthcare workers**

Harvey (1989) refers to resentment and anger being projected onto professionals for the manner in which the diagnosis was relayed to the parent, or the delay in the diagnosis as professionals dismissed parental concerns (Shah, Chandler, and Dale, 1978 in Meadow-Orlands (1994); Williams & Darbyshire, 1982 in Moores & Meadow-Orlands, 1990:307).

One of the participants in this study confirmed the findings of the previous author by projecting his feelings of blame and anger onto the doctors who treated his child, as seen in the following quotation:

“She was early, I think so about six months. The baby was in an incubator. I say like I blamed the doctors because she was in the incubator, I know that 90% of the children that come out of the incubator have problems or they are deaf because of the loss of oxygen”

There was a general sense among the participants that healthcare professionals lacked compassion or understanding of hearing parents’ feelings. Participants experienced reluctance on the part of healthcare professionals. One of the participants painfully described the lack of sensitivity of a healthcare professional who tested her son’s hearing and described her experience as follows:

“...some health professions are very cold... he’s already cold by showing his back to us, he wasn’t very friendly it was like “I’m just doing my job here, just accept your child is deaf” and a lot of things went through my mind.... No empathy was shown, nothing”

The findings suggest that if a diagnosis had been presented in a gentler and more positive manner, it would have resulted in participants reacting a little better (Waldman & Rouch, 2005).

In contrast, another parent recalled how a group of healthcare professionals showed concern towards them as a family when informing them about their child's hearing loss diagnosis.

“They were all sad looking and needed to know whether we needed a priest and whatever to come and hold our hands”

Martin & Clark (2006) and Knight (2007) indicate that healthcare professionals seem to be unaware of their great responsibility in presenting diagnostic results. Their matter-of-fact attitude in conveying the diagnosis can have an enormous effect on hearing parents' emotions. Similarly Healey (1997); Dare & O'Donovan (2002); Dale (1996) and Harvey (1989) emphasise that the manner in which the diagnosis is explained or conveyed to parents can have a prolonged and direct effect on the parents' attitude towards their child and the way they adjust to the situation. Although there is no way to cushion the shock, a sympathetic attitude and an understanding attitude towards parents' feelings could assist in their coping better, as suggested by Northern & Down (2002).

- **Hearing parents' anger about delay in the diagnosis**

The findings of this study indicated that anger and blame were also projected onto healthcare professionals who dismissed participants' concerns about a possible hearing loss in their child, thus resulting in a delayed diagnosis.

One of the participants described how frustrated and angry she was when she received the prolonged medical diagnosis of her daughter's deafness. She was angry at the way she was treated, and how her own observations of her baby's hearing loss were ignored and dismissed at his 9-month check-up at the clinic, and how the nursing staff just did a random hearing test and nonchalantly recorded his hearing test as normal. Ross & Deverell (2004) state that hearing parents tend to feel anxious when they experience difficulties in obtaining a definite diagnosis of hearing loss, or when there is a delay in the diagnosis. Therefore, as suggested by Young & Tattersall (2000) an early diagnosis helps hearing parents to make plans and decisions concerning their child.

The participant described her experience as follows:

“we had the general check up at the clinic when a baby is 9 months, they did that check-up and I still remember, and then this nurse had like a bell by his ear and then he turned/moved, but I think maybe he didn’t hear the bell he just moved, maybe it was because of reflexes/sight because I can’t remember that time but I know it was a bell, he looked, and then the sister just wrote on the folder that he can hear”

Similarly another participant spoke of how he and his wife already knew at 3 months that their daughter had a hearing problem. After being told by healthcare professionals that they were over-protective, the hearing loss was eventually diagnosed when their daughters was 9 months old. He recalled the experience as follows:

“3 months oldwe suspected that there was a problem with her hearing. From 3 months to 9 months we went to clinics, doctors whatever facilities were available to try to have this child tested. We were absolutely certain that she had a hearing problem and everybody told us that we were nuts, you over protective, you this and that and the other and then finally...at 9 months old and after twisting people’s arms and forcing them we were sent to Red Cross Hospital. They were so shocked that it had taken health workers so long including doctors to have her tested properly...look we know that she is deaf all we need to know is for you to confirm it so that we can move forward”.

In the case of another participant, a diagnosis of deafness or blindness was expected because the mother had contracted Rubella during her pregnancy. She was informed of all the possible consequences to the unborn baby, as well as her different options. When the baby was 9 months old, she was convinced that something was wrong and kept on asking the nurses at the day hospital to check her baby’s hearing. She was only rebutted by them and responded as follows:

“they (nurses at the day hospitals) kept saying that there is nothing wrong with her, her hearing is fine... I was angry...my mom told them that the child can’t hear because she can’t even see properly so they said no we must give it time say so after a year...eventually then they checked it and found that she was deaf, I couldn’t believe it... I went to lots of people and they kept on saying different thing”

A study conducted by Yoshinaga-Itano (1998) cited in Dumont & St. Onge (2013), indicates that an early diagnosis before 6 months, is crucial for the development of a child with a hearing loss. An early diagnosis can lead to an early intervention programme. For instance Yoshinaga-Itano (2003) indicates that language development is affected by the age at which the hearing loss is detected. Luterman (1999); Pipp-Siegel, Sedey & Yoshinaga- Itano (2002) in Damico, Müller & Ball (2012) reinforce the argument that early identification and early intervention have shown a decrease in family stress.

The findings revealed that some participants suspected that their child suffered from hearing loss and became angry and frustrated at the delay of the diagnosis from healthcare professionals. The findings confirm some parents' constant struggles in the delay of the diagnosis as they struggle to get an appointment or a referral. The argument of early identification and early intervention is reinforced by the findings made by Luterman (1999) in Dumont & St. Onge (2013) who asserts that early intervention can reduce stress on parents. Furthermore Zand & Pierce (2011:90) state that the earlier the identification of the hearing loss takes place, the quicker the response will be in starting early intervention strategies to assist the child.

4.3.2.2 Hearing parents' experiences with regard to their planned pregnancy

- **Hearing parents' shattered dreams and plans**

Davis and Cunningham (1985) in Shohov (2004) postulates that people tend to construct mental models of their future activities. Therefore receiving news of a pregnancy, future parents tend to build up a picture of their future family and parenthood. Their whole future is constructed around a healthy "normal" child. Therefore a diagnosis of a child's disability, according to Dale (1996) can lead hearing parents to feelings of anxiety, shock, and confusion, and into a world of much uncertainty. Kurtzer-White & Luterman, (2003) also explain that a family may experience intense grief as they try to make sense of the loss of a future they once envisioned for themselves and their child, a future of lost dreams. They speak of a feeling of helplessness, shock, and confusion, and of total disbelief. Their world has suddenly come crushing down on them after receiving the unexpected diagnosis of their child's hearing loss.

Being well established professionals in their jobs and having planned their pregnancy, one of the participants described her experience:

“I remember how we planned for the little one; everything was so perfect you know. I had my dreams for her like any other mom. We had dreams for her.....“We had everything plan, you know, the preschool, the school the aftercare and so and so but with a deaf child all of these things change you know. Suddenly you find yourself at Dr rooms and then attending speech therapy classes, having to consult this one and that one, so yes our time was consumed with all of this. You know this is not what we had expected”

All parents have dreams for their children; they want them to be happy and successful but most of all they want their children to be healthy, according to Moore (2009). However the news of a disability can leave parents feeling sad, and according to Hornby (2000) parents may tend to dwell on the past and the present, and view the future with apprehension. For some participants sadness accumulated into a loss of dreams that they had for their child as most parents dreamt of a perfect baby.

The unexpected news of their baby having a hearing loss could devastate parents' expectations. Most teenage mothers will experience additional challenges when they learn that their child has a disability and will require the support of family. Dare & O'Donovan (2002:6) state that when single parents give birth to babies, they will be in need of parental support.

One of the participants confirmed the previous findings by stating:

“I was devastated and sad because this was my first child and I was so young, I didn't know she was deaf because I was so young”

According to Ross & Deverell (2004); Scheetz, (2001) and Marschark, (1997) this was not the future parents had envisioned for either themselves or their child and therefore their dream of the perfect child was shattered.

In contrast with the previous findings, one participant reported that she had taken the time to research their child's diagnosis in pursuit of finding answers to their questions and commented as follows:

“We immediately went onto the internet to look for answers. We wanted to know what hearing loss was”

According to Kriegman & Palmer (2013) some parents will cope with their painful emotions by taking constructive action; they will go in search of answers or information to satisfy feelings for greater productivity and accomplishment.

- **Hearing parents' immediate acceptance based on religious beliefs**

In contrast to many of the hearing parents who were shocked by the diagnosis of their child with hearing loss, one participant believed that their deaf child was a gift from God and immediately embraced their child's hearing loss when it was diagnosed. There was no denial; there was an acceptance readily based on the fact that this child was special, as expressed in the following quotation:

“We felt that we were given a child like this. She is the only one in the family, no history of deafness anywhere. That this is a special child and if she is special then as parents we were, because we were given this responsibility out of how many others, she was special...a special child from Allah”

This finding is in agreement with Kriegsman & Palmer (2013) who postulate that through their spiritual belief and practices, parents may find strength, hope, relief and even a sense of hope. However, Hornby (2000) reports that a traumatic loss can make a person question their beliefs, religion and the values they hold so dear to them.

