



Caregivers' Experiences of the Diagnosis of Hearing Loss

by

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RHRELF001

*Submitted to the University of Cape Town in fulfilment of the requirements for a
Masters Full Dissertation*

MSc Audiology

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ACKNOWLEDGEMENTS

This study would not have been possible without the support I have received over the last four years. It touched my heart, mind and soul and challenged every fibre of my professional as well as personal life. This research study was juxtaposed to my life in so many ways and the parents' stories took me on a roller-coaster of emotions with them.

So let me start by saying thank you to the parents who shared such intimate, personal, life-changing and important stories with me. This study is in honour of you. May your voices be heard and may our profession grow in understanding of your experiences and know how to serve you better in the future. Thank you also to the schools and institutions that put me into contact with these amazing and brave parents.

I would also like to thank my supervisors, co-author and mentors. You are an inspiration. Your guidance and especially your patience are unparalleled! Dunay, the smartest woman I know, thank you for being the inspiration and motivation that kept me going when I did not think I could carry on any more. For welcoming me into your life and going on this journey with me and being so concerned for me not just as a researcher, but also a friend. Harsha, thank you for your advice and encouragement and immense insight, illuminating so many things that were yet uncharted territory to me. For your patience and guidance that helped shape this study into what it is now. It was an honour!

To my husband; for sticking it through with me and helping me in those dark hours when I wanted to quit; for checking, proof-reading, becoming a reference guru and making sure I got it done! To my family for your gentle enquiry and excitement at every hurdle passed. To my peer-reviewers, interpreter, editor and colleagues who have supported me throughout this time; to my bosses and head of department giving me time off and asking with genuine interest what the project is about.

CAREGIVERS' EXPERIENCES OF THE DIAGNOSIS OF HEARING LOSS

To the Lord God Almighty, thank you for reminding me that in the end it is all for You.
Thank you Jesus for making me realise and understand again and again that we all have a purpose and everything that happens with us can be turned to good.

ABSTRACT

Knowledge of the impact of a diagnosis of hearing loss in children on their caregivers and the nature of their relationships with professionals during this process is inadequate in South Africa. The purpose of this study was to understand the experiences and perceptions of caregivers of diagnosis of hearing loss in their children. A qualitative, retrospective, narrative inquiry research design was used. Participants who were purposefully selected included one couple and 12 caregivers in the Tshwane Metropolitan area. They were interviewed using an in-depth interview method. The narrative data was subjected to in-depth thematic analysis. Three themes emerged from the data: 1) The catastrophic emotional impact of diagnosis, 2) The good and the bad of professional interaction, 3) Imbalanced relationships, strained resources and resulting identity threats. The discussion focused on the deeply emotional nature of the participants' experiences and the changes that ensued during and following the diagnosis of hearing loss in their relationship with their child and the wider community and how this impacted on their sense of identity. The study concluded that diagnosis has extensive, pervasive and disruptive effects on caregivers and that the professional plays an important role in shaping that experience. It thus makes recommendations for a humanistic, family-centred, paediatric audiology practice.

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CHAPTER ONE

INTRODUCTION AND RATIONALE

1.1 Overview of the Chapter

This chapter begins with an orientation to the study followed by the rationale, the study context and the aims of the study. An overview of the chapters is then presented followed by definitions of key terms and abbreviations used in the study.

1.2 Focus and rationale for the study

The study focuses on caregivers' experiences of the diagnosis of their child's hearing loss. To orientate the reader, the study rationale is provided which explains why the study focuses on hearing loss as a disability. The type of hearing loss in children, globally and in South Africa (SA) is also described. Thereafter, the context of the study is provided and the research question and aims are provided.

1.2.1 Hearing loss and its implications.

“Disabling” hearing loss, defined by the World Health Organisation (WHO) as more than 30 dB in children over the frequencies of 0.5, 1, and 2 kilohertz (WHO, 2013), is the most frequent birth disorder in the world (Olusanya, Neumann & Saunders, 2014). In 2009 Swanepoel, Störbeck and Friedland estimated that approximately 2000 babies are born worldwide every day with permanent, bilateral severe-to-profound hearing loss. This statistic does not even take into account other types of hearing loss such as transient conductive (e.g. due to otitis media), medical (e.g. meningitis), permanent conductive (e.g. due to middle ear malformations) or mild-to-moderate or unilateral sensory-neural hearing loss (Swanepoel et.al., 2009). Audiological management of these types of hearing loss vary with regard to amplification and further intervention. This study however, garnered participants whose

children would be categorised as having a permanent, bilateral severe-to-profound, “disabling” hearing loss. In South Africa, which has a population of 54 002 000 (Statistics South Africa, 2012) as many as 17 babies are born daily with congenital/early-onset infant hearing loss (Swanepoel et.al, 2009).

The impact of permanent, bilateral severe-to-profound hearing loss on communication has long-lasting and far-reaching effects on and implications for on an individual’s life (Tomblin, Oleson, Ambrose, Wallker & Moeller, 2014; Olusanya et al. 2014). Hearing loss during infancy and early childhood contributes to the poor acquisition and development of effective communication skills as it restricts the child’s access to speech and language input (Tomblin et al., 2014; Le Roux, Swanepoel, Louw, Vinck & Tshifularo, 2015). Communication skills remain the greatest predictor of future academic success (Rosetti, 2001) and thus it is no surprise that children affected at a young age by a disabling hearing impairment may be subject to limited educational attainment and thus limited vocational options in adulthood (Jacobs, Brown & Paatch, 2012; Venail, Vieu, Mondain & Uziel, 2009; Bowe, McMahon, Chang & Louvi, 2005; Bowe, 2004; Capella, 2003). This problem is further exacerbated by the financial cost to the child and family of managing the disability. It also poses a cost to wider society, due to the fact that there is a considerable cost to the state to accommodate people with a disability who are not financially independent (Mohr, Feldman, Dunbar, McConkey-Robbins, Niparko, Rittenhouse & Skinner, 2000). These costs to families and societies are even higher in developing countries, especially in light of profound sensory-neural hearing loss often being managed with expensive cochlear implant (CI) amplification that are not state funded (Saunders & Barrs, 2011).

To counter this high cost to the state most developed countries have implemented Universal Newborn Hearing Screening (UNHS) as a standard hearing screening procedure with objective electrophysiological measures so as to create an opportunity to identify infants

suffering from congenital/early hearing loss within the first months of their life (Olusanya, Wirz & Luxon, 2008). Children who have been identified have the opportunity to keep up with the speech and language development of their normal hearing peers up until 3 years of age, thereby creating the foundation for further learning (Fulcher, Purcell, Baker & Munro, 2012; Moeller, 2000; Yoshinago-Itano & Sedey, 1999). Therefore, UNHS is seeing greater support in developing countries as well (Olusanya et al., 2008). Thus, evidence based protocols (Yoshinago-Itano, 2004), implemented by professional or state bodies, are eliminating parental suspicion of hearing loss and thus provide caregivers with life-changing information that they did not expect very early in their child's life (Luterman, 2002).

To summarise, hearing loss as a “disability” can be characterised as unique from other disabilities in young children: it is both invisible, and being identified early. From the point of diagnosis it holds drastic consequences for communication which consequently affect a child's whole life from that point onwards in terms of education, vocation and socialisation.

1.2.2 Caregivers experience of the diagnostic process.

Having introduced the complicated playing field of children with hearing loss and their families attention is now drawn to the first step in the long and winding road of managing the hearing loss: the hearing assessment (Meinzen-Derr, Lim, Choo, Buyniski & Wiley, 2008). Considering the multi-faceted and far-reaching implications of the diagnosis of congenital/early-onset, severe-to-profound hearing loss, caregivers are confronted with difficult decisions as well as questions about possible management of their child's hearing loss and what implications that may have for them and their own lives.

It is thus no surprise that the impact of this news of diagnosis on caregivers is often described as “parental stress” and has received some attention in the literature (Hintermair, 2004; Hintermair, 2006; Lederberg & Golbach, 2002; Meadow-Orlans, 1994; Meadow-

Orlans, Dyssegaard & Smith-Gray, 1995; Pipp-Siegel, Yoshinago-Itano & Sedey, 2002; Meizen-Derr, Lim, Choo, Buyniski & Wiley, 2008). The time of diagnosis is reported to be a particularly stressful time for parents of children who are deaf/hard of hearing, regardless of the age of diagnosis (Meizen-Derr et al., 2008).

In the diagnostic assessment process the outer, middle and inner ear are tested. After testing the diagnostic process includes giving by feedback to the client/caregiver and making further referrals (Northern & Down, 2002). In this process caregivers typically engage with professionals, particularly the audiologist, who determines and conveys the diagnosis. This study seeks to understand how caregivers relate to professionals, especially the audiologist. Finally the study examines the personal impact of the diagnosis on the caregiver.

1.2.3 Study Rationale.

Caregivers of children who were diagnosed with severe to profound hearing impairment experience a life changing event at the point of diagnosis (Burger, Spahn, Richter, Eissele, Lohle & Bengel, 2005). Thus, it is important to lend an ear to their experience as told from their perspective, since client-centred care, which is the audiologists' professional role and responsibility, only works if clients' needs are addressed. Thus in order to remain professional, the audiologist needs to be aware of the various social and psychological factors as well as the socio-economic, political and cultural background of clients that impact on their perceptions, expectations and consequent behaviour (Naudé & Bornman, 2014).

There is literature describing how caregivers and patients/clients experience other disabilities including physical disabilities (Graungaard & Skov, 2006; Kruijzen-Terpstra, Ketelaar, Boeije, Jongmans, Gorter, Verheijden, Lindeman & Verschuren, 2013), other communication disabilities (Keenan, Dillenburger, Doherty, Byrne & Gallhager, 2010;

Mitchell & Holdt, 2014; Chamak & Bonniau, 2013; Andersson, Miniscalco, Gillberg, 2014; Strunk, Pickler, McCain, Ameringer & Myers, 2014; Moodie-Dyer, Joyce, Anderson-Butcher & Hoffman, 2014; Coogle, Guerette & Hanline, 2013; Hayes & Watson, 2013), as well as life-threatening illnesses such as cancer (McGavin, 2013). But hearing loss is unlike other disabilities. It is invisible, can manifest early and has a far-reaching effect on an essential, functional component of life - communication.

During the diagnostic process the audiologist does a case interview, clinical observation of the client, as well as technical testing and protocols which might include ABR and ASSR. These are part of the test battery to help describe hearing with a great amount of detail (Hall, 2010; HPCSA, 2007; Mount Sinai Hospital, 2005; Northern & Down, 2002; Hall & Mueller, 1997). This process requires technical skills and advanced training (Swanepoel, 2006). Yet, despite technological advances and re-conceptualised intervention approaches, which include early identification of hearing loss through UNHS, one thing has remained constant: the need to support caregivers through the difficult and emotional journey of dealing with the diagnosis of their child's hearing loss (Kurtzer-White & Luterman, 2001).

Audiological support in sharing the diagnosis with the caregiver usually takes the form of informational- and personal adjustment counselling (Hodgson, 1994 and Kricos, 2000 in Margolis, 2004). Both are necessary as information counselling presents the patient and his/her family with relevant information to understand the disorder and consequently take the necessary steps to manage it. Personal adjustment counselling aids the individual to deal with the psychological implications of the news (Margolis, 2004), so as to take ownership of the problem and bring about change (English, 2009). Thus, the solution to implementing correct principles for breaking the news of hearing loss seems to lie in personal adjustment counselling. However, for it to be successful, understanding the caregivers' diagnostic

experience and the emotional responses to the diagnosis of hearing loss is critical (Meizen-Derr et al., 2008).

Although parents may encounter and interact with other professionals on their journey to diagnosis; such as ENT's, paediatricians and other medical general practitioners, the audiologist remains a key role player in conveying and describing the hearing loss in a child. This professional position and knowledge raises concern as it raises the questions whether technological ability in diagnosis has out-paced the clinician's ability to plan and implement appropriate counselling for parents or caregivers to enable them to ask searching questions and come to grips with the implications of the diagnosis (Kurtzer-White & Luterman, 2001). Perhaps because training programmes are required to provide education and practical experience in the implementation of test batteries, the emphasis of training is on clinical skill and the interface with the equipment rather than on the ability to communicate the results in a sensitive manner (English, 2008). Audiologists thus carry a larger responsibility as they enter a potential downside of early diagnosis where a new and increased demand is created for technical expertise and consequently lesser emphasis is placed on counselling (English, Naeve-Velguth, Rall, Uyehara-Isono & Pittman, 2007). Therefore if audiologists are trying to improve practice in this area one way to achieve this is to have a close understanding of how caregivers experience this process (Wever, 2002).

A recent study from the University of Kwa-Zulu Natal (Ratanjee, 2014) looked at perceptions of audiologists (mostly in the private sector) of skills in the area of counselling adult patients who need amplification. From this study it emerged that conscious advancements have been made to counsel patients with hearing loss. All the participating audiologists agreed that counselling promotes successful intervention outcomes and better hearing aid use. However the study also concluded that most participants spent the majority of time giving counselling in terms of information and not in terms of providing assistance

for patients to come to terms with the diagnosis and how to live with hearing aids. It was argued that audiologists might lack confidence and skill in counselling or have inadequate time to provide this service. All participants rated their counselling skills high, especially for information counselling, but the majority of participants indicated a need for more training to improve their counselling skills. The study thus highlights the need to focus more on counselling in the curricula as well as in supervision in the clinical training of students of audiology to enable them to meet their patients on a more personal and emotional level (Ratanjee, 2014).

These emotional experiences of caregivers specifically have most commonly been described as grief and loss in the literature (Clark & English, 2004). Hewson (1997) argues that previous “grief work” has assumed and applied concepts of grieving to children with “loss of ability” without the necessary empirical verification. Thus, theory is appropriated and applied from generalist studies. But, what is needed is to deepen our understanding of how caregivers experience specific conditions like hearing loss. Although possible new directions in grief work have been explored with adjustments being made to grieving models to suit personal-adjustment counselling, as evidenced by a lecture given by English in 2008 (Luterman, Kurtzer-White & Seewald, 1999), audiologists (including English, 2008) commonly revert to an old and unwieldy “death and dying” theory from a medical model (Kübler-Ross, 1969). This model includes five steps: denial, anger, bargaining, depression and acceptance (Luterman, 2002). The “new” grieving model suggested by English (2008), shows new directions in counseling with “how to” tips emerging to guide paediatric audiologists in counseling parents and caregivers (Pichler, 2008). These suggestions include presenting the information to the parents at two levels below their reading level, using familiar terminology, keeping sentences short etc. (Pichler, 2008). However, these guidelines relate to information counselling and not to personal adjustment counselling.

Further, the development of guidelines for personal adjustment counselling took nine years from the time it was first suggested by Campbell in 1998 (as cited in Luterman, 2002). However, these guidelines were not developed from research done on the emotional reactions specific to the audiologic field, but rather from a study where female participants were asked to put themselves in the shoes of a patient diagnosed with breast cancer (Mast, Kindlimann & Langewitz, 2005), a diagnosis significantly different to that of infant/child severe-to-profound hearing loss. Thus, personal adjustment counselling has made use of theories that have been applied without much thought for the context, even though one cannot simply transfer knowledge from contexts as this knowledge may not be applicable. To further complicate matters, the South African context in which this study is conducted is even more unique.

South Africa is a diverse country often described as the “Rainbow Nation” with 11 official languages and their cultural groups to match (Swanepoel, 2006). The audiologist in South Africa thus has to deliver services in a multiracial, multilingual, and multicultural context meeting diverse and challenging needs, also within the paediatric population (Swanepoel, 2006). There is also cultural diversity in the perception of hearing loss; for example, Swanepoel’s (2006) study reported that African families tend to be more fatalistic and so are more passive about hearing loss. Research on emotional responses to diagnosis has been done mainly in Western (European and American) countries. Therefore caregivers in SA are likely to exhibit a much wider range of different responses to diagnosis. But this diversity might enrich professional practice if understood properly.

In light of this diversity the role that caregivers’ play in the life of their disabled child or grandchild and how that role is shaped by the disability is important. Literature has shown how caregivers’ roles and identities change and are threatened when faced with disability (Woodbridge, Buys & Miller, 2011; Landsman, 1998). South Africa’s diverse cultural and

societal context creates an even more complex situation for counselling as caregivers are coming to terms with the diagnosis of hearing loss (Landsman, 1998).