- **Acceptance by a deaf father himself**

Another hearing participant recalls how her deaf husband was very happy that their daughter was diagnosed with hearing loss. His happiness was based on the fact that he now had someone to talk to. Damico, Müller, Balls (2012) suggest that deaf parents tend to be less emotionally distressed when they find out that their child has a hearing loss.

“My husband, oooo he was so happy that she’s deaf because he says now he can have someone to talk to”

Moore (1987) in Terri Feher-Prout (1996) states that hearing parents tend to find the diagnosis of deafness in a child highly stressful, whereas deaf parents will almost immediately welcome and accept a diagnosis of deafness in their child. Schlesinger & Meadow in Feher-Prout (1996) point out that deaf parents tend to take the diagnosis of their child’s hearing loss in their stride as they will be able to communicate with their child from birth. Likewise Paul & Jackson (1993) in Adams (1997) report that deaf parents do not experience adjustment problems, unlike hearing parents, who experience difficulty in adjusting to their child with a hearing loss. Freeman, Carbin & Boese (1981) in Swanwick (2012:4) suggest that deaf parents will respond more positively to the birth of their child with a hearing loss than the hearing parent, especially because they will use sign language for communication.

4.3.3 Theme 3: general experiences of post-diagnosis on the way forward: "it’s a journey”

The research questions allowed participants to reflect on their personal journey, and all indications led to the conclusion that their journey was a process of practical decisions around issues such as education, communication and independent living. It was a journey of practical arrangements and seeking professional help. It was also a journey of emotions, including mental and physical exhaustion. Some days were filled with grief, depression and anger, and other days it would be acceptance, accomplishments and celebrations. The following sub-theme unpacks the participants' experiences of the way forward after the diagnosis of their child’s hearing loss.

- **Hearing Parents’ Journey of Decisions and Practical Arrangements**

Medwid (1995:12) states that “being deaf in and of itself does not create the problem, but the context in which deafness occurs”. The family therefore need to make the necessary adjustments in order to accommodate the child's realistic needs and progress. Feher-Prout (1996) and Medwid (1995) state that the family's perception of hearing loss, and how they define hearing loss, as well as the resources at hand, will make it easier or harder for parents to adapt and develop to their child’s hearing loss.

One of the participants wished "if only" they had known what the journey had in store for them, "if only" somebody had told them what their journey would entail. He was obviously speaking to the challenges of raising a child with a hearing loss.

"....but if we knew what the journey would be about, wow then it would have being a different thing. There was nobody that could tell you left, right, centre or anything..... our life had to adjust"

Another participant reflected on his family's journey of adjustment which in itself brought about new challenges and frustrations. He described how the family constantly had to be aware of their daughter's limitations and then make sure that she was included in all activities. This in itself put pressure on the family hardly having time to relax and enjoy outings.

"We had to be conscious of her presence at parties, at Christmas times, at the table, breakfast table and during our quiet times..... We had to adapt"



- **Hearing parents' journey of emotions and miscommunication**

Communication and the lack thereof was the central concern for all the hearing parents. All the participants expressed the enormous communication conundrum that they faced, and how emotionally and physically tired it made them. Two participants described their journey as a "journey of lots of misunderstandings" leading to frustrations" for both parent and child. They explained their frustrations as follows:

"There were lots of misunderstandings and frustrations for both of us as parents"

"The communications, sometimes we don't understand each other then we both frustrated"

These findings are in agreement with those of Bristol, Gallagher & Schopler (1988) and Fisman, Wolf & Noh (1989) in Olsson (2008), who assert that communication barriers between hearing parents and their child with hearing loss were identified as an irritation and frustration factor, causing tremendous stress, soaring emotions and tensions between family

members. Flasher & Fogle (2003) report that often one parent takes on the responsibility to repeat and restructure information in the home, in order for all to be understood, as conversational interaction can become less through misunderstandings. Swanwick (2012:5) asserts that it is often the mother that takes on the role of the effective communicator with the child. The mother often becomes the intermediary between the family and the child (Luterman & Ross, 1991) in Swanwick (2012: 5).

The following three quotations bear evidence of this notion and demonstrate the role of mothers with regard to the challenges of communication between the child with hearing loss and the rest of the hearing family members:

“Being like the interpreter for her and the family and sometimes taking the lead in everything man”.

“She has this blankness on her face like she does not understand then I have to repeat me or her until she become like frustrated or like I can say..... Angry with me, but I also become angry with her because I must repeat all the time. I’m tired sometimes and sometimes I must repeat to her and to her daddy, like I’m in the middle man, oh it’s tiring”

“but there are times when S is frustrated with her father..... then I must again explain to him what she said and that, that makes me so cross.... it takes time to understand her and it takes up my time to explain to him again.... I get angry when she speaks to him and he doesn’t know what she is saying”

Although hearing parents expressed the need to communicate with their child, they often became impatient and dismissive in their body language towards the deaf child, as expressed by the following participants:

“Sometimes I am so tired that I just tell her anything which is wrong and then I feel guilty and so bad as I am actually lying to her because I am tired. Sometimes also I don’t have the time and it is very difficult”

The following comments by hearing parents are illustrations of the frustration experienced by hearing parents and their child with a hearing loss pertaining to communication challenges they faced.

“It’s not easy to communicate with her”

“....to learn sign language, to learn all these things....”

“I felt that I’m a failure to her because I don’t understand her I can’t communicate with her.”

“There are times that I understand what he says and he is trying to pronounce the words and ja sometimes I don’t understand what he is saying”

“The feeling is, “ you don’t understand me when I talk, you don’t listen to me when I talk to you and when I tell you something then it is mainly because we can’t, we simply can’t communicate with them.”

“Communication is a stress factor for me.....his lack of communication is limited. I always tell myself he can’t express himself verbally and like sign language classes, no one told me about sign language classes.my mommy said you must learn sign language because we can’t understand him.I can sign that basic stuff but to sign fluently I can’t”

“Sometimes I am very tired and I have to repeat things to her and I become really mad and cross”.

Similarly one male participant lamented how alone he felt in dealing with all these communication issues between his spouse, children, school and hospital.

“...I has to communicate with Z and then talk to the doctors, so it’s very frustrating, I feel very alone.”

The findings of Schlesinger and Meadow in Ross et al., (2004) support these findings and allude to the difficulties in communication for most hearing parents which constitute a major frustration for them. The findings are equally supported by Meadow-Orlans, Sass-Lehrer, & Mertens (2002) who make reference to communication struggles in the family, and together with Steinberg & Bain, (2001) in Meadow-Orlans, Sass-Lehr & Mertens (2002) identify that communication struggles are further compounded in families due to perceived time pressures, the child's inability to understand complicated information, and the emotional state of parents. Often one hearing parent acts as the "interpreter" for the other parent, causing stress and tension between parents. Luterman (2004) cited in Damico, Müller & Ball (2012) states that hearing mothers generally have no experience with hearing loss, and have to deal with grief while simultaneously learning how to communicate with their child. The study is also consistent with the literature as provided by Meadow-Orland, Sass-Lehrer & Mertens (2003: 30) who are of the opinion that mothers are better at communicating with their child with a hearing loss than fathers, and often take on the responsibility of ensuring clear communication in the family.

- **Hearing parents' journey of emotional and physical tiredness**

All the participants spoke of their everyday frustrations, and the tensions, sheer physical, mental and emotional exhaustion they experienced. All eleven participants shouldered everyday difficulties that arose from bringing up a child with hearing loss.

One of the participants described her personal journey and emotions as follows:

"You on a roller coaster of emotions, sometimes it goes well and then someone says something or you are confronted with a limitation then down goes the emotions again"

Another hearing parent admitted to struggling along her journey with adjusting to her new challenges especially after having planned her pregnancy. Her perceived journey of motherhood did not include a diagnosis of a disability and the additional exhaustion that went with it. She explained this journey as follows:

“It was so time consuming and tiring.....there was days when I was How can I say, just tired, tired of all the struggles”

Nine of the participants lamented how the responsibility of looking after the child with the hearing loss became the main responsibility of one parent, causing mental and physical exhaustion. Hooyman & Kramer (2008) and Nielsen (2008) state that it is not abnormal for one parent to assume full responsibility for caring for the child 24 hours a day.

“She is still dependent on us, it’s almost like I’m her support, her everything and sometimes I feel that everything is too much.....”

- **Hearing parents’ journey of discipline and supervision**

Discipline and supervision of the child with hearing loss posed a challenge for most of the hearing parents. Often the lack of understanding and communication compounded the discipline issue for the parents. A few of the participants acknowledged that disciplining their children with hearing loss was a tiring and challenging experience. Participants often had to put up with other people’s insensitive comments that the child with hearing loss was naughty and thus not conforming or acting to the norms of society.

One of the participants described her own feelings of helplessness, anger and resentment towards her daughter out of sheer frustration as she struggled to discipline her daughter. She also gave the impression that she believed her daughter would grow out of her deafness (Dare & Donovan, 2003, and Dale, 1996). She constantly complained how naughty her daughter was and how she would not listen to her parents. One cannot help wondering whether she blamed her daughter for her hearing loss and the stress that she as a parent was experiencing.

The aforementioned participant expressed herself as follows:

“It was very difficult because we couldn’t understand at the beginning..... and the people use to say that she is naughty and throw tantrums and I had to see the behaviour clinic” And it was very difficult because we couldn’t understand her and she was very aggressive and that made her very rebellious and aggressive. She was very violent and aggressive towards us...And it was very frustrating at the beginning”

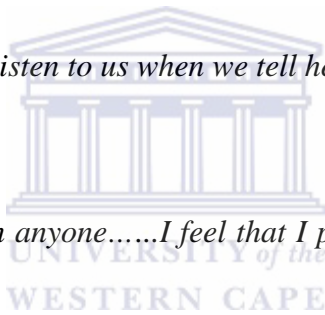
“They don’t understand or they will say she is naughty and..... Joh, she is very busy, she is up and down just busy with her things, she doesn’t get tired, that is a real problem.”

“Yoh she is naughty and I have to talk and talk with her all the time.....but oh, K stresses me a lot, she takes a lot of energy out of me. K has a lot of energy, she does her own thing.....It is a headache yoh, to take her shopping with me; she stresses me in the shop. She is here and then gone again. The people in the shop will stare when we talk to her or when she talks to us but joh, she don’t want to listen, she is naughty man”

“Can’t even take Y with to the shops.....because he is too hyper and they say Y is too rude and he is naughty and he doesn’t listen and everything.”

“.....she does not want to listen to us when we tell her to go to sleep, she is very active.....”

“I can’t just trust her with anyone.....I feel that I prefer to look after her myself and be there for her at home”



The issue of discipline of the child with hearing loss also caused tension and stress between the parents. When one of the participants was not sure how to discipline her daughter and lacked her husband’s support in assisting her, he thought it best to resolve the problem by “hitting her”, because he did not understand her. The mother was however of the opinion that the problem cannot be solved in that way and she spoke with sheer exhaustion in her voice. Another participant expressed her husband’s annoyance when he felt that his wife always sided with their daughter with a hearing loss. She explained this notion in the following quotation:

“I don’t know always what to do..... She is becoming her own person and she push boundaries and sometimes I don’t know how to handle it then now and then I speak to my husband then he say “you must hit” the child, but I can’t just hit the child you can’t solve things by hitting her all the time.....I took on the maternal role, the

mother and the father and I took on that extra role. It wasn't easy to raise her.....I'm the one that discipline A, I tell her this and that"

"Her dad says I always take her side in stuff which is not always like that. I didn't want any more children and I think that is also what cause the tension between me and my husband because he still want but I couldn't..... we always fighting..."

"So even with my wife is not involved with S, the whole thing is around me, her schooling, her communication, her problems, everything is through me. But when it comes to real issues, feelings, emotions, my wife can't help her, so it's my job.....and then my own family, my wife and children are not supportive in that way."

Another participant, who is the step-mother of a child with hearing loss, indicated that her husband was unable to communicate with his child with hearing loss, thus shifting his responsibility on to her, and creating tension in the household. She explained the situation as follows:

"At times I will be cross with my husband that this is his child now I must sit with the child, teach her, frustrated in not understanding her, I must take care of his responsibility now, why must I sit with this, why must I, this is your child all the why's and sometimes he frustrates me because I must make him understand what she is saying and I must tell him to talk to her, so it wasn't rosy, it was difficult"

In contrast to the above-mentioned experience that created tension in the family, the following hearing mother was of the opinion that if the marriage bond between her and her husband had not been so strong, she would not have coped so well:

"So we learnt to cope and having a strong marriage helped... I must say that I drew my strength from my husband...If it wasn't for him I think I would have ...struggled more."

The fact that mothers are mostly responsible for the discipline of children, is supported by Baxter (1989) and Singer (2006) as quoted by Olsson (2008). Seltzer, Greenberg, Floyd & Pettee (2001) indicate that mothers often feel overwhelmed, stressed, frustrated and angry at

shouldering most of responsibility of disciplining a child with hearing loss. The overall conclusion as confirmed by a study of Shohov (2004) is that hearing mother's experience extraordinary stress in parenting a child with a hearing loss. Most of them are limited in holding employment or participating in activities outside their homes due to the need for full time parenting of their disabled child (Shohov, 2004).

- **Hearing parents' journey of schooling and independent living**

Scholastic adjustment and decisions about education choices also presented a challenge for participants. Some of the participants were anxious and concerned about the quality of education their child would receive and whether the education would prepare their child for life beyond school, beyond their care and prepare them for independent living.

One of the participants, whose daughter underwent two cochlear implants, opted to have their daughter attend a mainstreamed school. Swanwick (2012:200) states that children who have cochlear implants at pre-school age are more likely to attend mainstream schools. The same mother's concerns centred on the teachers' abilities to understand her child and whether the other children would interact with her. She was empowered enough, though, to inform the teachers about her daughter's hearing loss. Similarly Flasher & Fogle (2003) report that when a child with a hearing loss enters a mainstream education system, the teachers need to know what accommodations need to be made to meet the child's educational need. Literature also points to the fact that hearing parents are often concerned about the isolation of their child with a hearing loss in mainstream education (Roeser & Downs 2004: 422). According to Alur & Bach (2009:164) parents can become apprehensive about their child being teased, the adjustments the child has to make, the teachers' attitudes and the support the child would receive in the class.

The following quotations demonstrate the hearing parents' concerns which were centred on their fear for the attitudes of teachers and children at a mainstream school.

“Parents are normally excited for their children going to school for the first time; I on the other hand was really scared for her and not really excited.”

“You worry if the teacher does understand your child, if the other children will play with her

“I was worried about enrolling her in a mainstream school.....Sometimes teachers can be insensitive and talk with their backs to the children while writing on the board and then W comes and complains at home and this infuriates me. I can see that W has to pay extra attention in class and sometimes comes home tired and frustrated. I read up on how people who depend on lip reading can be frustrated and moody”

“I thought how other children will react to herwhen they see these things (pointing her finger) behind her ears. You know children can be so cruel and even their parents.”

The progress of children with a hearing loss depends on their parents' involvement with their schoolwork. Once again, the support with schoolwork often fell onto the shoulders of the mother or the parent that took the most interest in the child with a hearing loss. For many participants the attitudes of teachers added to their already stressful experience, with some teachers being very inconsiderate to the emotional needs of the parents. The following examples illustrate how hearing parents struggled to assist their children who attend a school for the deaf with homework:

“Like how they recruit their teachers now I am saying shouldn't this person have some compassion for the deaf, willing to give more of their time because these are deaf kids? The teachers tell you straight “listen I have a life too”, but you are a teacher, “no but I have a life too they will say”

“The school also make me so cross. I want to take O out of the school but the social worker said I must try to solve the problem first with them before I do anything. But now I must like worry and do this. With my other two children I didn't need to see the teachers or worry so much.”

“I wrote to the teacher that “if I don't understand how must M understand?” So she said that M must pay more attention in the class. Sometimes I feel mad especially at

the teachers. I admire them teaching the deaf children but they don't have deaf kids at home (angry) and they expect us as parents to teach the child."

"I asked the teachers how to communicate..... and the teacher explains to me that I must use the lowest language to help her."

Parents were very concerned about whether their children would be able to develop **independence** after attending a school for the deaf.

The following quotations from hearing parents illustrate their concerns:

" I am stressing at the moment about what's going to happen after school, are they going to cater for him till grade 12, because the school does not have grade 12"

"My concern was for her and her future because I mean, I have seen a number of children now stuck in a void because of their education"

"How do you take 18 months to finish a grade? We rely on the school and the school had nothing to offer.....so school was really a nightmare. To negotiate with teachers, wow.....I mean most of these kids leave school with grade 8 maybe grade 9 if they were doing well"

".....so I questioned the kind of education their child has and why he were so poor at communicating and writing. Now I started to worry about what is going to happen to my child after school and whether the school prepared children to live independently from their parents one day."

Roeser & Downs (2004:422) state that most parents who chose to have their child educated at the school for the deaf were not happy with the academic accomplishments of the child. These authors suggest that the schools for the deaf should evaluate their standard of education and the low expectations that they have for children with a hearing loss, especially when they are not adequately preparing them to compete in a complex world. Although parents were concerned about the quality of education and whether school was preparing a child with a

hearing loss for their future, parents also had a role in instilling confidence and self-reliance in their child. Ogden (1996:64) believes that giving deaf children a strong emotional base will assist them in becoming independent and productive individuals. Ogden (1996) supports the idea that parents should encourage independence and allow the child to make mistakes and not become totally reliant on parents. Parents can be loving but not overprotective; they should instil confidence and not dependence. Luterman (1999) suggests that a parent's responsibility is to create an independent child and to help them to take responsibility for the choices they make. Confident parents lead to confident children.