This experiential study therefore focuses on the South African caregivers' experience of diagnosis as this will provide insight on their expectations of treatment and desires for management of their child's hearing loss, thereby making them partners in the diagnostic process to achieve more realistic, sustainable and successful outcomes of intervention (Clark, 2014). Audiologists are key role players in service provision, especially at the point of diagnosis where decisions are also made regarding the further management of the child and his/her hearing loss. This study thus aims to engage with this important issue at the beginning of the journey with the most important role players - the caregivers -and listen to their stories and personal accounts of the diagnosis of hearing loss in their child. The researcher listened to caregivers and heard, in their own words on a very personal level, what they recalled to be the essence of this experience.

1.3 Study Context

The researcher targeted geographically accessible institutions and programmes in the City of Tshwane. The Tshwane Metropolitan Municipality lies within the north-western part of the Gauteng province, South Africa, as depicted in the figure below. Gauteng is one of nine provinces in South Africa and although the smallest province with a land size constituting only 1,4% of the total country's size, it is the hub of RSA's economy, contributing to one third of the national economic growth (Gauteng Provincial Government, 2011).

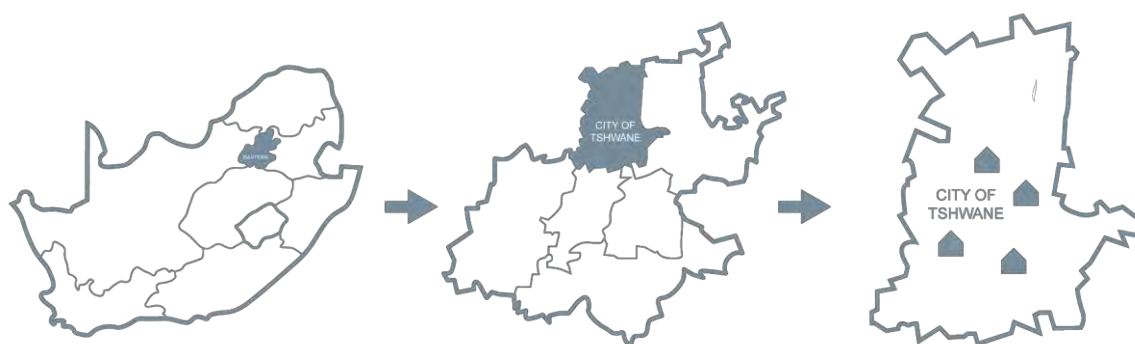


Figure 1: Images of South Africa, Gauteng Province and the City of Tshwane (as adapted from www.geda.co.za and <http://mappery.com>, 2011)

Although being the nation's economic hub, the economic situation of the public varies largely depending on the specific area in the region they live in. There is actually a large proportion of the total population of 2 553 648 who are uneducated and unemployed. The unemployment rate is at 24.2% with youth unemployment at 32.6%, and the poverty rate at 27.86%. Only 34.2% of people have Grade 12 schooling as their highest level of education (Tshwane General and Regional Overview, 2013). The participants in this study were residing in or were from the vicinity of the following Tshwane Metropolitan Municipality areas: Mamelodi, Centurion, Queenswood (Pretoria), Jan Niemand Park (Pretoria), Eersterust (Pretoria), Atteridgeville, Soshanguve, Hammanskraal, Brits, Kwaggasrand (Pretoria).

The size and diversity of Tshwane Metropolitan Municipality is unique in that it comprises urban, rural and industrial areas each with their own challenges and characteristics. These areas are further divided into regions: region 1 (north-west), region 2 (central northern), region 3 (central), region 4 (south-west), region 5 (north-east), region 6 (south-east), and region 7 (east). Wealth and good basic service delivery is mainly concentrated in the southern and south-eastern regions, with the eastern and northern parts having some access to services (Tshwane Regional and General Overview, 2013). In the 2011 national census there were about 2,921,500 people living in the Tshwane Metropolitan area. The

following ethnicities were presented in that sample (Statistics South Africa, 2012): Black African, White, Coloured as well as Indian though a great majority of people are part of the Black African ethnic group.

The number of official languages in South Africa amount to 11 different languages. The languages from most to least spoken as depicted by the 2011 national census are Sepedi, Afrikaans, Setswana, Xitsonga, English, isiZulu, isiNdebele, Sesotho, Other, Tshivenda, isiXhosa, SiSwati and Sign Language (Statistics South Africa, 2012). Thus the researcher included participants who spoke various languages spoken in the Tshwane region including : Afrikaans, English, Zulu, Sepedi and seTswana, as well as South African Sign Language (SASL).

The audiologist in South Africa, and especially in the Tshwane Metropolitan Municipality, has to deliver services in a socio-economically diverse, multiracial, multilingual, and multicultural context meeting different and challenging needs, especially within the paediatric population (Swanepoel, 2006). These services are delivered in contexts where cultural groups and races are in very close proximity to each other, as 12.3 million people live in Gauteng (Statistics South Africa 2012).

Audiology services are located in regions 2, 3, 5 and 7 of the Tshwane Metropolitan Area, making them accessible to most of the population. The regions with the least access would be regions 1 and 6 due to travelling costs and time. These service facilities sites are diverse in terms of ethnicity, language (including spoken language such as English, Afrikaans and seTswana, as well SASL), communication modes, state versus private schools, and inclusive versus exclusive schools. A description of each school is listed in Appendix Bb for further reference.

1.4 Overview of Chapters

In Chapter 2 the historical and theoretical concepts underpinning the study are discussed. The literature review covers the topics of childhood illness, disability and specifically studies on hearing impairment in the experience of caregivers. Chapter 3 presents the methodology of the study. The rationale for a qualitative design study is explained and the sampling method, data collection procedures, data analysis and ethical considerations are discussed. Chapter 4 discusses the results of the study and is divided into three themes. In Chapter 5 the results of this study are discussed and then related to the literature. In Chapter 6 the conclusion of the study is presented in relation to the aims followed by an analysis of its strengths, limitations and implications for further research and clinical practice.

1.5 Definitions of Key Terms

The following definitions apply to this study:

Auditory Evoked Potentials (AEP):

These are the changes in nerve and brain electrical activity in response to sound, i.e. an electroencephalogram (EEG). A sample of the fluctuations caused by the presentation of sound in the ear can be recorded by a computer which averages out the overall small fluctuations of EEG response to sound. These EEG fluctuations can then be seen as a series of waves or peaks defined by their amplitude as a function of time after the sound stimulus was introduced. A computer is used to process the incoming fluctuating EEG to determine hearing thresholds. The Auditory Brainstem Response (ABR) and Auditory Steady-State Response (ASSR) are two such tests done on small babies or other patients who are unable to do behavioural audiological testing (Cone-Wesson, 2003).

Autism Spectrum Disorder (ASD):

This is an umbrella term used to describe disorders which affect a person's ability to communicate and interact socially with other people as well as their ability to make sense of the world around them (AFA, 2012).

Cochlear Implant (CI):

This is a medical device that allows people with hearing loss to hear better (AdvancedBionics, 2014).

Congenital or early-onset, pre-lingual, permanent, bilateral, severe-to-profound sensory-neural hearing loss:

Upon receiving a hearing diagnosis this would be the description of the type, degree and symmetry of a hearing loss. Congenital refers to the hearing loss being from birth, whereas early-onset means that the hearing loss presented itself shortly after birth (ASHA, 2015). Pre-lingual means that the onset of hearing loss occurred before any language has been able to develop (ASHA, 2015) Bilateral refers to the symmetry meaning that both ears are presenting with a hearing loss and severe-to-profound describes the degree of the hearing loss to be 56 to 91+ dB (ASHA, 2015). Sensory-neural describes the nature of the hearing loss where there is damage to the inner ear; the cochlea and/or the nerve pathways from the inner ear to the brain. Permanent refers to the fact that the hearing loss cannot be medically or surgically corrected (ASHA, 2015).

deaf:

This refers to the physiological state of being deaf and refers to people who are deaf, but not part of Deaf culture (ASHA, 2015).

Deaf:

This refers to the culture that is formed among Deaf people who group themselves into this category mainly due to their language use (ASHA, 2015). It is capitalised much in the same way as “South African” is.

Diagnosis:

Diagnosis in this context refers to the point in time where the hearing loss in the child is identified and labelled.

dB:

Decibel. Unit expressing the intensity of sound.

Experience:

This study rests on the participants' experience with hearing loss in their child. Experience provides someone with first-hand, actual observation and practical acquaintance with an event. From this event subsequent knowledge is obtained from that observational encounter to provide certain life truths and meaning to that person. This qualitative experiential study seeks to uncover that experiential knowledge which in itself is the mechanism for attaching meaning to the lived encounter of diagnosis of hearing loss in their child (Frank 1998;Kathard, 2001).

Hearing Loss:

A hearing disorder is the result of impaired auditory sensitivity of the physiological auditory system. A hearing disorder may limit the development, comprehension, production, and/or maintenance of speech and/or language. Hearing disorders are classified according to difficulties in detection, recognition, discrimination, comprehension, and perception of auditory information. Individuals with hearing impairment may be described as deaf or hard of hearing (direct quote taken from ASHA, 2015)

International Classification of Functioning (ICF):

The International Classification of Functioning (ICF), disability and general health is a classification system of health and health-related entities. It is the WHO's means by which to measure health and disability and is used as the international standard to describe and measure health and disability. As the functioning of an individual is affected by his/her context the framework also includes a list of factors from the environment (WHO, 2001).

Narrative Inquiry:

Narrative inquiry was the design of choice for this study as it argues that how we make sense of our world is through stories and where telling stories is how we naturally experience and tell of our experiences in our lives (Clandinin & Connelly, 2000). Therefore, telling one's own story is an efficient way of accessing experiences.

Parent/Caregiver:

A caregiver is widely understood to be someone who cares for another person, paid or unpaid, family or not, and who tends to the basic or medical needs of another. A parent is a person who has begotten or borne offspring; i.e. a biological mother or father. This study's participant selection made no distinction between these two classifications as long as the person caring for the child at the time of the study was present at the diagnosis of hearing loss. However, seeing that all participants were the biological parents of the children, these two terms are used interchangeably in the study.

Practitioner-Client/Patient Relationship:

This term was coined by Pillay (2003) who refers to a clinical moment in which the practitioner, in this case the audiologist, and the patient, in this case the caregiver of

the child, enter into an unspoken liaison and relationship that holds consequences for further management of the child's hearing loss.

South Africa (SA):

The Democratic Republic of South Africa is the southernmost country of the continent of Africa. It is comprised of 9 provinces with 11 official languages with diverse ethnicities and cultures. It is often referred to as the Rainbow Nation and celebrates 20 years of freedom in 2014 and equal rights since the Apartheid Regime ended in 1994 (Swanepoel, 2006).

South African Sign Language (SASL):

This is the manual form of communication predominantly used and taught for those individuals who are deaf and part of the Deaf community of South Africa (DEAFSA, 2013).

World Health Organisation (WHO):

WHO is the directing and coordinating authority for health within the United Nations system. It is responsible for providing leadership on global health matters, shaping the health research agenda, setting norms and standards, articulating evidence-based policy options, providing technical support to countries and monitoring and assessing health trends (WHO, 2015).

CHAPTER TWO

LITERATURE REVIEW

2.1 Overview of the Chapter

This chapter provides the theoretical concepts and literature review informing the analysis of how caregivers experience the diagnostic process for hearing impairment in young children. The topics include a discussion of: The nature of the diagnostic process; when the diagnosis usually occurs in a child's life, especially in South Africa; and how the process and interaction unfolds in the client-clinician relationship.

It highlights the importance of the specific experience of receiving the diagnosis and why that is important; the nature of the diagnostic process being life-changing and the importance of caregivers being encouraged to tell it from their perspective. The researcher then reviews literature pertaining to parental experience of hearing impairment, other communication and physical disabilities as well as experiences with child illness. This review paints a picture of where the audiological profession is in terms of understanding the parents' perspective.

Literature searches consisted of peer-reviewed articles cited in MEDLINE, CINAHL, ERIC, EconLit, MasterFILE Premier, E-Journals, Africa-Wide Information, Health Source – Consumer Edition, Health Source: Nursing/Academic Edition, Humanities International Complete, MasterFILE Premier, PsycINFO, PsycARTICLES, ScieinceDirect and Academic Search Premier electronic databases.

2.2 Theoretical Concepts

2.2.1 The diagnostic process.

This study is about how caregivers experience the diagnostic process for hearing impairment in their child. Therefore a description of the diagnostic process is warranted to situate the particular point in the process that this study focuses on. There are many different aspects to the diagnostic process. The diagnostic protocols for identifying and describing hearing loss in infants and children have slight differences depending on age and are designed to promote uniform and evidence-based intervention and management with the clients' best interest at heart (HPCSA, 2007; American Academy of Audiology, 2003). These procedures require specialised skills and training to be executed, especially if a child needs to be referred for further electrophysiological measurements to measure their Auditory Evoked Potentials (AEP) through Auditory Brainstem Response (ABR) or Auditory Steady-State Response (ASSR). Audiologists in South Africa are trained at a tertiary institution for four years to be able to do so and often require additional training to be able to execute these AEP testing procedures accurately (Swanepoel, 2006). The diagnostic procedure generally involves the following test batteries (test batteries are important for cross-reference purposes):

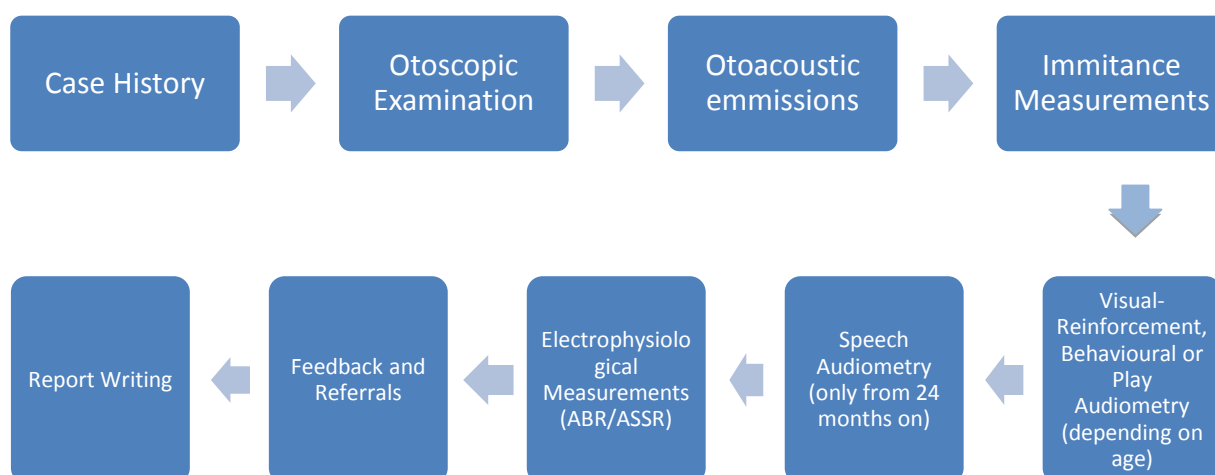


Figure 2: Paediatric Diagnostic Protocol (Northern & Downs, 2002)

The focus of this study was at the point of 'feedback and referrals' where the diagnostic information is shared with the caregiver of the child. According to a recent study by Le Roux et al. (2015) the diagnostic information is received by caregivers in South Africa at an average age of the child of 15.3 months, with a gap of 5.3 months between suspicion of hearing loss and the diagnostic testing. Diagnosis is generally made due to parental suspicion since UNHS, although reported to be implemented more frequently, is not yet wide-spread in South Africa and only 10% of the 1 million babies born every year will automatically be screened for hearing impairment (Le Roux et al., 2015). Thus the caregivers' journey with hearing loss often starts much sooner than the actual diagnosis, as their suspicions lead them to visits to the general practitioner, paediatrician and/or ENT. There are often numerous professionals that caregivers will interact with prior to and during the diagnostic process as was the case in this research study.

At the point of feedback and referral the audiologist steps into the role of news giver as well as inevitably counsellor, since the caregiver up to that point mostly only guessed at possible problems and experiences severe stress when the diagnosis is confirmed (Gilbey, 2010). This has implications for the practitioner-client relationship. With stress levels and emotions running high the relationship between practitioner and client becomes critical as their intake and recall of information can be hampered (Watermeyer, Kanji & Cohen, 2012). Clinicians can either empower or hinder the parents' capability to deal with the diagnosis in their child and thus has a great influence on future outcomes of intervention (Clark, 2014; Naudé & Bornman, 2014; Leach, 2005).

Stress alone, however serious, is not the only factor influencing the resulting relationship between clinician and client or the possibility of further successful intervention outcomes. The relationship is further complicated by the fact that the diagnosis of hearing loss has been documented to negatively impact on the quality of life in parents of children

with speech and hearing impairments (Aras, Stevenovic, Vlahovic, Stevanovic, Kolaric & Kondic, 2014). The stress that the diagnosis brings is well documented in literature (Hintermair, 2004; Hintermair, 2006; Lederberg & Golbach, 2002; Meadow-Orlans, 1994; Meadow-Orlans et al., 1995; Pipp-Siegel, Yoshinago-Itano & Sedey, 2002; Meinzen-Derr, Lim, Choo, Buyniski & Wiley, 2008), but Aras et al. (2014) also emphasises the far-reaching consequences the diagnosis of hearing loss has on the quality of life of parents. It additionally singles out hearing loss to have the greatest effect on quality of life as all five health domains to contribute to health related quality of life are affected.

2.2.2 Counselling in audiology.

Thus it is widely acknowledged that counselling is an essential dimension of professional service delivery, but the most effective ways of practically implementing it is still elusive. To counter the possibility of delayed intervention success and harm to the emotional well-being of the client the audiologists engage in information and personal-adjustment counselling (English, 2009; Hodgson, 1994 and Kricos, 2000 in Margolis, 2004). However, the literature reveals that what the audiologist actually does is mostly focussed on informational counselling (Watermeyer et al., 2012; Ratanjee, 2014) or on adult adjustment counselling to wear hearing aids (LD DiLollo, A DiLollo, Mendel, English & McCarthy, 2006; Ratanjee, 2014). Little is known about what personal adjustment counselling implies and practically looks like at the moment of giving feedback to caregivers on the diagnosis of hearing loss in their children, from the caregivers' perspective.

To clarify what audiological counselling entails: informational counselling is described as the giving of information, as well as expert instruction and guidance on hearing loss, the technology available for amplification and other services available to the client regarding the ear as a hearing organ (Tye-Murray, 2009). Ratanjee (2014) reports that audiologists feel well-equipped to give such information and also spend more time on this as

supposed to other forms of personal adjustment counselling. Personal adjustment counselling considers the emotions and identity of the client, thus delving more into more psychological make-up of the client to enable the client to come to terms with and accept the hearing loss and the reality of the disability through repositioning and adjusting values and priorities to continue to lead fulfilled and productive lives (Tye-Murray, 2009).

In Ratanjee's study (2014) South African audiologists rated their counselling skills to be high (mostly informational counselling), yet still felt a need for training. This hints at the difficulty that personal adjustment counselling poses for clinicians. This correlates with the findings from Grenness, Hickson, Laplante-Lévesque, Meyer & Davidson's (2015) study that states that audiologists in Australia serving the geriatric population missed all the initial opportunities to build rapport. The patients' psycho-emotional concerns were mostly not acknowledged or addressed. The audiologists' utterances during the conversation were dominant and mostly related to information counselling. Shared decision-making hardly occurred and thus patient involvement hardly occurred. When there was time however for patient input during diagnosis and discussion of management greater success and satisfaction was experienced by patients (Grenness et al., 2015). Both studies recommended further examination on audiologists' communication styles on intervention outcomes, as well as an appeal for a more patient-centred audiological rehabilitation practice.

Those who have devoted themselves to improving practice in terms both of training audiology students and developing tools for personal adjustment counselling in practice, especially among families, have built their knowledge on dealing with caregivers' "stress" (as described in literature) on an old and insufficiently contextualised medical model of grief and dying (English, 2008). In the literature there is however still a lack of information despite English's 2007) work on developing an Audiological Counselling Evaluation (ACE) tool

dearth. This tool was developed to address and improve the applicable training of students on the psycho-emotional areas of hearing loss for parents with young children.

This poses the question why there is a lack of interest in or dearth of information on personal adjustment counselling in particular in the field of audiology, i.e. the emotional and identity challenges that the news of hearing loss holds for adult clients as well as caregivers of young children who are diagnosed with hearing loss. One possible explanation emerges when one considers the way that the relationship between practitioner and client tends to be understood.

Naudé and Bornman (2014) in their review of publication over a period spanning 30 years to analyse literature regarding ethics in audiology, emphasise this dearth of information in clients' emotional needs even though the importance of the clients' view was highlighted as this perspective adds a critical dimension which can assist professionals in understanding the needs of their clients. As Naudé and Bornman's (2014) review indicates, there has been an attempt at moving away from the medical model, where the patient is seen to receive medical care, to a client with autonomy to decide the management of their health with the professional. However, as the literature review by Naude & Bornman (2014) highlights, the very terms used from "patient" to "client", indicate that there is still a problem with the positioning of the professional vis-a-vis the client as the person generating revenue to make a profit (Naudé & Bornman, 2014); i.e. the clinician is the person with power who because he/she receives money for services and is obliged to deliver a service that the professional is in control of and asks money for - not as a partner who has a voice to decide management options for themselves.

2.2.3 Client- and family-centred counselling and intervention

Although the study by Naudé & Bornman (2014) relates to adults receiving services within the field of audiology, it points to the professional practice paradigm into which the clinician finds him/herself immersed. As Pillay (2003) has argued, at the heart of the practitioner-patient relationship still lies a dualistic interaction of power. The speech-language practitioner/audiologist is positioned as the “powerful expert” and the patient as the “sick person” needing help. The audiologist claims this position of power as his/her identity as the profession is still influenced by the medical model and its rituals of empirical practice (Pillay, 1997).

In 2000 already, Kricos in Alpiner and McCarthy emphasise the move away from passive parental involvement, complying with the professional's recommendations, to parents being consulted about intervention goals for their child, to parental empowerment where goals are guided by their input. Yet, this “expert vs sick person” power dynamic is still highlighted in a study in 2014 by Grennes et al. that argue that patient-centred care and parent empowerment has not been well implemented in the field of adult rehabilitation in audiology. Grennes et al.'s (2014) study argues that although practitioner-centred care was born out of good intentions its focus is on the patient/client as a passive recipient of treatment options. It is criticised to be paternalistic. Although there has been a move away from practitioner-centred care and a more holistic approach is advocated since the 1970's, it has not seen great support in rehabilitative audiology, regardless of reported positive outcomes.

This is why there is more research and emphasis on technical procedures, clinical outcomes and informational counselling rather than on personal-adjustment counselling of clients in the literature. However, practitioners in South Africa within the field of audiology are becoming aware of the challenge to become more humanistic (Ratanjee, 2014). Abroad a

study done in Australia also found that audiologists nationwide show a preference for patient-centred care (Laplate-Lévesque, Hickson & Grennes, 2014). A stronger preference was especially seen among practitioners who were older, more experienced, in a teaching environment within community and education, or industrial audiology services. The participants in Laplate-Lévesque's study (2014) clearly acknowledged the value of building rapport with their client, but struggled most with the idea of letting go of their control of the topic of discussion of the session. Therefore a study of caregivers' experiences can add valuable knowledge to our practice.

Parents have reported that a disabling hearing disorder is perceived by them as a phenomenon that changes their lives (Burger et al., 2005). A lack of information increases the possibility of clinicians relying on and hiding behind tools and procedures - being unprepared for the onslaught of emotion, due to a lack of training or supervision, increasing the likelihood of a clinician-centred approach of care. This is even more alarming considering that UNHS is becoming more widespread (van der Spuy & Pottas, 2008) and that presenting the news without a structured counselling method and adequate plan, is sure to result in increased emotional pain and disruption for the recipient of the news (Mitchell, 2008).

Therefore this study aims to find out what the diagnosis means to caregivers; how they make sense of the process and tell it from their perspective. It tells of their experience that is shaped by context, by who they are, their backgrounds and life experiences and also by their experiences of the professional relationship with the audiologist in the process of sharing the diagnosis.

2.3 Literature Review

2.3.1 Introduction.

The caregivers' experience is important since experience, especially of a life-changing event, is the one thing that sticks with a person and imprints into a person's mind in a clear and poignant way (Kathard, 2001). Experience has the potential to change a person personally, emotionally and consequently also socially. Experience also has the ability to change someone's beliefs and attitudes so that he/she reacts in a different way to challenges and problems in their lives (Clandinin & Connelly, 2000).

Experience also shapes identity and adds to the fluidity by which identity is characterised. That means though identity is built up from foundational principles, it remains dynamic and changeable depending on experience (Clandinin & Connelly, 2000). In the literature identity threats have been recognised to exist among parents and also grandparents when faced with disability in their children (Woodbridge et al., 2014; Lukyanenko, 2013; Landsman, 1998). Though, these research articles range from a discussion of identities of motherhood, the identities of grandparents, and parents whose children are socially impaired and the child part of an escort service. They showcase the impact that disability has on parents' and grandparents' sense of belonging and meaning for their life, as it forces them into re-evaluating their values and principles. Though the impact changes depending on the type of disability and effects of the experience of disability are more poignant for parents than grandparents (Woodbridge et al., 2014; Landsman, 1998) the fact remains that the disability lives beyond diagnosis in a world that sees disability as 'abnormal'. Advocating for normality within that paradigm of thinking is what challenges parents' identity (Kemmerly & Compton, 2014).

Kremmery and Compton's (2014) research study for example looked at how students with profound hearing loss and their parents identified themselves: as Deaf or Hard of Hearing. They highlighted the fluidity with which their perceptions of themselves and of each other change according to social context. Parent participants emphasised how identity for their child first and foremost lay in their personality; - who they were as a person - and did not focus on the "othering" that disability brings with it. There was a call for acceptance, yet this was challenging depending on the context or relationship with others.

In this study, the focus lies on participants who are faced with the idea of disability very early on in their child's life, and on the possible new paradigms of thinking of disability that might challenge their identity, as with the studies above. The study will argue that by +understanding the caregivers' experience better one can learn what it means to be emotionally, personally and deeply affected by someone else's diagnosis of disability, and understand how better to assist caregivers on how to deal with it.

In order to understand these experiences, this study will listen to caregivers' stories. It is arguable that experiences are built up within narratives and fragments of continual narratives, i.e. stories. We tell of our lives using stories and do so in fragments of time and space. These experiences can be understood and reflected upon by the story-teller in terms of an interrupted or an unbroken line of narratives (Clandinin & Connelly 2000). Stories are the primary mechanism through which people attach meaning to experiences (Frank, 1998) and by telling stories random events start to become organised and portrayed as experience (Kathard, 2001). Thus experiences are best accessed through stories/narratives.

2.3.2 Overview of literature review.

This literature review presents the literature on the findings reported by caregivers about hearing loss and other disabilities in their children. It discusses these points by first

looking at the international literature on caregivers with the diagnosis of hearing loss in their children and then at one local study and how those compare. Due to the dearth of information regarding the experience of hearing loss diagnosis for caregivers of young children the literature review expands to include the experiences of caregivers of children with other communication disabilities, internationally and locally, as well as of caregivers with children with physical disabilities as well as caregivers experiences with the diagnosis of illness in their children and their consequent interaction with the medical profession. It ends with again highlighting the importance of this research study in the South African context.

2.3.4 Caregivers' experiences with the diagnosis of hearing loss.

The caregivers' perspective and experience is important for this study as it lends insight into what the growing trend of client-centred or family-centred care really means to them which has the potential to afford them the the right to speak their own truth on their own terms and with their own voice (Frank, 1998). The literature on how caregivers experience this diagnostic process is however limited.

Gilbey (2010), studying parents' experience in Israel, reports how several years had elapsed since Israeli parents' first diagnostic encounter with their child's hearing loss, but that these parents could vividly recall the emotions evoked and felt the day the news of hearing loss was broken to them. Themes that presented themselves out of Gilbey's (2010) study included:

- Strong negative emotional reactions such as shock and upset at the time when hearing loss was confirmed. These emotional reactions where furthermore described as unexpected and overwhelming.
- Parental dissatisfaction with *how* the news was broken to them by professionals who:
 - Used blunt language, showing very little or no empathy

CAREGIVERS' EXPERIENCES OF THE DIAGNOSIS OF HEARING LOSS

- Used too much jargon
- Focused too much on the “organ”, i.e. practitioners failed to recognise that parents have a child who is a whole, human being living within a family and a community. The child’s ear does not only need to be “fixed”, but they are also faced with a whole new world that they do not understand.
- Dissatisfaction with some practical issues such as the lack of flexibility in the availability of diagnostic tests
- Appreciation for information and having a ‘plan’ in place for the rehabilitative process

Gilbey’s (2010) study has been instrumental in a better understanding of caregivers’ experiences and what implications the diagnosis holds for them as individuals dealing with diagnosis of hearing loss in their child. The study is limited however in that it did not take into consideration the far-reaching effect a diagnosis of disability has on the caregiver outside of the diagnostic moment and the implications the disability holds for the coming-to-terms with the diagnosis for the caregiver’s relationship with their child and their identity within their wider social context. The South African context is diverse and nuanced with its complicated racial history, diverse ethnic, cultural and linguistic backgrounds that further complicate the far-reaching effect that hearing loss has on families and their hearing impaired children (Swanepoel, 2006). Thus further study into caregivers’ experiences is needed in SA.

The findings by Gilbey (2010) however shares similarities with another qualitative study about the experience of becoming a parent to a deaf child: A study done in the Flemish region of Belgium, following a phenomenological approach, by Bosteels, Hove and Vandebroek (2012) reported that parents went through a roller-coaster of negative emotions upon hearing the diagnosis of their child. Shock was the predominant feeling, followed by sadness and fear about how to now parent their child. Interestingly they also

pointed out that the psychological, social and emotional strain on parents with children with hearing loss is largely underestimated by audiologists, especially at the point of diagnosis.

The social strain points towards the fact that the experience that caregivers are reporting on is significantly influenced by and in turn influences their place in their community. Thus, it is important to look deeper and examine what caregivers are going through when faced with a disabling hearing loss in their child as it encompasses so much of their life and their child's life. Here similarities emerge to Gilbey's (2010) study where they referred to the clinician only seeing the organ/the ear and not the child.

Belgium is a welfare state, having implemented UNHS from very early on, and so one is able to transition quickly from screening to diagnosis to fitting and intervention. Thus in Bosteels' et.al (2012) study their participants could reflect differently on the implications of the diagnostic process after feedback was given, as after the initial shock their attention was focussed on being parents. The study's participants also commented on being appreciative of information, but that there was so much to process in such a short time that they felt overwhelmed and that it interfered with them being able to be effective parents of their child.

The earlier the confrontation with hearing loss, the study seems to indicate, the less time and space the parent has for reflection as early diagnosis forces them to act quickly and not be able to get to know their baby. The dependency on technological solutions and the emphasis and insistence on the correct use of technology seemed to also interfere with parents' need to care for their baby (Bosteels et al., 2012).

From their study, Bosteels et al. (2012) advocated for society to question and challenge the predominant type of support offered to families who have children with a disability, as it influences the idea of what being a healthy and flourishing individual means. The possibility of having a baby that can hear and talk due to advancements in medical and

technological treatment methods put pressure on parents to move as fast as possible in implementing these treatments, but disregarded the personal and social implications that a diagnosis of hearing loss brings with it (Bosteels et al., 2012).

Literature on family-centred counselling (Kricos, 2000 in Alpiner & McCarthy, 2000) as it applies to deafness furthermore highlights the support families need outside a disability framework. As culture and functioning is raised the context for family-centred intervention is described to include the following:

- active participation in the decision-making, planning and evaluating of their child's diagnosis and further management of it
- providing for the needs of the family and not just the child, yet sharing the responsibility of the child's intervention
- strengthening of families functioning by respecting, identifying and capitalising on the families strengths and coping mechanisms
- honest, unbiased and complete information

Implementing a family-centred model of diagnosis and management has shown to yield positive results. For example the child's behavior improves as the parent feels more empowered with enhanced teaching skills, participation of child and their siblings increases in the child's intervention programme and stress experienced by parents is reduced (Kricos, 2000 in Alpiner & McCarthy, 2000).