Austen & Jeffery (2006:85) consider that if parents have a more positive view about deafness and do not view deafness the way society defines it, then their child can grow to be independent and self-reliant. Therefore the concern should not be so much on teachers and the education system (which is equally important) in preparing deaf children for the future, but on parents' ability to accept and develop their deaf children into strong independent young people.

- **Hearing parents' journey of family dynamics**

Hooyman & Kramer (2008:202) state that often with the birth of a disabled child, family members may not know how to react or what to say to parents of the disabled child. Family dynamics came into play especially when all participants reported a change in family dynamics in order to cope with the young child with a hearing loss. Literature draws attention to the fact that many battles and conflicts in the family are centred around the child with a hearing loss (Meadow, in Ross et, al.2004). Seligman (2000) reports that disability (hearing loss) does not only affect the family but also affect the disabled person (the child with the deafness).

One hearing father explained how the family dynamics among the siblings of a child with hearing loss had changed and how frustrated he had become at their negative attitude towards their sister with hearing loss. The siblings felt that their sister with the hearing loss was being treated special by their father and thus impacting on sibling relationships. He also felt that his wife should have made the extra effort to learn to communicate with their daughter with hearing loss and not depend on him to intervene. Gargiulio (2010:430) asserts that often siblings can become jealous and resentful towards their brother or sister with a hearing loss when parents devote too much attention and time to them. The author furthermore suggests

that the best way for parents to avoid such family dynamics is to openly communicate about their concerns and differences.

“I’m telling her two siblings that they are not interested in their sister because they cannot communicate properly. They know just to show “away” like this.....I think that it was 10 times worst for me and the family. I always felt that the family was not interested”

Ogden (1996:70) views the “family as a network of relationships that affect each other”. The author warns that parents should not become so wrapped up in the child’s hearing loss that the needs of the others in the family are left to chance. Often the focus of parents is so much on the child with the hearing loss that the other members in the family feel they are less important. Some parents could interpret that members of the extended family are less interested in the child with the hearing loss and might not be aware that **their** attitudes as parents contribute to the relationships in the family.

With some of the hearing parents the researcher got the sense that they felt that they needed or were compelled to compensate for their child’s hearing loss. Austen & Jeffery (2006: 83) point out that because the child has a hearing loss, parents are naturally overprotective, make greater allowance for the child and often extend the boundary lines. The hearing parent becomes the protector and therefore wants to protect him or her from all unpleasant experiences. It is often not the child with hearing loss that is the cause of the tension or strain in the family but rather the parent who is overprotective. Austen & Jeffery (2006) caution that this overprotectiveness can cause the child with a hearing loss to become dependent on the parent and therefore lack coping skills. This in itself can hinder independent living, resulting in becoming dependent on the hearing parent for the rest of their lives.

According to Dare & O’Donovan (2003:240) in many instances family members might not know how to react and family members may see the child with a hearing loss as a “tragedy” and offer condolences instead of congratulations.

One young participant lamented the tension between herself and her sisters when there was conflict between her daughter with the hearing loss and other children in the household. This young mother who was constantly in the middle, defending and protecting her daughter on

the one hand and also trying to keep the peace as the house was already overcrowded. She obviously would have liked her daughter and cousin to get along. It was evident that she felt hurt about this and expressed herself as follows:

“She and her cousin always fights and there is always tension between me and my sister in the house cause they don’t understand her (sad, quiet). It would be nice to see them play together.”

Another participant recalls with sadness how her sons’ father who did not live with them did not seem to make any attempt to visit or have any contact with his son with hearing loss.

“His own daddy doesn’t care ... He gives nothing to him, nothing at Christmas, he don’t even phone or if it’s his birthday, he don’t phone or he don’t pick up the phone to ask how he is the child and so on, nothing nothing, it’s like he is embarrassed by his own child.”

Equally some of the participants also felt that the extended family showed no interest, and was visibly upset by this:

“It affected my extended family, they did not get involved and I did not involve them [in the upbringing of the child with hearing loss]. I just felt that if they wanted to, they would show interest. The extended family is not supportive”

Similarly another participant felt very cross and at the same time hurt when she watched her daughter play alone or “live in her own world” as her mother put it. She was referring to the attitudes of her in-laws with whom they were staying.

“It makes me so cross when she is all by herself and people don’t worry about her. I can see that it makes her heart sore and that she just want to be by herself.... Sometimes she wants to be with people but they don’t want to play with her”

One of the hearing fathers described how their daughter’s deafness changed their family dynamics and how it brought about a close bond between his immediate family members.

“We became closer very much close you know, she affected our lives. It brought us closer and it deepened our relationship with one another, it deepened, broadened and enhanced our faith in God because this little girl changed us”

Another two participants recalled how the fact that they had a good marital relationship helped them to cope with having a child with hearing loss and how they drew their strength and support from their spouses:

“...so we learn to cope and having a strong marriage helps”

“I drew my strength from my husband. He is always positive and always sees the positive side in life”

Although Braden (1994:46) identifies hearing loss as an added stress factor in the family system, Nielsen (2008) is of the opinion that sometimes it can be to the advantage of a family by bringing them closer together, helping them overcome challenges, and helping them as parents to appreciate the enrichment that their deaf child contributed to their lives.

- **Hearing parents’ journey of community perceptions**

“The biggest barriers in my life and the lives of others like me, was not deafness but the public views of deafness” (Thomas, 2009). This quotation by the parent of a deaf child summarises hearing parents’ experiences regarding socialising children with hearing loss in a hearing world.

Stigmatisation by family members and by the broader community was a general concern for the participants who took part in this study. Some hearing parents referred to their frustrations after experiencing people’s negative and sometimes hostile attitudes towards them and their child with a hearing loss. One of the participants recollected how church members were very insensitive towards him and his daughter with hearing loss when he tried to assist her in understanding the sermon. He recalled their stereotyped behaviour as follows:

“Frustration comes in with the congregation when they don’t understand and makes as if she is abnormal. I had to explain to the ministers and the congregation that she is deaf, that she cannot hear”

Hearing parents also indicated that they were reluctant to allow their child with hearing loss to wear their hearing aids for fear of scorn, embarrassment and ridicule by family and community members:

“Every time when he was there by his father his father took off the thing [hearing aid] because he was ashamed to let him walk with the things”

“When they gave him that ear piece at first I was too shy to walk in the road with him [child with hearing loss]. It was like hey what the people are going to say..... And a lot of time the people don't treat him right”

The attitude of community members towards children with hearing loss was also a concern for one of the participants whose deaf child went to a mainstream school. She admitted that she was afraid and embarrassed that her daughter would be stigmatised, and expressed herself as follows:

“I think I was more concerned ...or should I say afraid of the stigma... People always asked the same question or they would look at her and at the cochleas behind her ears. Yes I felt sorry for her and maybe for myself too or can I say embarrassed as I had to fend these looks and questions”

Another participant explained that her child with hearing loss did not want to wear her hearing aid in public:

“She herself doesn't want to wear a hearing aid in public as sometimes the people look. Even if we go out she doesn't want to wear the hearing aids.”

In the end it seemed that parents needed to feel comfortable with their child's hearing loss as well as their use of a hearing aid. They themselves were still struggling to understand and grasp the enormity of the disability, and people's attitudes and perceptions only added to the length of their journey. Flasher & Fogle (2003) state that although stigmatisation about disability has in some way lessened in society, stigmatisation still exists in sections of society, resulting in many people with hearing loss refuse to wear a hearing aid.

4.3.4 Theme 4: specific experiences of the way forward for hearing parents with a child with a hearing loss

- **Hearing parents' general need for the way forward**

Although having a child with hearing loss was an extremely painful journey for all the hearing parents, the majority of the participants realised they had to adjust their way of life in order to meet the needs of their disabled child. Although all the participants had reacted with shock, grief and denial, there were some who were more proactive than others. Some participants empowered themselves with knowledge about the disability itself in order to assist their child with hearing loss. Others tended to go through the emotions and accepted their fate as parents of a child with a hearing loss.

The following opposing themes described the experiences of parents and how they contributed to the way they accepted their child's hearing loss.

- **Hearing parents' experiences of self-empowerment vs. defeated acceptance**

Rappaport (1987) as quoted by Hintermair (2006) supports the notion that through empowerment people can take control of their own affairs, thus discovering their own powers and capabilities. Hintermair (2006) is of the opinion that empowerment of deaf and hard-of-hearing people begin with the empowering of families into which they are born. However it can be seen that finances and socio-economic status can be a contributing factor to coping and planning for the future.