There has been much research on parental stress levels associated with the diagnosis of hearing loss in young children, yet all of these more recent studies made use of questionnaires, scales and other quantitative data collection tools to yield their results and thus there is a dearth of information on caregivers own recollection or told experience of the

event of diagnosis (Hintermair, 2004; Hintermair, 2006; Lederberg & Golbach, 2002; Meadow-Orlans, 1994; Meadow-Orlans et al. 1995; Pipp-Siegel, Yoshinago-Itano & Sedey, 2002; Meizen-Derr, Lim, Choo, Buyniski & Wiley, 2008). Other searches in the literature for experience of hearing loss yielded results mostly pertaining to the experience of parents with the timely identification of hearing loss through UNHS and were all of a quantitative nature and did not yield in-depth, nuanced experiential results from the research participants (Munoz, Blaiser & Barwick, 2013; Cadoni, Agostino, Scipione, Ippolito, Caselli, Marcese, Pauludetti, 2005; Koroleva, Lantsov, Podosinnikova, 2000).

A local study by Van der Spuy and Pottas (2008) however identified some parental needs for support in multicultural and multilingual children with congenital or early-onset hearing loss, including:

- help in dealing with the intense emotions at diagnosis
- to be involved with the same audiologist throughout the diagnostic process
- a shorter waiting period for confirmation of hearing loss, as this period is especially traumatic
- information to be readily available in writing
- to be kept updated regarding technological advancements
- to be in contact with others in the same process
- guidance and support regarding financial management

These findings mostly relate to informational counselling. They do not reflect or explain deeper emotions or the role the practitioner played on the psychological and emotional level, as in Gilbey's study. However, the practical implications this study held for

parents was valuable and adds to Gilbey's study. The discovery in these studies of widespread feelings in caregivers of stress, distress and the need for a voice across multiple professional fields when faced with a life-changing diagnosis, call for an enquiry into the perceptions of South African caregivers. Gilbey's (2010) study told of the experience of Israeli parents and can thus not be generalised to the South African setting, as South Africa is shaped by different and unique socio-economic forces, infrastructure, health services, family dynamics, and perceptions of disability to that of Israeli or western parents (Swanepoel, 2006 and van der Spuy & Pottas, 2008).

2.3.5 Caregivers' experiences with other disabilities.

Although the focus for this study is on hearing loss, it is also valuable to look across to other fields dealing with caregivers' experiences of the diagnostic process. Other communication disorders for example could help to illustrate parental experience further. In the literature there are many reports on the communication/sensory/social disorder Autism Spectrum Disorder (ASD). These studies highlight the experience of parents with the disability and the strong negative emotions that prevail within a complicated cultural and societal set-up (Chamak & Bonniau, 2013; Andersson et al., 2014; Strunk, Pickler, McCain, Ameringer & Myers, 2014; Moodie-Dyer et al., 2014; Coogle, et al., 2013; Hayes & Watson, 2013).

A study in South Africa reports how parents feel an immense sense of grief at the diagnosis of ASD in their child, where the professional's reluctance to make a diagnosis added to their feelings of guilt and anger (Mitchell & Holdt, 2014). In another article the diagnostic process is described as extremely stressful although it takes a long time to make the diagnosis (Keenan, Dillenburger, Doherty, Byrne & Gallhager, 2010). As with congenital, severe-to-profound hearing loss, ASD is also initially invisible at birth and affects communication. The experience of parents of children with ASD echoes the negative

emotional experience of caregivers of children with hearing loss at the time of diagnosis, and thus it is no surprise that the recommendations from these studies also ask for more professional and public awareness of the child's disability, and how the caregivers and their child are affected when society and professionals add to their emotional and psychological strain (Mitchell & Holdt, 2014; Keenan et. a., 2010).

Literature even further away from communication disabilities, in the field of physical disabilities indicates that parents' experiences are emotionally loaded and that communication between parents and professionals was critical as it influenced the way in which parents coped with this new world and this new life with their physically disabled child (Graungaard & Skov, 2006). Repeatedly there is an expressed need for understanding of the parents and the great impact the broader context of the child's environment and family life and beliefs and attitudes in their community and culture has on parents and on the needs of parents and children in terms of support and resources (Kruijsen-Terpstra et al., 2013).

In the medical field there is also more attention being given to parents becoming the main partners in the care of their children. In a study by Van der Pal, Alpay, Van Steenbrugge and Detmar (2014) participants reported that their distress, stress and feelings of insecurity were better supported and alleviated when they received appropriate support and recognition of their worries and fears concerning their child. In oncology there has been emphasis on how practitioners deliver the news of a life-changing diagnosis as their communication style affects how the client perceives the clinician, how satisfied they are with the service and how they feel afterwards. The medical literature's emphasis thus repeatedly calls for a patient-centred approach (Watt, Dix, Gulati, Sung, Klaassen, Shaw & Klassen, 2011; Mast et al., 2005).

2.4 Conclusion

The literature highlights that when parents retell their experiences they remember their strong negative emotions, as well as their interactions with the professional and how both of these points influenced their coping strategies and emotions. The literature also signals that when faced with a diagnosis of disability caregivers had one thing in common: the need to be heard as individuals living in a now new world that does not make sense to them, and which is overwhelming to navigate in light of the pressures of societal norms.

CHAPTER THREE

METHODOLOGY

3.1 Overview of the Chapter

This chapter deals with illuminating the research aims and objectives further by describing the research approach and design, the sampling method, data collection procedures, data analysis and ethical considerations. This chapter hopes to clarify and validate the rigorous process and trustworthiness of the data.

3.2 Research Question and Aims:

Research question:

How do caregivers experience the diagnosis of their child's hearing loss?

Aim 1:

To describe the nature of the caregivers' experiences of the unfolding diagnostic process.

Aim 2:

To describe caregivers' experiences of their interactions with the audiologist.

Aim3:

To analyse how caregivers' experiences shaped their roles and identities.

3.3 Research Approach and Design

The study was dependent on participants sharing intensely personal information. Thus, a retrospective, narrative approach was selected for this study using in-depth interviews. A qualitative research approach was chosen as it is suited to answering the

research question which is interested in understanding the caregivers' experiences. As described previously, stories of experiences are how people interpret and attach meaning to their experiences and how they construct their world; and through narrative a platform is created where they can 'voice' and share this 'deep reality' with others (Merriam, 2009). The aims of this study directly related to these characteristics, as the stories told came from the participant's own interpretations and constructions of meaning. The next section will argue in more detail why this theoretical framework was chosen for this study.

3.3.1 The choice for qualitative methodology.

A qualitative, inductive methodology or approach was taken because it more easily identifies thematic patterns other than "seeking scientific laws" (Hayes, 1997). A patterned approach of quantitative methods, where questionnaires require questions and thus possible answers to be determined beforehand are a potential source of bias. Also, the nature of social encounters produce stories that are erratic and ordered according to themes, symbols and ideas that will not be revealed in a structured questionnaire (Wever, 2002).

The research question of this study sits more comfortably however within a hermeneutic interpretative paradigm where the meaning emerges through the interaction between the researcher and participant. The methodology thus required a dialogue between researcher and participant: A conversation or question-and-answer exploration of a situation or concept. Through this conversation the experiences were illuminated by a dialectic process where the situation or concept described by the participant was sought to be understood from more than one point of view by the researcher. The inquiries made by the researcher were based on what the participants' were telling of their experience and thus a qualitative inductive approach was chosen (Kathard, 2001).

The critique of qualitative research is that it may be subject to suggestion and subjectivity (Knutson, 1997). This is particularly true of qualitative researchers who believe that only one unchanging truth exists. Side-by-side with this critique runs the belief that people hold an array of truths and that a specific truth comes to the fore based on the context. The participant is influenced by setting, the tone of the interviewer, the format of the questions etc. This implies an active role by the researcher as the interviewer during the course of data collection (Wever, 2002).

Thus the researcher checked her interpretations to be “fit” and continually matched her interpretations to the verbatim transcriptions of the interviewee. This is because a narrative retelling is characterised by a person who speaks with a certain goal in mind, in a specific situation with certain intent (Wever, 2002). The interaction between speaker and listener thus brings with it certain constraints on content, roles and privileges whereby meaning is shaped (Robinson, 1996). It is of utmost importance that the researcher realises these dynamic roles and cautions against interpretations that are not congruent with the transcripts. Interpretations are rather to be easily recognised in the matched data presented (Glaser & Strauss, 1967), as was strived towards in this study. Researcher bias was furthermore overcome by reflexivity (see table 5) with rigorous, reflective journaling by the researcher.

3.3.2 Research Design.

Thus a retrospective, narrative inquiry research design was implemented for this research study with an in-depth interview as a tool. Narrative inquiry was the design of choice as it argues that our understanding and experience of the world consists of stories where telling stories is how we naturally experience and tell of our lives (Clandinin & Connelly, 2000). Therefore, telling one's own story is an efficient way of accessing experiences.

Narrative inquiry implies thinking within a “three-dimensional narrative inquiry space” (Clandinin & Connelly, 2000). The aims were designed within this three-dimensional space: stories were relived and told by the participants in a present situation/place, yet retelling a lived experience as lived in the past. In this way two of the three spaces were represented: place and temporality. The aims also looked inward into the feelings, thoughts, ideas and the responses at work during this experience, as well as outward unto the people and things present during the experience and how they influenced the caregivers. This related to the third space: personal and social interaction. By probing deeper in the in-depth interview the researcher was able to gain insight into the construction of caregivers’ implied and dreamed-about future for themselves and their children, and how the shaping of ideas of the future by the three narrative spaces took shape at the time of data collection, incorporating temporality, personal and social spaces (Clandinin & Connelly, 2000).

The study used retrospective storytelling. Concern may arise regarding the retrospective nature of the study, as this retrospection can influence the perception of emotions and happenings relating to diagnosis through subsequent management and recall difficulties. However, a retrospective study was specifically chosen as:

- Recollection proved to be a strength in Gilbey’s (2010) study as caregivers remembered feelings vividly and could recall encounters in detail. The researcher thus aimed to gain the essences of the experience through asking caregivers to retell their experiences. The vividness of recollection emphasises the great emotional impact that diagnosis has and parents remembered most vividly those moments they experienced and continued to experience as most traumatic.
- The retrospective design was purposefully paired with a narrative inquiry research design as it aimed to collect the caregivers’ stories and let their voice be heard on their

terms, within their context and an implied future which might be a lived present (Clandinin & Connelly, 2000). Thus this design was suitable as it rigorously recorded what things might have influenced and shaped the caregivers' experiences.

- The variation matrix (see Table 1) also ensured that this recollection took into consideration all the different influences that might have an impact on caregiver's perceptions of the diagnosis.

3.4 Sampling Method, Participant Selection Criteria and Recruitment

3.4.1 Sampling Method

This study used a purposeful sampling method. The logic and power of this method lay in that it aimed to select information-rich cases for in-depth study (Merriam, 2009). This implied choosing participants who were information-rich (Merriam, 2009) and could relate a great deal about the experience of going through the diagnostic process with their children.

An extension of purposeful sampling was that of maximum variation sampling. Maximum variation sampling turned the apparent weakness of heterogeneity in small samples, into a strength. It was achieved by using the following logic: If a pattern developed from a group of great variation, these patterns were of greatest interest and value in trying to describe the central themes associated with the experience of diagnosis of hearing loss (Patton, 2002). Considering the great variation in cultures, languages and backgrounds in South Africa (Swanepoel, 2006) this matrix was implemented to achieve a better South African representation.

Thus the researcher chose participants according to a matrix where each participant chosen for the study was as different to the next as possible (Patton, 2002). Below is a table with the different dimensions included in the matrix and the rationale for each.

Table 1: Dimensions used for this study's maximum variation matrix

<u>Dimension:</u>	<u>Rationale:</u>
Race	South Africa has often been described as the rainbow nation consisting of different cultures, languages, and races (Swanepoel, 2006). Identity is often understood in relation to others. The different contextual groups that are predominantly found in RSA including Black, Coloured, Indian and White with their different norm-related, stereotypical and often strained relations and different contextual influences (Adams, van der Vijver, Bruin & Torres, 2014) might have an effect on the experience of diagnosis of hearing loss and need to be taken into consideration.
Languages	Participants were varied in their mother tongue. Languages will include three of most dominant languages in the Tshwane Metropolitan area: seTswana, Afrikaans and English.
Residential school vs. day scholar	Caregiver's of children who were boarders vs day scholars were selected as these schooling options are available in Tshwane and may influence their experience.
Communication mode/s	<p>For the purpose of this study caregivers who had children who used any one of three main modes of communication were included:</p> <ul style="list-style-type: none"> • Spoken language • Signed languages (e.g.: South African Sign Language - SASL) • Total Communication (i.e. combination of spoken and manual forms of communication) <p>Although there are different dimensions and proponents within each of these communication modes to choose for persons with a hearing impairment, these are not relevant to the study (VAANI, n.d.).</p>

To give more in-depth and nuanced background to the term “race” that is used in the matrix above the history of the Apartheid regime needs to be elucidated here. This was a 40 year long race-based legislation that had SA divided: five black ethnic groups were separated from the rest of South Africa into homelands. The National Party’s rule was based on a false and unsustainable presumption of racial (white) superiority. In 1994 the first democratic elections were held, three years after President Nelson Mandela was released from prison after being captured by the National Party as a “terrorist” and through negotiations with the

then President of the National Party F.W. de Klerk the Apartheid regime was abolished and a democratic state introduced (Welsh, 2009). Post-Apartheid SA is still characterised however by these racial categories (Adams, et al., 2014). Thus, the 13 different participants that were selected (with one participant counted as a unit) adhered to the different dimensions of the variation matrix and are illustrated in the figures below using race as a background:

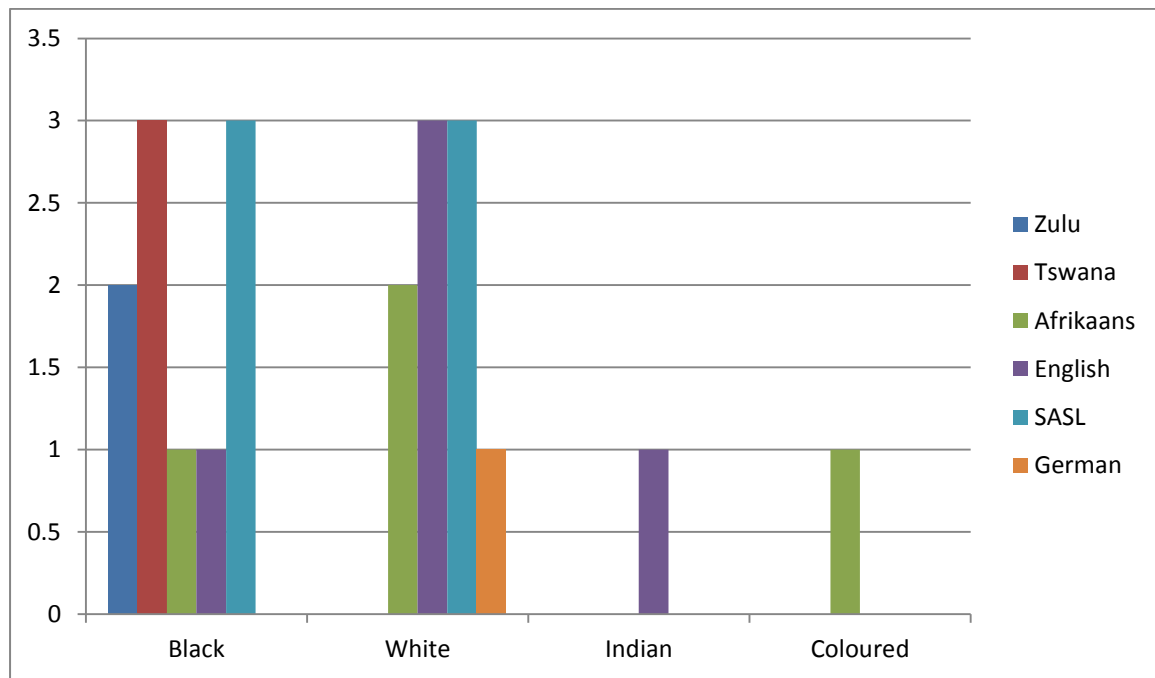


Figure 3: The languages spoken among participants as grouped into racial categories

Please note that the amount of languages spoken does not add up to the total number of participants as participants would indicate a different mother-tongue to what they spoke with their child. This is due to the fact that their child was often schooled in a different language to their own and thus they chose to speak to them in that language. The next figure indicates whether the participants' children were in a residential school or attending school as a day scholar.

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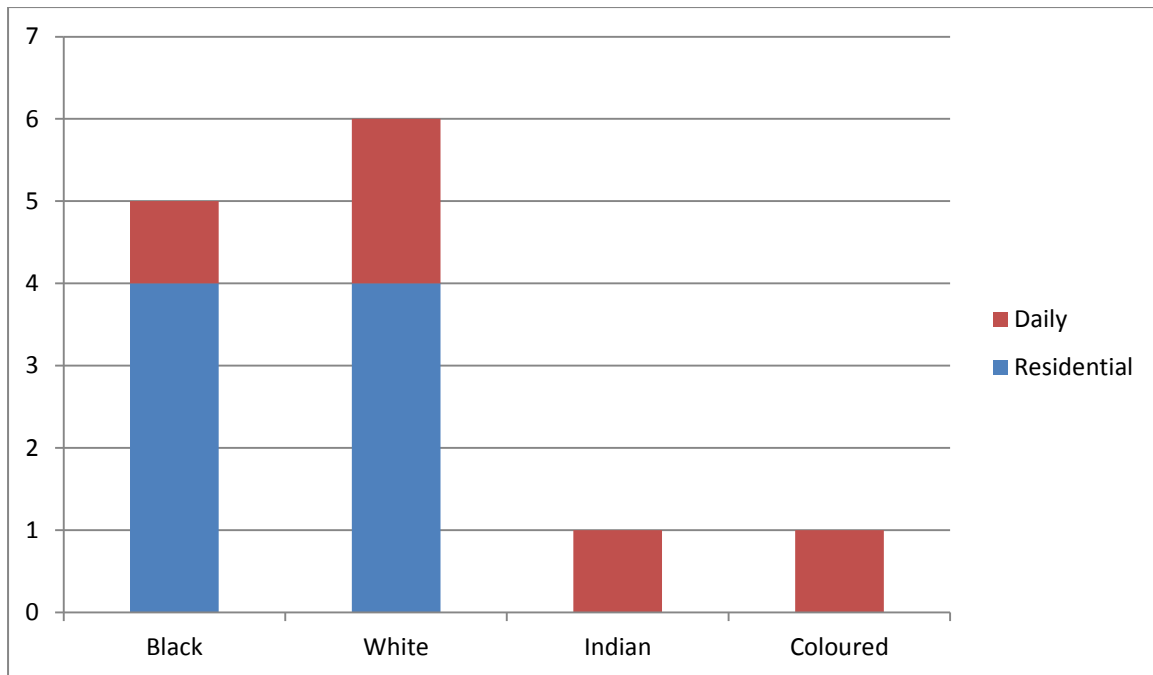


Figure 4: Amount of children who were in either a residential school or a day scholar according to race

The next figure depicts the type of language mode that was used at school and at home to communicate with the children, spoken or SASL. Majority of the participants used spoken language to communicate with their children.

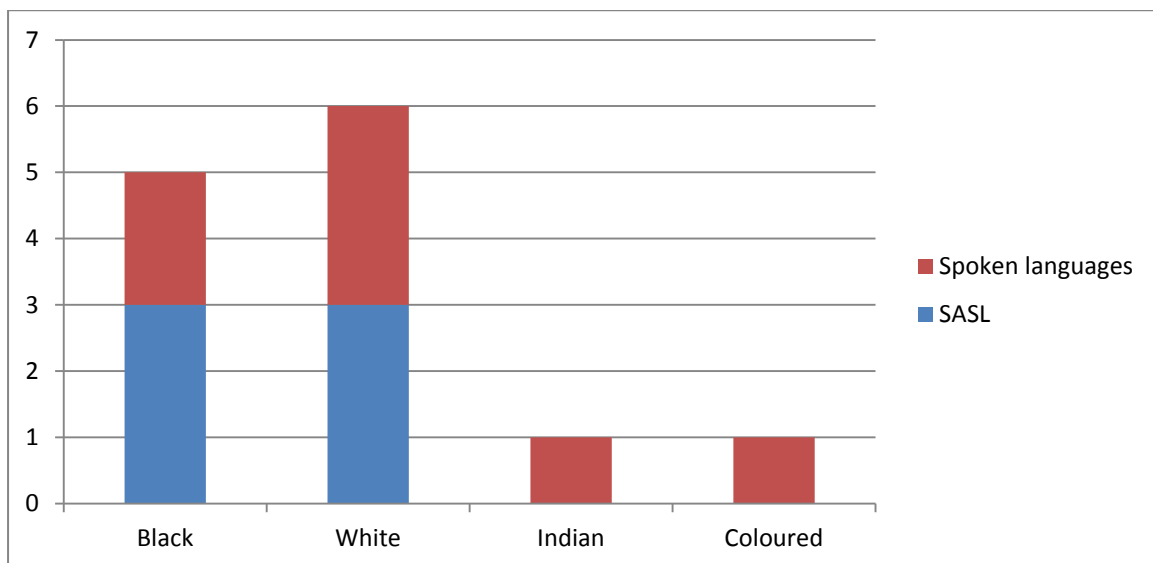


Figure 5: Mode of communication used for participants' children according to race

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The participants can furthermore be described by the regions from which they came in the Tshwane Metropolitan Municipality. This is depicted in greater detail in the table below:

Table 2: General descriptions and number of participants from the Tshwane Metropolitan Municipalities Regions (Tshwane Regional and General Overview, 2013)

Region	No. of participants	General description
Region 1 North-West (Soshanguve)	2	highest concentration of residents significant number of low level education high unemployment very low income poor living standards
Region 2 Central Northern (Hammanskraal and Brits)	2	low income but attracts young people as has some job opportunities due to tourism has some challenges in form of housing and social amenities, as well as upgrades on health clinics etc., but has good infrastructure in the areas in the region from which participants came from
Region 3 Central and Western (Atteridgeville and Kwaggasrand)	2	both participants came from the more western part of the central region which is characterised by a low income and expanding informal settlements one is from a rural residential township
Region 4 South East (Centurion)	1	falls within the triangular economic core identified by the South African Government having important economic growth due to activities including finance, retail, business services and real estate
Region 5 North East (Eersterust, Jan Niemand Park, Mamelodi)	3	good existing infrastructure, but poorly maintained high unemployment rate and those employed have a low income rate
Region 6 East (Queenswood)	2	second highest concentration of residents highest income per capita good access to services

The statistics from the South African study by Le Roux et al.'s (2015) coincides with the participants of this study who received diagnostic information at an average age of 17.75 months (Participants whose children were diagnosed after being infected with meningitis were not included into this average). All participants in this study received diagnostic information based on their or others' suspicions of possible hearing loss.

3.4.2 Selection criteria

Participants had to also had to conform to a set of criteria, as tabulated below (Merriam, 2009) so as to fit the aims of this study. In cases where both parents and grandparents, as caregivers qualifying from the criteria in tables 3 and 4, participated in the study it was granted and the interview held with both in the room was counted as one story.

Table 3: Participant inclusion criteria

<u>Inclusion criteria:</u>	<u>Rationale:</u>
Caregivers who: were present when permanent, “disabling”, sever-to-profound hearing loss was suspected and/or were present during the period of diagnosis and/or were involved in their child’s life from that point on up until the interview will be conducted can state they can recollect their experiences at the time of diagnosis	This criteria ensured that the participant selected was be able to relate what, how and why the process of diagnosis of hearing loss occurred with their hearing impaired children.
Caregivers of children who: are currently enrolled in primary school, high school or older	Caregivers needed to be in a place where they could reflect on their past experience without being in that initial sense of shock and grief as reported in the literature (Clark & English, 2004). This was done by making sure that the children were enrolled in school thereby having a number of years between interview and time of diagnosis. This criteria also ensured that themes which really had an impact came to the fore - as it did in Gilbey’s study (2010).
Caregivers of children who were willing participants who had information-rich stories that they were willing to share.	This criteria is important as it adheres to the ethical principles as laid out in this study under the 3.9 Ethics sub-heading.

Table 4: Participant exclusion criteria

<u>Exclusion criteria</u>	<u>Rationale:</u>
Caregivers of children whose: primary disability was not hearing loss	38.7% of children who are deaf or hard of hearing have additional conditions (Picard, 2004), i.e.

caregivers of children with multiple disabilities were to be represented. However, this was not to be their primary disability as this is what this study was aiming to describe.

3.4.3 Recruitment of Participants

3.4.3.1 The different institutions were contacted via e-mail and the information letter (see Appendix Aa) sent to the Heads of the different institutions.

3.4.3.2 A follow-up phone call was made as soon as confirmation of the e-mail was sent to the researcher and questions answered if there were any.

3.4.3.3 The Heads sent consent in the form of an electronic consent form (see Appendix Ba) and gave one contact person at the institution who would help with the distribution to all the caregivers' who would fit the selection criteria. These contact persons were all speech-language pathologists and/or audiologists who worked at the institutions.

3.4.3.4 A4 envelopes with the information letter to the participants (see Appendix Ab) were sent with the help of these individual contact persons at the institutions. These were personally delivered and collected by the researcher herself upon return from the caregivers.

3.4.3.5 Four of the five institutions gave consent to participate in the study. Three of the five institutions gave feedback of caregivers that were interested to partake in the study. The fourth was undergoing managerial changes at the time and it was difficult to get the information letters distributed to the caregivers resulting in no participants from this institution.

3.4.3.6 Fifty-six caregivers from the three institutions indicated that they would be interested in taking part in the study.

3.4.3.7 The researcher then used the variation matrix to ensure that a variety of different participants would partake in the study. She paid special care to liaise with the contact person at the school who knew the caregivers to make sure that one participant was as different to the next as possible using the variation checklist (see Appendix C).

3.4.3.8 The data collection only commenced once knowledge and consent (see Appendix B) from the institution and caregivers were given, ensuring that the participants read and understood their role in the research, their anonymity and rights. This served as prevention of starting participant negotiations with a set of formal forms and requests for signatures, which might have seemed puzzling to the participant, disrupted the building of rapport and the flow of the interview (Clandinin & Connelly, 2000; Rubin & Rubin, 2005). All participants were literate and none of the participants wanted an interpreter present except for P13.

3.5 Research Method.

An in-depth individual interview method (see Appendix D) was used (Gray, 2009). this method was selected because: there was a need for highly personalised data; opportunities for probing were required; respondents were not fully fluent in the language in which the interview questions were set up; it was flexible (Rubin & Rubin, 2005); it allowed the participants to tell their story without the researcher imposing her personal assumptions and influence on the participants (Hewetson & Singh, 2009); depth, detail, and richness, i.e. a variety of thick descriptions were sought (Rubin & Rubin, 2005)

The research method of choice was an in-depth interview because it caters for rich, deep and detailed information. These “thick descriptions” as first coined by Clifford Geertz (1973) in Rubin and Rubin (2005) are rooted in the interviewees first hand experiences and

these are best gathered and synthesised through in-depth qualitative interviews (Rubin & Rubin, 2005). This interview style is based on a naturalistic and interpretative approach to better understand participants' experiential and epistemological encounters. It thus requires a social encounter between researcher and participant and is thus an extension of ordinary conversation. It is built on the pragmatic skill of turn-taking, inquiring and commenting on what is said, yet goes beyond that by asking the researcher to listen to participants and hear the meaning of what they say. This then takes more skill than just ordinary conversation (Rubin & Rubin, 2005).

To get that level of depth, detail and focus the researcher worked out main questions and probes to encourage participants to continue with a point of interest (see Appendix D). The researcher had to be alert to pay attention to key words, a specific detailed train of thought or idea, and themes that started to emerge from the conversation and probe further into these. The in-depth interview style also cautioned to pay attention to listen for gaps and omissions and probe deeper into these as the participant allowed (Rubin & Rubin, 2005).

This interviewing style required the researcher to listen for the meaning of what was being said. When the researcher could not gather the meaning from the participant, she had to ask follow-up and/or clarifying questions to gain better insight and understanding of the point being made by the participant. It thus required more intense listening than a normal conversation would entail and a respect and curiosity to what participants were saying. It also asks for humility on the part of the researcher where she had to acknowledge if she did not understand something and asked about what was not yet known (Rubin & Rubin, 2005).

3.6 Data Collection Procedures

3.6.1 Interviews were held where it was most convenient for the participant to meet, e.g. at their home, or at another discreet meeting venue that was a comfortable

distance away from others so as to ensure privacy, or at the institution/school itself. The interviews varied in length with most being an hour and a half and others taking up to four hours.

3.6.2 Before the first meeting the participant was given a copy (electronically or in hard copy as negotiated with the participant) of the set of semi-structured interview questions (see Appendix D). This served the function of giving them the opportunity to gather their thoughts and relive the event/s in their memory before the interview even started.

3.6.3 Before the interview started the audio recorder was switched on.

3.6.4 The set of semi-structured interview schedule questions were asked (see Appendix D).

3.6.5 In one case the participant (using SASL) did not speak or feel comfortable with the language used by the researcher and an interpreter was used for the translation of the questions. The use of an interpreter to translate utterances and to be audio recorded as representative of the caregiver who used SASL was already explained and approved by the participant as seen in the information and consent letters (see Appendix B). The interpreter was briefed before the interview about the purpose, aims, design, and ethical considerations of the study (see Appendix F). The researcher asked the questions and then asked the interpreter to translate as exactly as possible, and translate back to the researcher what the participant said.

3.6.6 Whilst the researcher conducted the interview, she noted on a piece of paper all descriptive and reflective observations that were seen and heard during the interview

if necessary, i.e. all the things that happened, like gestures used or body language (Groenewald, 2004).

3.6.7 The researcher assigned codes to every recording specified by: date of the interview; and initial or follow-up appointment by a number. Each interview was electronically recorded, copied and saved in a separate folder on a personal computer.

3.6.8 After the interview, a biographical questionnaire (see Appendix E) was handed to the participant to be filled in. This was done so as to gain ethnographical information and prove how dimensions of the maximum variation matrix were represented. This was done after interview so as not to start the interaction off with a set of forms, but rather ease into the interview naturally (Rubin & Rubin, 2005)

3.6.9 After the interview the recordings were listened to and notes made as quickly as was reasonable and manageable within the confines of the researcher's workload. The researcher herself engaged in transcribing the interviews verbatim, stated when she summarised what the participant said, noted key words, phrases and statements by immersing herself into the recordings and the notes taken during interviewing. Researcher bias and nuance was addressed at this point where the researcher would reflect on her journal entries as to what the experience was like for her, thereby examining her own understanding and reactions to the interaction with the participant (Clandinin & Connelly, 2000; Rubin & Rubin, 2005).

3.6.10 A consequent draft transcription was produced for each participant, from the field texts collected by the researcher.

3.6.11 The researcher then verified these draft transcriptions with each participant so that the correctness of this summarised version of their narrative could be ascertained

so that trustworthiness and truthfulness was maintained. The necessary changes were made and saved on the same day as the corrections were received by the participant by e-mail or sms. When there was added information given in the e-mail it was also counted as part of the transcription.

It is important to note that the researcher engaged in continuous self-reflection in the form of journal entries during the proposal and continued to do so throughout data collection and afterwards. In this way she remained true to the methodology of narrative inquiry by recording and thinking of her own experiences of happenings and events in a particular time and space, in relation to the environment, her emotions and social interactions with the caregiver and others who were/are involved. The researcher strove to maintain a sense of wakefulness during this self-reflective process to issues such as narcissism - where the researcher may have become overly engrossed and self-absorbed with her own feelings and abilities; and solipsism - where the researcher's belief of reality became the only true thing that existed for her (Clandinin & Connelly, 2000; and Dictionary.com)

3.7 Pilot Study

Pilot studies should be included in qualitative research. One could argue that non-exposure to the field of enquiry may provide the researcher with a greater fascination for new information and would therefore accept stories at face value and reproduce these more faithfully (Sampson, 2004). However, the benefits of pilot study exceed this observation (Sampson, 2004):

- The researchers can prepare better for the research environment and thereby assess possible risks to researcher health and safety.

- The pilot study might inform the researcher on things that might not have been anticipated and to consider better lines of enquiry and thereby highlight gaps and wastages in data collection.
- The pilot study may aid the researcher in refining her interviewing skills and the semi-structured interview schedule.
- It could also show pitfalls of researcher bias and the researcher would be able to engage in how to find ways to decrease it in the main study.
- The study proposal was approved on the 28/10/2011 (HREC Ref: 416/2011) and the pilot study was thus conducted after this ethics approval was gained, namely on the 05/11/2011 (van Teijlingen & Hundley, 2001).