Two of the hearing parents who took part in this study indicated that they embraced their daughter's hearing loss with all its ups and downs. They also indicated that they had decided to empower themselves with information and choices and described their journey as follows:

“We immediately went onto the internet to look for answers. We wanted to know what was hearing loss and more importantly how we could cure it. I don't think we really thought about feelings, our feelings.....We did some research and were very interested in the cochlea implants. A professor advised us to have W's hearing tested to check her degree and kind of hearing loss. They showed us her audiogram of what she can and cannot hear and the degrees of hearing loss in each ear. We also decided

not to have another child so we can focus and spend all our energy on W. It is an emotional experience when you see your child's face light up when she hears sound for the first time. A kind of relief swept over me, just that she can hear was.... was so overwhelming."

"I found out, about a deaf culture and the reason why your child is so different to the other siblings.....what the experience was all about, what not to do like not to talk in the dark or with your face away. Logical things but it doesn't occur to you as it doesn't affect you. So when I found out about this thing called deaf culture I thought that I will be part of the school governing body. I struggled for a long time to get parents involved so that they can help when governing body decisions are madeand I guess that is why I am so involved even though a person doesn't have so much time. Involved to see where I can do my bit for the deaf."

Another father of a deaf child coped by putting his trust in God. Although his wife had to give up her work to look after their daughter, his family still drew their strength from one another. He expressed himself as follows:

"We became closer very much close you know, she affected our lives. It brought us closer and it deepened our relationship with one another, it deepened, broadened and enhanced our faith in God because this little girl changed us."

In contrast, some participants had an attitude of self-defeat with the view: "He/She has a hearing loss, so what can I do but accept it?" Beck (1991) in Shovhov (2004) refers to a parent's expectation to fail at being a parent of a child with a hearing loss and that these hearing parents tended to focus on failures and not success which often led to despair and sadness. It also seemed as if parents' sadness came about as a result of them not having access to positive support systems (healthcare workers, teachers, family members) which resulted in them experiencing unpleasant experiences regarding hearing loss according to Lewinsohn, Hoberman, Teri, Hautziner; 1985 in Shovhov; 2004).

The following quotes from hearing parents make reference to the feelings of hope and despair being experienced by some of them:

“I must accept the things I cannot change. I must just learn to deal with him being deaf”

“There is a light in this dark tunnel that I am in. I feel There is light but I still can't see, I still can't see.”

“I had to accept it; I had to deal with it, all the baggage that comes with it”

“We have to accept it (a defeated acceptance, attitude), what can we do.”

It became obvious from these quotes that these parents had come a long way in their journey of self-empowerment versus defeated acceptance.

- **Hearing parents' need for support**

All participants reported to receiving little or no emotional support from professionals when initially confronted with the diagnosis. The following quotes illustrate this:

“I had no one to speak to; I think if I had someone to speak to that time then maybe it would be better”

“...She [meaning the mother of the child with hearing loss] needs to vent her feeling her anger and frustrations”

“There was no one to really talk to; there were times that I wish I had someone to speak to”

“The psychologist was there to do the assessment...there was no follow up to ask if you are ok or do you need counselling, ...I think it would have helped me. Up until today I am still in a way confused”

A study undertaken by Rahi, Manaras, Tuomainen & Hundt's (2005) with regards to blind children, indicates that professionals have a direct impact on parents when providing emotional support at the time of the diagnosis of a disability. The hearing parents who took part in the present study also indicated a need to be guided into education choices and the

need to speak to someone about their experiences. They said that they had received only minimal support in terms of getting information on deafness or identifying the appropriate school for the child based on child and parental needs. Some parents felt that educational choices were made on their behalf on the basis of their ignorance about hearing loss, especially with they were still grieving for their child's situation. They expressed themselves as follows:

“I only got support at DeafSA, we have nothing at the school”

There's no manual you know “here, you have a deaf child, here's a book” so school was really a nightmare....”

Most of the participants also expressed the need for support groups which is in agreement with the findings of Luterman in Ross & Deverell, (2004). These authors also argue in favour of parental groups that can serve as a strong healing and educational tool for parents. Flasher & Fogle (2011) suggests that a support group for hearing parents would provide them with the opportunity to share their feelings, concerns on issues that they were experiencing.

Several hearing parents were also concerned about the lack of educational opportunities for their deaf children. They felt that the decision for a particular school for their child with hearing loss was based on their socio-economic status and therefore made on their behalf. Very little evidence showed that parents had choices in this regard. One of the hearing parents summarised it as follows:

“We were just referred to ...[school] ” .

It also became evident from the data that hearing parents received minimum financial support from the government to assist with transport cost to and from school, which in turn imposed financial constrain on the hearing parents.

4.4. Conclusion

Chapter 4 has dealt with the findings that emanated from the data collection in themes and sub-themes which were supported by numerous verbatim quotes from hearing parents. Four

central themes emerged from the qualitative data, namely 1) Shared/general initial emotional reactions during the time of the diagnosis; 2) Specific and individual behavioural and emotional reactions following the diagnosis of the child with hearing loss; 3) General experiences of post diagnosis on the way forward “it’s a journey”; 4) Specific experiences of the way forward for hearing parents with a child with hearing loss

These themes encapsulated the journey of the hearing parents’ experiences regarding their child with hearing loss. The findings provided evidence to suggest that when hearing parents were confronted with a hearing loss in their children, their journey included anger, blame, extreme sadness, shattered dreams, adjustments regarding decisions and practical arrangements, miscommunications, physical tiredness, decisions regarding discipline and supervision, education and concerns about independent living. These experiences were challenging to say the least, but also brought with them some parents' immediate acceptance of their child's hearing loss and self-empowerment by believing that the child's hearing loss need not define their way of life.

For the most part, the diagnosis was an emotional traumatic experience for the parents. All of them responded with general emotions of shock and grief. There were also very specific responses experienced by participants whose children had been born from unplanned and/or teenage births, and it seemed as if the deafness was a secondary trauma. Their responses included defensive mechanisms like blaming and anger. Other specific responses included acceptance of diagnosis and were seemingly influenced by religious beliefs and being deaf themselves. For the one parent who had made all possible preparations for the planned pregnancy, it was a “dream shattered”.

It was clear that all participants needed family support, but not all experienced such help – there were diverse experiences of the reactions of family at the time of diagnosis and post diagnosis. The post-diagnosis phase was experienced as an all-consuming adaptation, as family relationships, educational responsibilities, supervising of children, and communication are extremely challenging. Participants also mentioned their sensitivity for the influence of community perceptions of the deaf child, and their fear of stigmatisation of their children.

All of these issues led to emotional and physical tiredness and their expressed need for partner, family and community support. The planning for the way forward seemed to be influenced by socio-economic factors but also by participants' ability to do logical planning vs. a defeated acceptance.

The next chapter provides a summary of the findings, the limitations of the study, and recommendations for support mechanisms to be put in place to assist hearing parents raising deaf children.



CHAPTER 5:

SUMMARY OF FINDINGS AND RECOMMENDATIONS

5.1 Introduction

Chapter 4 discussed the research findings comparing and critiquing them against available literature. The aim of the study was to explore and describe the experiences of hearing parents' regarding their child's hearing loss. Data was collected via unstructured interviews and analysed to produce four main themes that reflected the hearing parents' experiences.

Chapter 5 gives a brief summary of the foregoing chapters with reference to the research study. It reflects on the goal and objectives along with the actions executed in attaining them. The introduction to the study, the literature review, research methodology, data analysis and the research findings will be briefly summarised. The chapter also gives the conclusions of the study as well as recommendations that resulted from the research findings.

Chapter 1

Chapter 1 provided an introduction and synopsis of the study undertaken. It introduced the problem statement as it relates to the experiences of hearing parents regarding their child's hearing loss.

It also provided the background to the research study. It briefly unpacked the psychological and emotional experiences and reactions of hearing parents who had a child with a hearing loss. Chapter 1 first put into perspective the prevalence of hearing loss internationally and nationally in order to gain a better understanding of the magnitude and complexities of the phenomenon. Secondly the chapter discussed the statistics currently prevailing in South Africa on hearing loss and deafness. Thirdly, it explained the etiology of hearing loss such as the inner workings of the ear, types of hearing loss, degrees of hearing loss, the function of a hearing aid and a cochlear implant. The definition of hearing loss was also discussed in terms of defining hearing loss within a disability and human rights framework. It unpacked the ideology behind the medical model and the thinking behind the human rights perspective.

The goal of the present study was to enhance the knowledge base of social workers in healthcare by exploring and describing the experiences of hearing parents regarding the

diagnosis of and caring for a child with hearing loss. Specific objectives were drawn up in order for the goal to be obtained. These objectives were the following:

- to explore the experiences and reactions of hearing parents upon the diagnosis of their child's hearing loss;
- to explore and describe the experiences hearing parents have of caring for their child with hearing loss;
- to explore the needs of hearing parents regarding the way forward.

With the goal and objectives in mind the researcher decided to employ a qualitative research approach using a descriptive and explorative design. The strategy of design was phenomenological in nature and was underpinned by an attempt to gain understanding of the experiences of hearing parents regarding their child's hearing loss. This study allowed for a specific human experience to be described to a researcher.