The process by which the pilot study was conducted followed the same guidelines and principles as the data collection and analysis of the main study. A more detailed description is added in Appendix H.

3.7.1 Changes and improvements made as a result of the pilot study

A quality evaluation was conducted on the researchers' interviewing style and can be found in Appendix H. The main aim of the pilot study was to prepare better for the research environment and thereby assess possible risks to researcher health and safety. More importantly the pilot study informed the researcher on things that might not have been anticipated and to consider better lines of enquiry and thereby highlight gaps and wastages in data collection and therefore the following things were learnt during the pilot study:

3.7.1.1 Participants may expect different things from the interview: building a rapport is N.B. E.g.: pilot study participant wanted to know how I came to do this before she felt comfortable to open up.

3.7.1.2 Checking of the correctness of the transcription by the participant should ideally be done electronically or telephonically, and not at a separate meeting, so as to save time and travelling costs to both participant and researcher. Thus notice was written attached to the transcription, stating that if there was no reply within a week, the researcher will assume approval of the transcription sent.

3.7.1.3 Interviews may take much longer depending on the participant. One needs to be ready for this and steer as need arises.

3.7.1.4 A gap that was noticed was concerning peer-reviewers. More peer-reviewers were needed, rather than only one peer-reviewer as stated in the proposal, so as to highlight those things that they would notice as codes within the transcripts, so that nothing was missed.

3.7.1.5 Wastages in data collection occurred with the transcribing of the data: The first summary did not need to be made; a verbatim transcription is all that is needed and to be sent to the participant for checking the correctness of the transcription.

3.7.1.6 Changes were made to the in-depth interview.

As the researcher's study aims were dependent on depth, detail and richness in the interviews; the participant selected for the pilot study – who was initially meant to not participate in the main study - was a very information-rich participant and it was decided to include the data of the pilot study in the main study (Rubin & Rubin, 2005).

3.8 Data Analysis

The aim of this process was to reflect on what the participants said in such a way so as to answer the research aims. The researcher aimed to construct vivid, informed and nuanced interpretations by classifying, comparing, weighing and combining the field texts so as to reveal patterns from the descriptions of experiences made and extracted the meaning and implication it held for the caregivers (Rubin & Rubin, 2005).

The data analysis followed the responsive interviewing model, as analysis (Rubin & Rubin, 2005). Data analysis occurred throughout the research. Uncovered variations of different meanings associated with an event/issue and the complexity of it involved the systematic coding and extracting of information from the field texts, making it easier for the researcher to retrieve the events, concepts, themes and questions within the transcripts combined coded data into units of same/similar topics in single interview and across interviews. Steps 3.6.6 - 3.6.10 during data collection procedure were the initial steps to data analysis. It is important to note that throughout the analysis process, data immersion took place where the researcher immersed herself in the data by reading, re-reading and asking herself the following questions throughout (Rubin & Rubin, 2005):

- What was the core point for each answer to a given research question?
- Which answer was new as compared to other answers from previous interviews?
- Which answers supported what the researcher already knew or learnt?
- Which answers changed the researcher's ideas?

By asking these questions and going through the recordings and transcriptions, the researcher got to know the (Rubin & Rubin, 2005):

- Concepts: ideas that were important, especially in answering the aims
- Events: happenings or situations that occurred at any specific time during the diagnostic process
- Topical markers: any names of people, places, numbers, schools, programmes etc.
- Theme: themes are those concepts, events and markers that were mentioned frequently, that answered the research question; that were a set of concepts, i.e. a typology; or figures of speech, slogans and symbols.

The participants' story was appreciated as a whole and was part of the analysis process. The researcher had to appreciate the meaning the participants were conveying through their story and appreciate the whole and not just parts of the story. This is why the researcher read and reread the transcripts as whole stories a couple of times before starting data analysis as this gave the researcher an idea of what they were trying to say as a whole and prioritise the essence of what they were all trying to say (Rubin & Rubin, 2005). As this was a narrative inquiry study design the data was analysed using a paradigmatic approach where common themes were traced across stories, characters and/or settings (Polkinghorne, 1995).

3.8.1 Coding and categorizing.

The researcher first identified and wrote up notable quotes from the verified transcriptions, so as to follow-up and determine their meaning and use it to look for relationships between interviews. The researcher synthesized different versions of concepts, events and topical markers so as to understand the overall narrative picture. Labelling/coding of each concept, theme, event and topical marker by giving it a colour together with a suitable name, took place so as to readily retrieve and examine all data units that occurred or referred to the same subject. The codes/data units were then grouped onto themes on a wall poster with post-its so as to see how the concepts were seen overall, and to examine nuances, differences, similarities, and what events had different meanings to people.

3.8.2 Synthesis into themes.

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The final synthesis of data was a detailed description of events and an attempt at an explanation of the how and why by the researcher, in the form of summaries which were then written up on another wall poster (Rubin & Rubin, 2005). The figure below shows a photograph taken of the wall poster that was used to code the data into themes with some close-ups as the poster was very difficult to photograph as it was rather large:

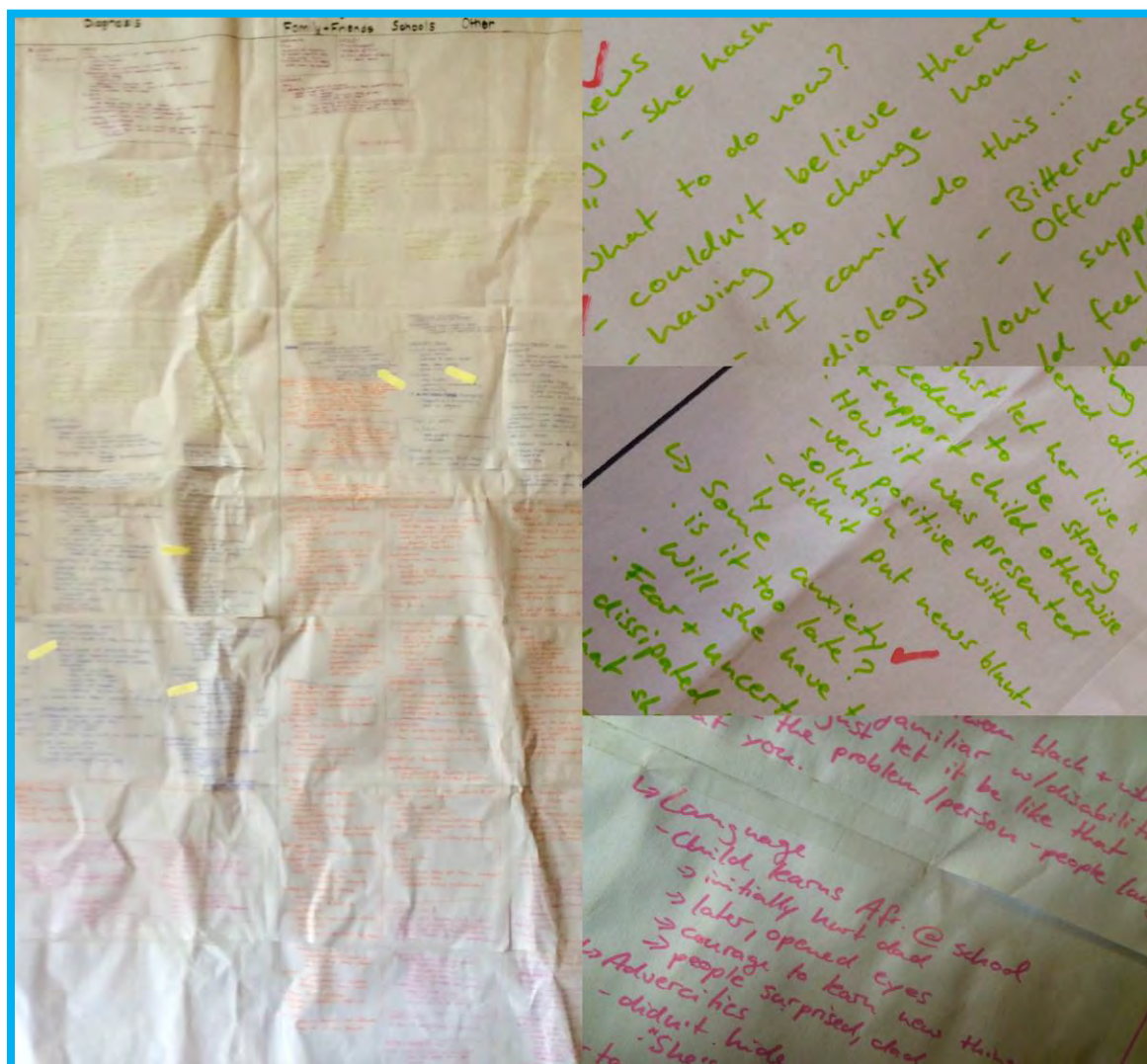


Figure 6: The coded data that was synthesised into themes

3.8.3 Representation.

The final written up research text was represented in the form of an analytical description of themes, and was peer-reviewed so as to verify that what was written was interpreted and transcribed correctly. The themes often referred to and quoted the verbatim transcription. The

quotes were referenced by the number given to the participant, i.e. participant 1 was labelled as P1 and then the page and paragraph number was indicated in the quote. An example of a quote and the keys used to describe it has the following format: "That was my first suspicion... very, very insecure." (P1 p. 4, 5)

The final written-up representation of the data included summaries, quotes, and vignettes. Vignettes are short stories compiled from verbatim narratives that tell of a collective truth without having to quote each participant individually (Rubin & Rubin, 2005). An example of a vignette used has the following format. The "EH" is used to indicate the researcher's initials:

I kept on thinking of how ... at least s/he was alive and we knew what we could do for the hearing loss. Somebody had answers for us. (Vignette by EH as deduced from transcripts from P2 p. 3, 4 & 6, 2; P7 p. 1, 2; P11 p. 4,5)

Thus a vignette is often longer than a quote, but includes numerous quotes from different transcripts. The researcher also used illustrations and figures to represent the data in a succinct way.

During this write-up of themes using these different representations the researcher built towards theory. The broader implications for this research were laid bare in the discussion, by looking at how the findings could modify, extend and perhaps create a new social or behavioural theory within the field of audiology towards caregivers of young children diagnosed with a hearing loss. This was done by (Rubin & Rubin, 2005):

- Looking at the researcher's own questioning pattern in the interview (or reflecting back on the questioning pattern of the interpreter, with the interpreter).
- Looking at the concepts and themes that were discussed together.

- Building on published literature.
- Reasoning on how different themes were interconnected.

3.9 Trustworthiness, truthfulness and rigour

An existing framework (Lincoln & Guba, 1985) was adapted as Lincoln and Guba first coined the term “trustworthiness” in 1985 and as it aids to best demonstrate how rigour was implemented to ensure trustworthiness, truthfulness, dependability, and credibility. These are discussed under four principles in the following table:

Table 5: The principles implemented to ensure trustworthiness, truthfulness and rigour:

<u>Principle</u>	<u>Technique</u>	<u>Process and rationale</u>
Credibility	<i>Persistent observation</i>	This implies having the opportunity to probe deeper by observing the participants behaviour, reactions and answers to questions as discussed in steps four and seven in the data collection procedure. This aided in identifying issues most relevant to the research question.
	<i>Member checking</i>	By having the summarised transcriptions checked by the participant, corrections of errors and wrong interpretations were made for adequacy and confirmation of data. Only one participant made changes to the transcription.
Transferability	<i>Thick descriptions</i>	Transferability is a means of achieving “external validity” by having provided thick descriptions by writing up field notes and texts, as one may then begin in analysing the interpretations for transferability to other participants, times, and settings.
Dependability	<i>Inquiry audit</i>	Dependability is achieved by having peer reviewers audit the process and product of data analysis, by challenging the transcriptions and interpretations made.
Confirmability	<i>Audit trail</i>	This was achieved by meticulously describing and storing: <ul style="list-style-type: none"> • all raw data • data coding and analysis products • data reconstruction and synthesis notes • any material containing reflections, intentions and dispositions • instrument development forms such as biographical questionnaires and the set of semi-structured interview questions

- pilot study results.

This was important so as to maintain a transparent description of all the research steps taken so as to be able to confirm and prove what was gathered and analysed.

Reflexivity

Reflexivity aided in confirming the findings of the research study by controlling researcher bias: being aware of own background, disposition, preconceptions, values, beliefs and positions through reflective journaling and also reporting all decisions, reasons for decisions, and logistics.

3.10 Ethics

This study adhered to the ethical principles as outlined in the Declaration of Helsinki (Seoul version, 2008), as described below. To ensure that the interpreter also adhered to these principles, the researcher had a meeting with him before data collection commenced and was sure that he understood and accepted the conditions under which this study was conducted (see Appendix F). Ethical approval for this study was approved by the University of Cape Town, Faculty of Health Sciences, Human Research Ethics Committee (see Appendix G).

3.10.1 Beneficence.

Beneficence refers to the prevention, protection or removal of harm to participants and the promotion of the common good (Coughlin & Beauchamp, 1992). All participants contributed to knowledge which could assist in developing counselling considerations in audiology service delivery. Also, their perceptions of this experience were acknowledged so that they became advocates for others who are trying to cope with the news of the diagnosis. Prevention of potential risks of this study is represented in the following table.

Table 6: Potential risks of the study to the participants

<u>Potential risks:</u>	<u>Prevention techniques:</u>
Being burdened by the loss of privacy and time spent commuting/completing interviews.	Privacy and inconvenience regarding interviews was minimized by maximum flexibility, e.g. not scheduling interviews at a time of busy holidays or close to important dates (Coughlin & Beauchamp, 1992).
Participants may (re-)experience emotional distress due to sensitive questions being asked during the interview/s.	Coughlin & Beauchamp (1992) argue that the likelihood of emotional distress may be greater when a stressful event was relatively recent; which does not apply to this study. Reformulation of sensitive questions to ease the participant into the interview were reviewed after the pilot study was conducted and analysed. In cases of severe emotional distress a referral system was in place to a private psychologist who is situated in Pretoria and therefore accessible to all participants, and who is familiar to the field of audiology.

3.10.2 Non-maleficence.

This ethical principle protects against potentially harmful acts that may impair the participant physically, that may lead to mental distress, or privacy breaches because of the highly emotive nature of the study (Coughlin & Beauchamp, 1992). As only privacy breaches were applicable to this study, the researcher did not violate the participants' privacy by encouraging the participant to participate through consecutive or persistent phone calls. Instead, the researcher sent mailed reminders of returnable consent letters through e-mail, post, or attached it to the school's weekly/monthly school letters, and offered to call back at more convenient times when participants were too busy to check transcriptions as this was unlikely to exert a controlling influence on the participant (Coughlin & Beauchamp, 1992).

3.10.3 Justice.

Distributive justice refers to the potential burdens and benefits of the research being evenly and fairly distributed among society (Coughlin & Beauchamp, 1992). This research study is just as:

- 3.10.3.1 it took into account the scope of the research aims, so as to fairly and purposefully select participants for the study; and this fairness continued by accurately describing these participants in the final write-up of the study.
- 3.10.3.2 it implemented maximum variation sampling whereby all possible ethnic, cultural and linguistic groups of the Thswane Municipality were represented.
- 3.10.3.3 it implemented prevention techniques of potential risks to all participants.
- 3.10.3.4 it did not exploit participants as the procedural steps were rigorously reported and all outcomes and findings were made known to all participants in a way that was timely and clear.

3.10.4 Autonomy and respect for autonomy.

This refers to privacy; being able to choose freely and on a voluntary basis to participate in a study whilst accepting responsibility through ones choices. This was achieved by the researcher relating relevant information to the participant in a letter (see Appendix A), in an understandable way (Coughlin & Beauchamp, 1992).

CHAPTER FOUR

RESULTS

This project aimed 1) to describe the nature of the caregivers' experiences of the unfolding diagnostic process, 2) to describe their experiences of their interactions with the audiologist and 3) to analyse how their experiences shaped their roles and identities. Data collection yielded rich information resulting in three main themes that relate to these aims specifically:


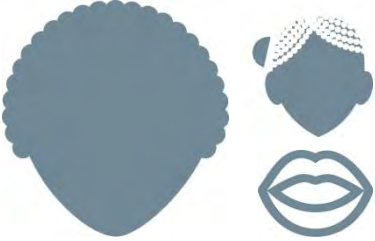
4.1 Aim One: The catastrophic emotional impact of diagnosis

4.2 Aim Two: The good and the bad of professional interaction

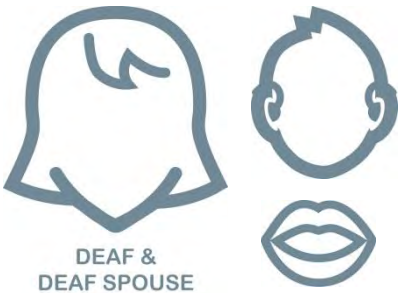

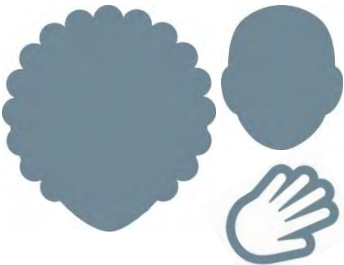
4.3 Aim Three: Imbalanced relationships, strained resources and resulting identity threats

The results of this chapter are presented in these three themes with specific sub-themes and categories. For each theme the verbatim data from the participants is provided in the form of quotes and vignettes (as explained in methodology). Not all quotes from each participant is used, but rather the most poignant and powerful quotes have been included. An in-depth description of each participant is provided to orientate the reader regarding the context for each participant and to emphasise the nuanced and diverse profiles of each participant.

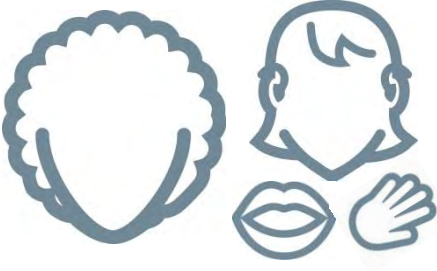
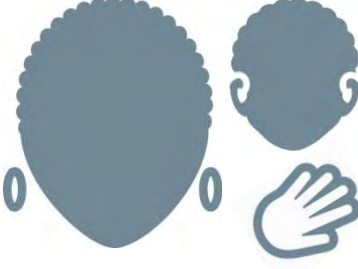
Table 7: In-depth description of research participants

	<p>Participant 1: P1 is a 45 – 50 year old white mother of an 18 year old daughter who was enrolled in a mainstream, residential school at the time of data collection. Her daughter was diagnosed with a bilateral, profound hearing loss at 9 months and received a cochlear implant when she was a toddler. Their communication mode is spoken language. They had to switch from their mother-tongue, German, to English; the main reason being that this would be the language of academic instruction for her daughter.</p>
	<p>Participant 2: P2 is a 30 – 35 year old black mother of a 7 year old daughter who was enrolled in an inclusive, day school. Her daughter was diagnosed with a bilateral profound hearing loss at 3 years of age after they had endured a long time of suspicion and insecurity regarding her development. She was also a premature baby with many complications that threatened her life at birth. She was also unilaterally implanted with a cochlear implant when she was still a toddler. Their mother-tongue is Zulu, however both parents speak to their children in English</p>


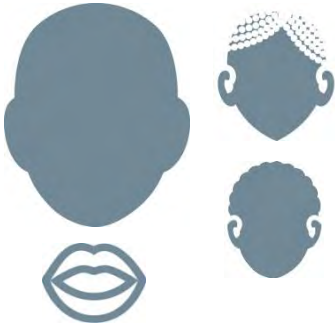
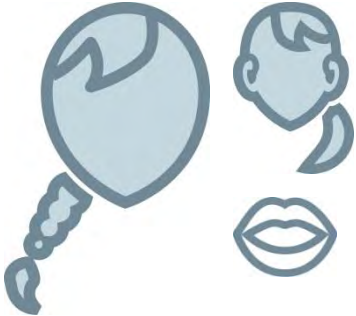
CAREGIVERS' EXPERIENCES OF THE DIAGNOSIS OF HEARING LOSS

 <p>DEAF & DEAF SPOUSE</p>	<p>Participant 3: P3 is a 30 – 35 year old white mother of a 10 year old son who was enrolled in an inclusive, day school. She herself is deaf as well as her husband. She attended mainstream school and her husband a residential, signing school. They speak English to their son, but he is bilingual and fluent in both SASL and spoken English as the parents speak SASL to each other, but not always to their children. Here they will often sign while using spoken language at the same time. He was diagnosed at 8 weeks and wears hearing aids.</p>
	<p>Participant 4: P4 is a 40-45 year old Indian mother of a 15 year old boy who was enrolled in an inclusive, day school. He was diagnosed with a bilateral, profound hearing loss at 15 months. He was fitted unilaterally with a cochlear implant at 4 years and attended an inclusive education model from 2 years of age. They use spoken language (English) to communicate.</p>
	<p>Participant 5: P5 is a 30-35 year old black, Tswana-speaking mother of a 16 year old boy who was enrolled in a residential school. He was diagnosed with a hearing loss at 18 months and attended a signing school from school-going age. This participant was joined by her own mother and due to cultural respect was welcomed to stay and give her input during the interview.</p>

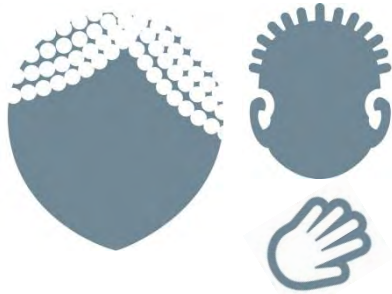

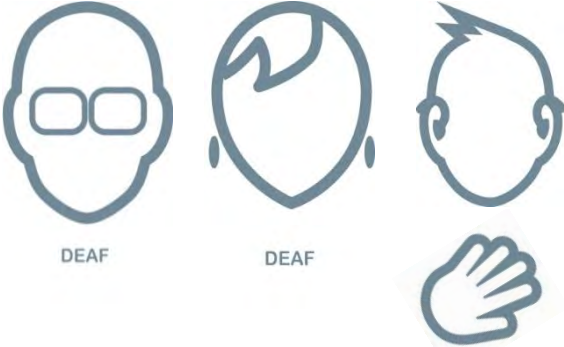
CAREGIVERS' EXPERIENCES OF THE DIAGNOSIS OF HEARING LOSS

 An icon depicting a caregiver and a child. The caregiver is shown as a large, stylized head with curly hair. The child is shown as a smaller head with a hand near their mouth, symbolizing communication or hearing loss. The entire icon is rendered in a light blue color.	<p>Participant 6: P6 is a 50+ white mother of a 25 year old daughter who was enrolled in two residential schools where in the one she was first instructed in spoken language (Afrikaans) and in the second one, from which she matriculated, in SASL. She speaks both languages fluently and attended tertiary education. This participant was able to pin-point German Measles as the cause for her congenital, profoundly deaf child who was diagnosed at 13 months of age and fitted with hearing aids.</p>
 An icon depicting a caregiver and a child. The caregiver is shown as a large, stylized head with curly hair and two small circles representing earrings. The child is shown as a smaller head with a hand near their mouth, symbolizing communication or hearing loss. The entire icon is rendered in a light blue color.	<p>Participant 7: P7 is a 30 – 35 year old black, Tswana-speaking, single mother of an 8 year old daughter who became deaf as a cause of meningitis at 2 years and 7 months. She was diagnosed with a profound, bilateral hearing loss at the age of 3. She attended a residential, signing school and the mother communicates with her in SASL. The mother revealed during the interview that she herself had not completed her school career and was struggling financially.</p>

CAREGIVERS' EXPERIENCES OF THE DIAGNOSIS OF HEARING LOSS

	<p>Participant 8: P8 is a 30 – 35 year old white, Afrikaans-speaking, single mother of an 8 year old girl who was diagnosed at 18 months with a bilateral profound hearing loss and implanted unilaterally at 2 years of age. She first attended a mainstream programme, then a residential school where spoken language is taught and then at the time of the interview a residential school where the mode of communication is SASL. She now communicates with her child only in SASL.</p>
	<p>Participant 9: P9 is a 30 – 35 year old black, Tswana-speaking father of two deaf girls where one was attending a residential, Afrikaans school for the hard of hearing and the other was still at home. He predominantly spoke of the eldest daughter who was diagnosed at 3 years and 6 months, She was 9 years at the time of the interview.</p>
	<p>Participant 10: P10 is a 35 – 35 year old coloured, Afrikaans-speaking mother of a bilaterally, profoundly hearing impaired daughter who was seven years of age at the time of the interview. She was diagnosed at the age of 2 and a half years and attended a residential school. The parents' main mode of communication is spoken language, although they do know some informal signs.</p>

CAREGIVERS' EXPERIENCES OF THE DIAGNOSIS OF HEARING LOSS

	<p>Participant 11: P11 was a single, Zulu-speaking black mother of the age of 30-35 years of an 8 year old boy who was diagnosed with his profound, bilateral hearing loss after falling ill with meningitis as a baby. He was 8 months old when he was diagnosed with a hearing loss. He was attending a residential, signing school. The mother's main mode of communication is SASL.</p>
 <p>DEAF SPOUSE</p>	<p>Participant 12: P12 is an English-speaking, white father of two deaf children, whose wife is also deaf. Both children attended an inclusive, day school. The girl was 14 at the time of the interview and the boy was 12. They were diagnosed at 16 and 13 months respectively and it is believed that there are genetic causes for the hearing impairments. Their main mode of communication is spoken language.</p>
 <p>DEAF DEAF</p>	<p>Participant 13 and P14 : P13 and P14 are a married couple who are both 50+ age old SASL speakers, both proficient in written Afrikaans and the mother in spoken Afrikaans. They have a son who was 27 years of age at the time of the interview. Their son attended a residential, signing school and was diagnosed at 6 months to have a bilateral, profound hearing loss. They have one younger daughter as well who is hearing. Their interview was counted as one unit as the translator did not separate one speaker</p>

	from another.
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4.1 Theme 1: The catastrophic emotional impact of diagnosis

The sub-themes for this theme are worry, shock, hurt and an array of other emotions associated with steps to coping. These reflect the different emotions that occurred during the time participants experienced the diagnosis of hearing loss in their child. A detailed analysis of the nature of the emotional journey will be provided in this theme.

4.1.1 Worry.

Worry is defined as a feeling or a cause to feel anxious or troubled about an actual or potential problem and allowing oneself to ruminate on that difficulty (O’Gorman, 2012). Thus worry is a diffuse and temporal problem that has the potential to occur more than once across a certain timeframe, i.e. it is pervasive. The majority of the participants expressed a feeling of worry or anxiety across the diagnostic timeline, but especially before the diagnosis.

Initially the worry was focussed on the likelihood that a disability would be diagnosed, as parents of children with congenital hearing loss did not have a reason to suspect hearing loss in their child. It started to become a guessing game, where they didn’t know if their child did or didn’t hear and started testing for it. They compared their child’s listening abilities and development to other children or their own, hearing children. It caused distress in some parents as they would start self-diagnosing and go through different sets of disabilities such as autism.

That was my first suspicion: why didn’t she get startled, because Petra* did. Petra* cried. (P1 p. 2, 2) “And then I started to already worry and I started to test.” (P1 p. 2, 3) “... but still it stayed there, it niggled all the time.”(P1 p. 2, 4) I thought: “Ah! I’ve got an autistic child”, because any new environment makes them like huh (sucks in breath) very, very insecure. (P1, p. 4, 5)

This guessing game and the fear of the unknown catapulted the parents into a frenzied search for answers. They would ruminate on it as the participant said above “it niggled all the time (P1 p. 4, 2)”. When it got to the diagnosis the majority experienced a great sense of shock at the confirmation of diagnosis. By contrast those whose children had been hospitalised before spoke of a sense of relief, because their child had survived and the search for what went wrong at birth and why the child was consequently not developing as expected came to a conclusion. A vignette has been used to illustrate this:

I kept on thinking of how s/he could have died and that I can be grateful that s/he is still alive and with me today. With all the things that were happening and her/his development being so slow and not knowing if there could have been brain damage or not we finally had answers as to why s/he was acting the way s/he was. It was because of this hearing loss. But s/he had made it out alive and that was the most important thing. Although it was still sad and unfair, at least s/he was alive and we knew what we could do for the hearing loss. Somebody had answers for us. (Vignette by EH as deduced from transcripts from P2 p. 3, 4 & 6, 2; P7 p. 1, 2; P11 p. 4,5)

Participants further expressed worry about how they would communicate with their children using spoken language and how they would form relationships with them. There was an actual fear of signing expressed by some participants who also said they had lost a dream for their child as they held the view that their child would then no longer be part of their ‘normal, hearing’ world.

Because we don’t want that she speaks signs language, we would like her to learn to talk.” (P10 p. 2, 1) “... because the problem was, why we also did everything so hastily, it is because the lady explained to us that [...], when the age of four comes it

will be difficult for a child to learn to speak. That was our biggest fear. (translated by EH for P10 p. 2, 2)

The feeling that I had was that: "How am I going to communicate with him?" I asked myself. (P5 p. 6, 9)

This fear holds close connections to what participants believed about disability and institutionalisation. They saw signing to be equal to a separate life to which they would have no access as they do not speak the language. In this way they could potentially not only lose the dream they had for their child to be able to function in this world, but also the potential bond they could have had, as is made possible with having the same language.

Realities and difficulties that participants faced within their context are important to note here as it created a specific nuance for each story. Although anxiety of what a child's future may hold was expressed often, certain contexts called for a specific script.

For example P13 is a deaf couple who themselves told of how difficult it is for a deaf person to find a job because they struggle to communicate with people in the hearing world. Thus while still suspecting the hearing loss they explained that they already knew that their son's life would be difficult. They worried especially about when their son would have to function in the hearing world and find a job. The father raised this concern more during the interview as he had experienced great difficulty coping in the hearing world.

It is much more difficult for a deaf person than for a hearing person to get work, so we were not worried about him as a person, but rather what his chances and options were for the future. (P13 p. 5, 3)

Hearing participants also worried over their child's future pertaining to communication and on how they would cope in this hearing world. Participants thus had

strong beliefs over early detection of hearing loss as this could have optimised their child's spoken language acquisition.

P7's story is especially multi-layered as she told of how she herself has struggled in her life as a young, single mother. She worried about her child's communication, but had added anxiety as she reflected on her own life, never having finished school and struggling to find a job and provide for her child. Thus, if her child had a disability, she worried about how much more her child would suffer.

When I remember that I'm going to die and then who's going to look after my child if she cannot hear, she cannot talk? Because I can see life is so unfair you see, so first of all when they tell me that she cannot hear, I feel so bad. And where I am suffering; I didn't go to school, so I was just imagining that what will happen to my child? Because she can't hear, she can't talk, what about me I'm normal, but I'm suffering, so... (P7 p. 2, 5)

Worry infiltrated the participants minds beyond the actual experience of having a child with a hearing loss. They reflected back on worrying about what might have caused the hearing loss and what future implications that might hold for their children, for example getting married and having deaf children themselves. This then also explains why participants' search for the cause of the hearing loss was still a question they would like to have answered, even at the time of the interview.

It's now still, because she's a girl and it's still, I mean, it's a big thing: where did it come from? She will get married, hopefully, and she will you know... Where is the cause of the matter and if it is genetical, she shouldn't have children, because her children will, may be deaf... it is a concern of mine, it is. It's still, I don't think it will ever go, because I can't put my finger on it and say oh it was that.(P1 p.6 to 7)

4.1.2 Shock.

Participants responded in a nuanced way to the shock they experienced at the time of diagnosis. Parents of children who were hospitalised reported some relief when the diagnosis came, yet it was still a shock to have a child who was diagnosed as profoundly deaf. Parents of children congenitally deafened had a prolonged period of suspicion and expressed shock at the confirmation of news of their child having a hearing loss.

Although participants were worried over a possibility of hearing loss, thus anticipating a problem, they still experienced confirmation as shocking news. A few specifically admitted to having always suspected it, yet it still felt like “cold water running down your back (P8 p. 4, 1)” and although some claim to have been prepared for the news, the hope remained that it wouldn't be as bad.

... we were prepared for the news, but we didn't realise how serious it was, you know. Because I thought he would survive with just hearing aids, but then we heard that it was much, much more... uhm, I really can't say you know, what went through. I think the both of us were in a state of shock... (P4 p. 3, 3)

All participants used very emotive language to explain this feeling of shock, repeating the word 'shock' often during the interviews. It was the one word that was used the most across all interviews. There was a sense of disbelief that it had actually happened to them, as is represented in the quote below:

God, what have I done? Why me? Not to say it must happen to someone else, no, but it was just a shock. It was very shocking. What happened was; I used to sit, just staring at something, not being aware that I'm looking at this thing, like there were many things in my mind. Why my child? (P8 p. 5, 1)

Participants were aware that a disability was possible and that no-one was exempt from this possibility. However when faced with this reality themselves there was a sudden, acute realisation of their world, as they had experienced it and come to know and perceive it, coming to an end. Their quotes show that they knew they would have to come to terms with this problem, but that initially it was overwhelming, a cataclysmic shift and change to their world.