Four themes were drawn from the data analysis which was generated through unstructured interviews with eleven hearing parents regarding their experiences of their child's hearing loss. These interviews with the permission of parents were audio-taped and later transcribed verbatim leading to the four themes identified. The methodological approach in gathering qualitative data included purposive sampling, data coding and data analysis. The data analysis was discussed in the findings. The validity of the research was subjected to member checking (supervisor) and based on the criterion of trustworthiness. Ethical consideration was discussed in detail and the permission from the UWC Ethics Committee was obtained for the implementation of the study, thus adhering to research ethics.

Therefore Chapter 1 set out the planned processes of implementing the research study and the methodology to be implemented to describe hearing parents' experiences regarding their child with a hearing loss.

Conclusions drawn

Chapter 1 provided the evidence to suggest that the prevalence of hearing loss is growing every year worldwide. As suggested by the literature consulted, 718 000 infants are either born with, or acquire early-onset permanent hearing loss every year. In South Africa alone it is claimed that 10% of its population has some kind of hearing loss. Furthermore evidence

suggests that 90% of deaf and hard-of-hearing children are born to hearing parents. It is further argued that because 90% of children with a hearing loss are born to hearing parents, the etiology of hearing loss is not clearly understood by such parents, making their journey more complex and emotionally turbulent.

Therefore Chapter 1 set out the planned processes of implementing the research study and the methodology to be implemented to describe hearing parents' experiences regarding their child with a hearing loss.

Chapter 2

Chapter 2 presented a comprehensive literature review of theories underpinning grief and loss, hearing parents' response to the diagnoses of hearing loss of their child, the role of professionals at the time of the diagnosis, identifying stress as a major contributor, and the impact that the diagnosis has on siblings of the child with hearing loss. It also discussed hearing loss and the consequences that it has on the family.

The ultimate focus of this chapter was to provide a literature review on the experiences of hearing parents raising children with hearing loss, describing grief and loss as an emotional response and the consequences it had on the family. It also addressed the emotions, strain, behaviour and responses of hearing parents upon the journey after their child had been diagnosed with hearing loss.

The literature defined grief of parents with a child with hearing loss within the disability context. The influences of various grief theories as a response to grief and its evolution over time were discussed. It took into account the period from 1948-1968 focussing mainly on the task-based theory. The task-based theory was based on the premise that parents needed to complete certain tasks during their time of grief, in order for them to heal. It further discussed the parental responses to grief which were more of a response to the medical model of disability. These responses were characterised more by chronic sorrow, parents feeling sorry for themselves and feeling powerless. Various findings were drawn from various authors who supported the stage base theory, the period stemming from 1969-1989, that of parental response to disability responding to death and dying. A brief critique of the stages model was discussed and it was seen to be too limiting in its approach, citing professionals as being the main obstacle for parents to grieve properly.

From 1990-2010 the transformative theory was introduced that asserted that parental responses to disability were attributed to attitudinal behaviours in society regarding disability. It suggested that human beings construct their truths and they make meaning of their loss by processing the grief the way they experienced it.

Parents' reactions were also defined in this chapter giving impetus to the emotions experienced and the impact of a child with hearing loss on a family, recognising the diversity and complexities in family responses to this phenomenon. Stress was also identified as causing strain on the family as a whole and emphasising the kind of choices that need to be made with regard to the child with hearing loss's future, with specific reference to the medium of communication with the child, educational needs of the child and the additional financial strain resulting from the child's hearing loss.

Chapter 2 furthermore discussed the role of the health care professional in presenting diagnostic results to families advocating for professionals to be more sensitive in their approach. .

Conclusions drawn

The literature review provided a greater understanding how over time parents respond to grief as a result of their child's hearing loss. It transcends from a pathological view where medical practitioners have a greater influence to a phase where parents have more control and understanding in their experience of parental grief and loss in relation to the disability.

Chapter 2 therefore provided for the theoretical framework that guided the understanding on hearing parents' reactions to their child's hearing loss.

Chapter 3

The implementation of the research methodology as outlined in Chapter 1 was explained in detail in Chapter 3. It outlined the steps regarding the methodology undertaken which led to the overall findings and conclusion of the research. The research goal and objectives set out the parameters within which the research was undertaken.

The population and sampling procedures were further elaborated on in Chapter 3 along with the selection criteria for the participants. A phenomenological strategy of design was

employed to explore and describe the experiences of hearing parents regarding their child's hearing loss. This strategy of design included the use of an unstructured interview so as to engage with the hearing parents, allowing them to tell the story about raising their child with hearing loss and to gain an understanding of their lived experiences., The data collection process included a pilot study which ensured that the research instrument was appropriate to generate the required data before the researcher continued with the actual data collection of the study. Subsequently 11 unstructured interviews were conducted with hearing parents with a child with hearing loss. Additional data was generated from field notes. The phenomenological data analysis was undertaken as suggested by Creswell (2007) and Klenke (2008) which included transcribing 11 interviews from the audiotape and field notes, re-reading through the data, exploring common themes that were repeated in each interview and short comments/observational notes, highlighting the central experiences of the participants, coding the information into segments/groups before adding meaning to it, putting the data into themes, categories and sub-categories and then lastly presenting the findings of this study.

The trustworthiness of the data was discussed, referring to the strength of the qualitative data analysis. This was done through the applicability of research which refers to the degree to which the findings of the research could be applied in other contexts. Secondly the neutrality of the study spoke to the conformability of the data and its interpretation, which involved an independent coder who audited the findings of the research. The dependability or consistency of the data was ascertained with the assistance of peer assessments done with the research supervisor. This allowed the researcher to speak to her supervisor and reflect on methods deployed during the cause of the study. This discussion centred on trust in the integrity and credibility of the study.

Ethical considerations upheld the principles of nonmaleficence or welfare of participants, posing no harm to the participants. These ethical considerations included the autonomy of participants, which refers to respecting the rights and dignity of participants, bearing in mind that their consent to participate in the research study was voluntary and that this participation included the right of participants to withdraw from the research at any time without reasons. Pseudonyms were used to conceal the identities of participants therefore adhering to the principle of confidentiality, and thirdly that the research would pose no harm to the

participants in that there was no risk or harm to the benefits, welfare and rights of the participants.

The researcher also explained how she used self-reflexivity, thus becoming aware of her own influences on the research process, and the credibility of the research which had to be maintained at all times.

Finally the limitations of the study were pointed out, such as fewer female than male participants. The fact that some participants struggled to “keep to the story” of their child’s hearing loss was another limitation.

Conclusions drawn

Chapter 3 concluded that the research methodology that was planned and implemented for the research study was deemed to be appropriate to execute the research study. It allowed the researcher to generate rich, in-depth findings on the experiences of hearing parents with regard to their child’s hearing loss.

Chapter 4

Chapter 4 discussed the findings of the research study which were collected by means of unstructured, individual interviews and the data analysis.

Firstly the demographics of the participants interviewed were set out, such as the gender, age, language and education of the participants in the research. Secondly the findings in relation to the hearing parents' experiences were discussed. The experiences of hearing parents relating to their child’s hearing loss were presented in themes and sub-themes, and supported by verbatim quotations from the participants. The findings were then compared and contrasted with literature.

The findings as discussed in Chapter 4 are summarised in the following discussion.

Theme 1: Shared/general initial emotional reactions during the time of the diagnosis

As stated in Chapters 1 and 2, literature alludes to the fact that 90% of children with a hearing loss are born to hearing parents who often have no inclination or idea about deafness.

Therefore the reaction to a hearing loss diagnosis for hearing parents conjured up feelings of shock, confusion, disbelief, denial, blame, sadness and anger.

A diagnosis that included words like deafness or profound deafness were a shock to hearing parents who had no concept of what these terms meant. Relentlessly questions were asked to make sense of the diagnosis, often seeking a second opinion.

Hearing parents related that they experienced an immense sadness when their child was diagnosed with hearing loss. Some parents who readily accepted their child's hearing loss were able to cope far better with the diagnosis than parents who seemed to be stuck in their process of grief. Literature was drawn from various authors who warned that hearing parents go through more than one stage at a time, experiencing chronic or reoccurring sadness, and the grieving process continued as it posed different challenges across the lifespan of the child.

The response to the diagnosis reflected on the personal strength of parents individually and as a family unit. Some parents' responsiveness to disabilities was in relation to the medical model, often reflecting a defeated acceptance of the disability. Evidence in the study supported the view by Ferguson (2002:125) who identified parents who saw themselves as the suffering parent, feeling sorry for themselves and seeing the disability as a burden, giving the impression that they are powerless parents. These parents found it very difficult in accepting their child's hearing loss.

The study also revealed parents as identified by Ferguson (2002:125) as being more aware, adapting and understanding of their child's disability who were therefore viewed as "adapting," "evolving," and "supportive". Their attitude spoke of empowerment which assisted them to progress more easily through the stages of grief.

The undertone of the findings also suggested that family dynamics had a huge impact on hearing parents' emotions, as they felt that immediate and extended family members did not make the effort to have a relationship with the child with hearing loss. Feelings of blame, guilt and anger characterised the stressful relationships between parents, immediate family and extended family members. Some of the hearing parents' family systems did not provide a supporting and enabling environment.

Theme 2: Specific and individual behavioural and emotional reactions following the diagnosis of the child with hearing loss

Emotional reactions such as feelings of blame were a common thread throughout the findings. Blame was internalised, projected onto God, health care professionals and even onto the biological father of one of the participants. Feelings of anger and resentment were also expressed, which led to sheer helplessness among hearing parents of children with a hearing loss, at times. However, some hearing parents found comfort in their belief and faith that God had blessed them with a child with a hearing loss.

There was also evidence from the study to suggest that there was not enough support given by professionals, and that they lacked sensitivity when disclosing the diagnosis of hearing loss of a child to hearing parents. Professionals, such as nurses, doctors and audiologists seemed detached from the diagnosis evoking feelings of hopelessness on the part of hearing parents. Hearing parents were presented with poor explanations thus contributing to feelings of confusion, sadness, anger and blame. Experience by hearing parents revealed that parents felt that their encounters with professionals were marked by poor explanations, insensitivity, and a lack of partnership and honesty, devoid of any emotions.

The theme also discussed the sub-theme of planned pregnancy with plans for the future in which most parents dreamt of the perfect baby. The majority of hearing parents shared how their dreams for a healthy child were shattered once their child was diagnosed with hearing loss. However, two of the participants immediately accepted their child's hearing loss, one aided by the parents' religious beliefs and the other based on the fact that the father was deaf himself.

Theme 3: General experiences of post-diagnosis on the way forward: "It's a journey.."

Hearing parents spoke of their enduring journey of love, frustrations, suppressed emotions and sacrifices which eventually became the order of the day for them. The journey brought about challenges that included miscommunication and educational choices. Hearing parents expressed their concern about the limited educational choices for their child with hearing loss, causing further worries/concerns for the future.

Some parents described their challenges of being responsible for facilitating communication between their spouses and their child with hearing loss. Some spouses were overwhelmed

with tiredness and often suppressed emotions which did not argue well for the family relationships in the house. Generally, mothers were depicted as having high levels of stress as they took on the primary role of taking care of the child with hearing loss. Frustrations also emerged when hearing parents experienced communication barriers with their deaf child causing social interaction to be difficult for them.

Theme 4: Specific experiences of the way forward for hearing parents with a child with hearing loss

Negative and prejudiced attitudes and ignorance about deafness from the broader community also exacerbated feelings of hurt and pain felt by hearing parents. Wearing hearing aids and having visible cochlear implants was an emotional concern for hearing parents as they feared stigmatisation and marginalisation towards their child with hearing loss. There was a real concern visible as some parents felt that if their child with hearing loss was not accepted by the broader community, then their future would also be marred by negative attitudes in the workplace and limited future opportunities.

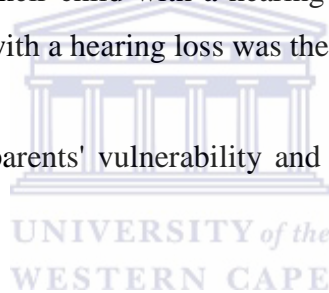
The findings spoke for the need to establish parent support groups and a greater partnership between parents and schools/teachers and parents and healthcare workers. Hearing parents were of the opinion that supportive relationship between the different stakeholders could act as a safety net for hearing parents. Parent support groups were a welcome suggestion as parents would not feel alone in their experiences. A need was expressed for healthcare workers to be empathetic towards hearing parents and not to be dismissed or rebutted when expressing their concerns as hearing parents. There was an obvious need to vent, but to vent in a safe environment that would not cause harm to themselves, their deaf children or to family members. The findings revealed that hearing parents received no counselling support. All the participants advocated the need for counselling, just to speak to someone about their experiences.

There was a strong need to be empowered with information on issues such as deaf culture, sign language and different school options. Hearing parents indicated a need for teachers to understand the challenges that parents were facing in assisting their children with schoolwork coupled with all the other challenges they were facing. The general perception was that hearing parents wanted to be heard and understood and supported by teachers, healthcare practitioners and the community.

Conclusions drawn:

As pointed out in the research, 90% of children with a hearing loss are born to hearing parents. Therefore reactions of shock, confusion, anger, guilt and blame were understandably the first reactions of the hearing parents who took part in this study. Questions were posed to seek some form of understanding how and why their child had a hearing loss, especially when hearing loss was not a phenomenon in the family. These emotions were not only internalised by the hearing parents but were also projected on to the healthcare professionals, who were often described as being insensitive and unsympathetic in relaying the diagnostic results. Their journey included concerns for their child with a hearing loss, concerns such as education, independent living and family and societal attitudes towards them and their child. Sometimes hearing parents almost drowned in their despair, but had to make the most of their unplanned journey. In some instances the strain and pressure in the family life centred around the deaf child causing strain and discord in the family. However, notwithstanding all of these challenges, one participant saw their child with a hearing loss as a blessing from God, and another believed that their child with a hearing loss was the reason for their family cohesion.

The findings spoke of hearing parents' vulnerability and their need for understanding and support.



5.2 Conclusion

In conclusion Chapter 5 presented a summary of the present research study. The summary included the: the background to the research problem, its goal and objectives, the literature review consulted, the methodology used in implementing the study and finally the findings of the study.

Based on the findings, the researcher has made the following recommendations with a view to encouraging further studies on such a limited research topic, and calls for a better understanding of psychotic thoughts, feelings and behaviours of hearing parents as stated by Walter & McCoyd (2009).

5.3 Recommendations

The following recommendations are made so as to assist in furthering the understanding of the emotional impact a child's hearing loss has on hearing parents. The recommendations are

made with a view to stimulate similar research and debates especially in South Africa, where very little research is done on deafness in general. The following recommendations are made:

Healthcare professions and organisations for the deaf

The need for health care professions to assist hearing parents to understand the etiology of deafness. This understanding should include inter alia: 1) the function of the inner ear 2) the types of hearing loss 3) degrees of hearing loss 4) the audiogram as an illustrative tool leading to a better understanding of what the child can and cannot hear.

Social workers and organisations of the deaf:

- Organisations of the deaf need to establish parent support groups for hearing parents. The parent support group could act as a safety net for parents and is used as an empowering tool. The parent support group can act as an emotional sponge or sounding board for parents to reflect and ventilate in a safe non judgement environment. A support group can also facilitate learning as it can invite speakers on various topics of relevance for example on deaf culture or sign language.
- Deaf role models can also be invited to inspire hope for hearing parents. These support groups should be established by organisations for the Deaf or at schools for the Deaf.
- A further recommendation is made in support of public awareness programmes. In the findings hearing parents spoke of the lack of sensitivity of the general public towards them and their deaf child. These public awareness programmes could go a long way in alleviating public ignorance. Hearing parents too can play a role in public awareness programmes through social media networks for example, blogs, articles, sharing information and concerns.
- Similarly, sign language classes can be presented and taught to provincial departmental staff and the broader public and be incorporated into public awareness on deafness.

Social workers and professional counselling:

- Social workers and psychologist should extend counselling to the child with hearing loss as they may experience frustrations and jealousy when they realised that they are different to their hearing siblings especially in communication competencies and speech skills. At an appropriate age a deaf child can be informed the following information 1) to how they became deaf 2) what type of deafness they have 3) with the help of an audiogram, the degree of deafness. The child should be informed whether his/her deafness is progressive and if there are any other disabilities linked to his/her deafness. They should also be aware whether their hearing loss is progressive or linked to another illness later in life. To avoid such confusion and often trauma in later life, it is recommended that from a certain age children should be informed of their type of hearing loss and its consequences in later/adult life.
- All parents should be involved in counselling once their child are diagnosed with hearing loss in order to assist them with their journey of grief and adjustment to the challenges of raising a child with hearing loss.
- Seeing that the process of grief is often a lifelong journey for hearing parents, social workers and health care professionals should be alert as these families may present with emotional problems during any period of the child with hearing loss.

Universities and Research Institutions:

- Closer collaboration should take place between organisations for the deaf and various Universities regarding **curriculum** planning in training of social workers, psychologist, audiologist and paediatricians to deal with the emotional aspect of hearing loss on the family and on the child with the hearing loss.
- Audiology students can be encouraged to develop a tool to access the effectiveness of audiology treatment received especially when counselling parents on the diagnoses of their child's hearing loss. This tool could assist in gauging hearing parents' concerns and possible referral for counselling.

- It is further recommended that a survey be conducted among mothers indicating the desire to have their baby's hearing screened after birth. Early intervention strategies could assist hearing parents in acquiring coping skills from the time of the early diagnose.

Healthcare professionals at hospitals:

- Various provincial, private and children hospitals should be approached and be advised where to refer hearing parents for counselling or with regards to information on deafness.
- It is also recommended that infant screening for high-risk infants with a family history of permanent childhood hearing impairment, or risk indicators such as in-utero infections such as CMV, rubella, Malaria, or HIV or postnatal infections to be tested.
- There should be a policy intervention with regards to newborn screening in South Africa. It is recommended that the proposal becomes a policy or an intervention strategy from the Department of Health that is implemented. The policy should advocate for early hearing detection programmes in all provincial hospitals from birth to the age six as an example.

Department of education:

- Collaborations between parents of the Deaf, organisations for the deaf, and the Department of the Education to take place and to encourage the education curriculum for the Deaf to be on par with mainstream schools.
- The Education Department should consider education in deafness as a specialised field with special curriculum attention given to sign language with all teachers for the deaf being conversant in sign language.
- Educational programmes at mainstream school should be encouraged e.g. life orientation programmes should encourage interaction between hearing schools and schools for the deaf. These programmes will go a long way in dispelling negative attitudes and encourage acceptance of diversity.

5.4 Recommendations to be considered for further studies

- The scope for participants in further research of similar nature needs to include more fathers, as their experiences could differ substantially from those of mothers.
- A study could be undertaken with deaf adults to explore and understand their experiences and dynamics of growing up in a hearing family
- Comparative study could be made with deaf parents raising deaf children, and compare their experiences to those of hearing parents

By employing a qualitative enquiry the goal and objectives have been met in so far as exploring and describing the experiences of hearing parents on the diagnosis of their child's hearing loss are concerned. The researcher is of the opinion that the goal and objectives as set out in this research study having been reached. It has succeeded in exploring and describing the experience of hearing parents regarding their child's hearing loss.

5.6 Conclusion

“Run your fingers through my soul. For once just once, feel exactly what I feel, believe what I believe, perceive as I perceive, look, experience, examine for once; just once understand” –

Gina Watt, parent of a deaf child – Putz (2012:63).

This study presented an opportunity for greater understanding of hearing parents' experiences regarding their child's hearing loss. It allowed for the exploration and description of the thoughts and emotions of hearing parents when they were given their child's diagnosis. It gave hearing parents the opportunity to describe their experiences in caring for a child with a hearing loss, and furthermore explored the needs of hearing parents in terms of the way forward.

For many hearing parents, their response to their child's hearing loss fell within the medical model. This is understandable as the majority of the hearing parents knew nothing about hearing loss, hence their fear and apprehension about the future of their deaf child. The findings showed that grief was a recurring experience for the parents. Various developmental stages or milestones in the child's life could re-trigger emotions of sadness and anger, causing grief to become an integral part of the hearing parents' emotional life. However, it is

especially noteworthy to mention the positive reactions of two hearing parents who, notwithstanding the challenges they faced, embraced their child's hearing loss and sought to empower themselves with information.

This study also indicated the need for healthcare professionals to work hand-in-glove with hearing parents, forming partnerships to the benefit of the child with the hearing loss. This partnership can assist hearing parents to a better understanding of their child's difficulties, and reduce the anxieties felt by the parents.

There is no doubt that the journey experienced by hearing parents was one of endurance, patience, long-suffering, hurt and love. It therefore brings to the fore the need for emotional support and counselling for individual parents, parents as couples, and for the entire family.

However, the journey has revealed hearing parents' tenacity and resilience, and their strength to overcome their adversity.



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INFORMATION SHEET

Project Title: The Experiences of Hearing Parents on the Diagnoses of their Child's Hearing loss.

What is this study about?

This is a research project being conducted by Ronel Davids at the University of the Western Cape. We are inviting you to participate in this research project because you are a hearing parent of a child diagnosed with a hearing loss. The purpose of the research is to explore and describe the experiences of hearing parents on the diagnosis of their child's hearing loss.

What will I be asked to do if I agree to participate?

You will be asked to participate in a one on one interview with the researcher. The research study itself will be conducted during the period 2011 – 2013. The one on one interview will take place in a neutral setting preferable at a location that is comfortable and suits the needs of the participant e.g. the client's home. The researcher will ask the participant one question leading to an informal discussion between the researcher and the participant.

Would my participation in this study be kept confidential?

We will do our best to keep your personal information confidential. To help protect your confidentiality, all data collected will be kept confidential and only the researcher and the participant will have access to the information. Anonymity will be ensured by providing participants with pseudonyms. All data collected will be handled with confidentiality as stipulated in a contract undertaken between researcher and participant. All information will be kept on the computer which only the researcher will have access to.

If we write a report or article about this research project, your identity will be protected to the maximum extent possible.

What are the benefits of this research?

The research may not be designed to help you personally, but the results may help the investigator learn more about hearing parents feelings and experiences after they have being told that their child has being diagnosed with a hearing loss. We hope that in the future, other people might benefit from this study through improved understanding and showing sensitivity towards hearing parents of children with a hearing loss.

What are the risks of this research?

There may be some risk from participating in this research study. Participants might become emotional when describing their feelings. These feelings can range from sadness, powerlessness, guilt, anger, etc. The researcher will abide by her code of ethics as a social worker and employ skills such as empathy, sensitivity, respect, etc.

Do I have to be in this research and may I stop participating at any time?

Your participation in the research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time, you will not be penalized or lose any benefits to which you otherwise qualify. The participant will be informed of their right to withdraw from the research at any time and for any reason.

Is any assistance available if I am negatively affected by participating in this study?

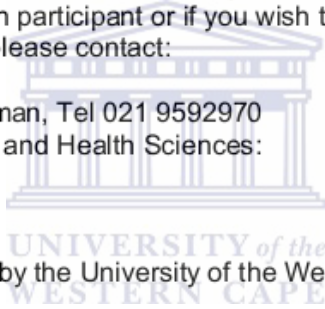
At the end of each interview the researcher will ask the participant to discuss their feelings and whether the interview has assisted them in any way. This will be a form of debriefing after discussing such a sensitive subject. It may be necessary for the researcher to refer participants to suitable professionals for therapeutic counselling.

What if I have questions?

The research is conducted by Ronel Davids from the Department of Social Work at the Department of the Western Cape. If you have any questions about the research study itself, please contact Ronel Davids at 0814709370. Should you have any questions regarding this study and your rights as a research participant or if you wish to report any problems you have experienced related to the study, please contact:

Head of the Department: Dr N Roman, Tel 021 9592970
Dean of the Faculty of Community and Health Sciences:
University of the Western Cape
Private Bag X17
Bellville 7535

This research has been approved by the University of the Western Cape's Senate Research Committee and Ethics Committee.



INFORMED CONSENT

Title of Research Project: The Experiences of Hearing Parents on the Diagnoses of their Child’s Hearing loss.

The study has been described to me in language that I understand. I freely and voluntarily agree to participate in the research as explained to me. My questions about the study have been answered. I understand that my identity will not be disclosed and that I may withdraw from the study without giving a reason at any time and this will not negatively affect me in any way. This research project involves making an audiotape of me. The audiotape will only be used for the purposes of this research.

_____ I agree to be audiotaped during my participation in this study.

_____ I agree to be audiotaped during my participation in this study.

Participant’s name.....

Participant’s signature.....

Witness.....

Date.....

Should you have any questions regarding this study or wish to report any problems you have experienced related to the study, please contact the study coordinator:

Study Coordinator’s Name: Dr M de Jager

University of the Western Cape

Private Bag X17, Belville 7535

Telephone: (021)959-3674

Cell: 083 3062599 Fax: (021)959-2845

Email: mdejager@uwc.ac.za



CONSENT FORM

Title of Research Project: The Experiences of Hearing Parents on the Diagnoses of their Child's Hearing loss.

The study has been described to me in language that I understand and I freely and voluntarily agree to participate. My questions about the study have been answered. I understand that my identity will not be disclosed and that I may withdraw from the study without giving a reason at any time and this will not negatively affect me in any way.

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Participant's signature.....

Witness.....

Date.....



Should you have any questions regarding this study or wish to report any problems you have experienced related to the study, please contact the study coordinator:

Study Coordinator's Name: Dr M de Jager

University of the Western Cape

Private Bag X17, Belville 7535

Telephone: (021)959-3674

Cell: 083 3062599 Fax: (021)959-2845

Email: mdejager@uwc.ac.za

The Administrator

Deaf Community of Cape Town

Gordon Road, Heathfield

Cape Town

Dear Ms F. Adams

RE: Permission to conduct a research study with the hearing parent group at your office.

I hereby formally request permission to conduct a research study into “the experiences of hearing parents regarding their deaf child’s hearing loss” as part of my Masters studies at the University of the Western Cape. Please find attach a copy of my research proposal as discussed with you.

This research study has being cleared by the University’s Ethics Committee. Should you need any further clarification on the matter, please feel free to contact myself or my study supervisor, Dr Mariana De Jager of the University of the Western Cape, telephone (021) 959-3696, fax: (021) 959-24670, email: mdjager@uwc.ac.za

Your assistance with regards to this study will be highly appreciated.

Kind regards

Mrs Ronel Davids

(M.A. Student)

Date: _____