4.1.3 Hurt.

If shock was the initial feeling with most participants, feeling hurt was the next dominant emotion, often experienced closely following after the initial shock of the news. There were many dimensions of hurt at the event of diagnosis as illustrated in the below figure.

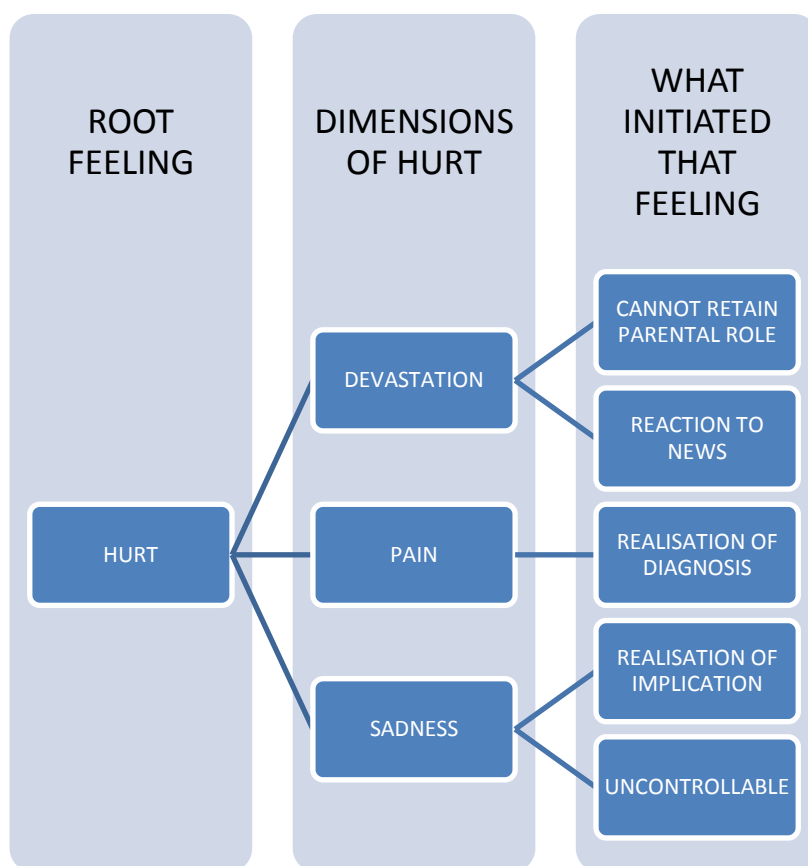


Figure 7: Figure depicting different dimensions hurt and what event initiated that feeling to occur.

Participants retold their experiences of a profound tragedy and agony that they felt. This emotional strain that they experienced was often described in cataclysmic terms, showing how they now faced an absolutely new world and reality.

4.1.3.1 Devastation.

The feelings of despair were evident. Participants felt devastated at their inability to retain their parental role of protecting and comforting their child. Since their children had no language or means of communicating with them, even speaking in a soothing voice when they were being tested or subjected to injection or medication became a traumatic experience. Therefore, before the diagnosis was even given the testing process was already making parents despair at their inability to fulfil their children's basic need for comfort and understanding. This caused trauma not only on account of the child, but also on the part of the parent:

Oh my word, it was agonizing, she didn't want to sleep! She was on my arm and it was getting wilder, and wilder, instead of calming down, so the medicine actually did the opposite. (P1 p. 4, 4) And because she had no language I couldn't comfort her.”
(P1 p. 12, 1)

She was even fed up with those tests in a way, because seeing those machines she just like cry, it was hurting a bit (pointing to his heart), but we had to be strong. (P8 p. 2, 3)

The feeling of devastation was tangible at the news of the confirmation of diagnosis and soon after. Participants recalled this vividly: “With that one it was tough, with that one. It was very hurtful, like I can't explain the feeling, but it was very sad, very sad; but that's how it is, that's how it was.”(P9 p. 7, 2)

4.1.3.2 Grief.

Participants grieved the fact that their child had lost something. Again, what exactly they had lost and why they felt this way was rather vague. In this process their perception of and worry about disability emerged: They questioned why their “small, innocent” (P2, p. 8, 2) child had to go through this and why they as parents had to go through this as well. They did not know the implications that deafness would have for their child. All they knew was that their child’s future would not be one which they had imagined it to be before the diagnosis.

Why did she have to go through so much? You know, with a child you feel let it happen to me, then she can just grow, I’ve been through enough, I can live with this. And she can be just normal. She doesn’t deserve this. (P2 p. 8, 2)

These participants’ children were already attending school and realising communicative and academic success, yet the participants explained that going back to the event of diagnosis and reliving that experience they still felt a sense of grief. A vignette is used to sum this up.

When you ask me to go back and remember, it is difficult. I feel extremely sad. It’s like you had a dream and now it is lost. It is your child! You are sad. Yet there is nothing you can do. Life is tough and whatever you have to do, you have to do. Yes, there was an expectancy that you have for your child’s life and his/her future and that’s why remembering this event, it just pulls at your heart strings (trying to fight back tears). It was a tough moment in your life and it gets to you. So I don’t know what it is.” (done by ER from transcripts from P12 p. 6, 2 & 11, 1; and P8 p.9)

4.1.4 Emotions associated with the steps to coping.

When faced with such a cataclysmic event at diagnosis that created such a deep feeling of hurt, participants had to experience the process of being forced to assume a new

identity – the identity of a parent with a disabled child. This sub-theme thus touches on aim three outlined above: participants' experience that their identities start to be challenged, and which will be further discussed in theme 3 of this chapter. This sub-theme and its categories deals with the process participants described of coming to grips with this new identity. These categories are not fixed points along a time continuum, but rather a fluid series of sites of emotional experience as feelings last and stay, as well as come and go. These are illustrated in the figure below:

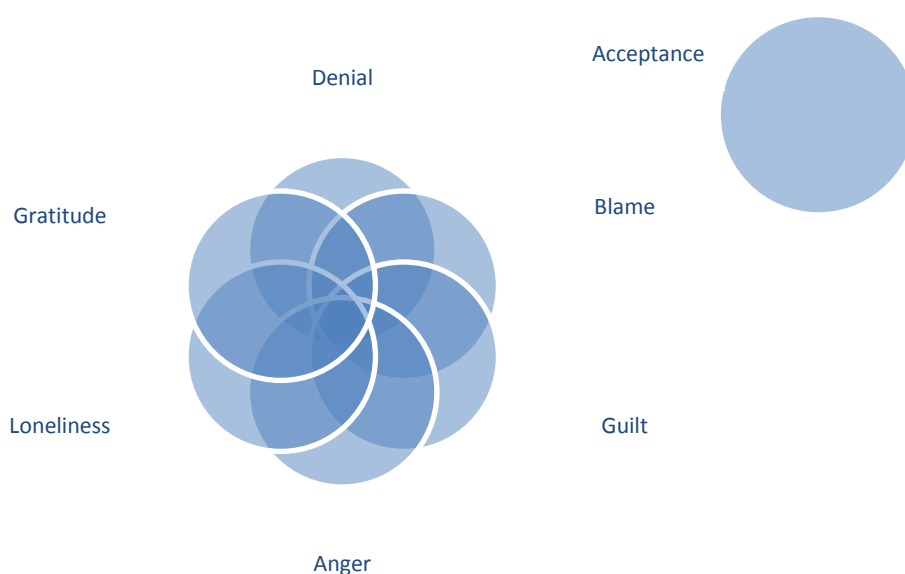


Figure 8: Emotions that were mentioned in order to come to terms with the news and gain a sense of acceptance of the diagnosis

It is important to note that “acceptance” in the diagram above stands separate from the rest of the list. This is because some participants did not have to change their identity as they themselves were deaf. Thus, being the parent of a deaf child when they themselves were deaf meant that they had first-hand experience with the disability and didn’t feel their life had changed much although they too had emotions associated with the diagnosis.

4.1.4.1 Acceptance.

All the deaf participants expressed a feeling of acceptance of the diagnosis. They believed that having a deaf child would make communication easier, since they would have more of a connection with their child, and they emphasised that they didn't see their child as different. They wanted to have the best of the world they know for their child, be that the Deaf or hearing world.

The participants (P13 and P14 where the interview was counted as one unit), entrenched in the Deaf world, spoke of the natural connection they felt with their deaf child as they knew how the deaf world worked. The other participant emphasised that her child would not be different just because he's deaf and shouldn't be treated differently. She argued that he was intrinsically part of the hearing world, just like any other 'normal' child. These points are illustrated more clearly in their quotes.

We didn't have a problem with having a deaf or a hearing child, but we knew that it would be easier to communicate with a deaf child... (translated from Afrikaans to English by EH for P13, p. 8, 5)

But I think, because I'm also deaf, so I accept that person, and I accept it and everything. (P3 p. 5, 6). Just because he's deaf he mustn't get special attention. Treat him the same, like he's normal. (P3 p. 6, 4).

P3 was a strong advocate for the acceptance of deaf children within the hearing world. She urged hearing parents to release the coercive grip of a prejudiced view on disability. She cautioned that when one does not step out of the denial and accept the implications of the news, one runs the risk of further delaying ones child's progress and ultimate success, as the child is essentially able to be "normal": "I want to say to the normal, hearing parents that they

must accept almost immediately, because if they can't accept then the child won't grow up normally."(P3 p. 8, 6)

4.1.4.2 Denial.

Participants' experience highlights their difficulty with the news of diagnosis. They spoke of their hope for a diagnostic mistake and one also went for a second opinion to confirm the diagnosis.

I didn't really believe it in the beginning. I wanted to make dead sure. There was still hope... That is why we went again for the test and did the ABR again. (-translated from Afrikaans to English by EH for P8 p. 3, 3-4) When the doctor told me the first time that he already suspected it, it was already traumatic for me, because I didn't want to hear that. You don't want your child to have that... (-translated from Afrikaans to English by EH for P8 p. 2 2, 1)

It was difficult to acknowledge the permanency of the diagnosis. The impact that the news had on some of the parents was a life-long battle of chronic sorrow. One participant spoke of her spouse and his difficulty of forming a relationship with their child, a difficulty that persisted even at the time of the interview when the child was an adult, married woman:

... but my husband did. He got up and ignored the man (the ENT - ER) completely and said to him: "You don't know what you're talking about." and walked out... Even today, she can sense it from her father's side... so throughout her whole school career up to adulthood he and she... I don't think it was a healthy father-child relationship." (- translated from Afrikaans to English by EH for P6 p. 6 p. 5, 5 and p. 7, 2)

The struggle with accepting the diagnosis was coupled with the implication that it held for the participants' life. This spouse's way of dealing with the diagnosis was to move into rejection and resistance where he did not need confront the pain. However, in most cases

this denial phase seemed to be a necessary step in the process for these participants to make a conscious decision to deal with their child's disability and acknowledge the loss to themselves and the world: "There like as a father, as a mother, you have to be strong."(P8 p. 5, 1)

4.1.4.3 Anger, blame and guilt.

Anger, blame and guilt often coincided with each other as participants, when they felt angry also felt a certain amount of guilt, and when they blamed others, they also blamed themselves. The participants were devastated.

Participants described the anger they felt when confronted with the news of diagnosis. Instead of denying the possibility of the hearing loss in their child, they reacted with anger as their expectations for their own life and that of their child's was now disrupted. This triggered a "fight" reaction towards the bearer of the news:

But you become angry at that person – very angry. If you are someone who is offended very easily or who becomes angry just like that, you'll 'moer' (hit very hard – EH) the person with the chair you're sitting on as if he's the one who's caused everything."(P8 p. 8, 1)

In one case the mother became angry with herself since she believed she had brought this onto herself: "I think I would have been angry with myself you know, I went out I slept with a guy, I became pregnant and this is what happened." (P5, p. 8, 3)

In most instances, participants didn't react with anger, however, but rather started blaming others or themselves for the hearing loss. This stemmed from a feeling of guilt, in some cases caused by the belief that parents had somehow contributed to or caused the hearing loss in some way, for example through prematurity and other medicinal intervention for an unrelated illness:

I've been blaming myself since Louise's* birth. So really, it devastates me and I get back to that moment of me, maybe I didn't take care of myself during the pregnancy? ... And then I go back and blame myself ... maybe when she was small I should have been more aware of what was happening with her..." (P2 p. 11, 3)

This feeling lingered and transcended far beyond the actual diagnosis as it was fuelled by their belief that they contributed to their child's problem. A few participants reported that they blamed the professionals since had the doctors and other professionals picked up the hearing loss sooner it would have been much better as they could have then intervened much earlier and have the child progress faster.

You know what, I blamed the doctor. I blamed the doctor, because I felt that if he, in the time that she was in hospital, he had noticed it and told us, we could have made a plan or at least could have done something about it." (- translated from Afrikaans to English by EH for P10, p. 7, 2)

They also expressed a fear of being blamed by their spouses for the hearing loss: "... I can't say that it started becoming bad, but he told me that if there was really something wrong, that he would blame me for it..." (- translated from Afrikaans to English by EH for P10, p. 3, 4)

4.1.4.4 Loneliness and gratitude.

Some participants spoke of an immense sense of loneliness after they had received the new of diagnosis. This loneliness related to the physical state of being left alone with no-one to stand by the participant as well as the feeling of being left alone with no guidance.

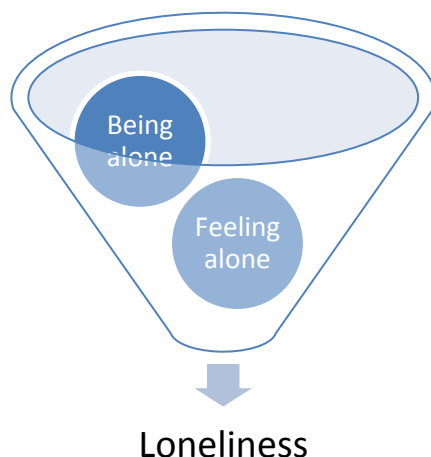


Figure 9: Dimensions of being left and feeling alone contributing to the feeling of loneliness

4.1.4.4.1 Being left alone. Some participants who expressed the state of being alone were single mothers and explicitly explained that not having a spouse and being left alone to deal with the implications of the child's deafness was hard: "... like when Don* was doing this and that; most of the time, I was alone. That's why I said it was hard..." (P11, p. 4, 4)

This feeling of being left to face the implications of the news alone was evident. They also reported how the family and other people after the diagnosis handled the news. This was perceived as hurtful and intensified the feeling of loneliness.

So the congregation must face this now. There, that's how it is... Ya, that's just how it is, it's just hopeless. She is deaf, and we have to face it, and the faster we face it, the better... We felt dropped. (P1 p. 10, 4-5)

4.1.4.4.2 Feeling alone. However the physical condition of being alone was trumped by the feeling of being left alone with no-one to help. This feeling came across strongly.

How must I do this? You know you get this rejection type of feeling of “I can’t do this. I can’t have a child that’s deaf. It’s not me. It’s not my child. What must I do now?” ... Because you know you feel so lost. You’re hanging here and you don’t know where to turn to... (P1 p. 15, 1)

When participants received sufficient help and guidance this feeling dissipated and they felt cradled in the guidance they received. “And then this lady, the audiologist, she was very positive about it, and she said: “Ok, this is the way we can go about it.” And immediately that fear and that uncertainty sort of rolled out of the room...” (P2 p. 3, 2)

How help was offered by the audiologist giving the news played a big role in how the news was received and how supported the participants felt. Some participants felt that the information they received was not sufficient and they felt left alone to work out how to handle the news emotionally. They required more empathy and an understanding by the professional about how they felt.

I can’t say that the professionals were a big help. I felt very alone. I wish she could have put it more softly or try and see it from a parent’s perspective, because I always felt like they were the learned doctors, but they didn’t know how I felt. I actually felt cold and dropped like a sack of potatoes. She was too correct wanting me to deal with it by myself. It was as if she was saying that it was my child, so I had to deal with it and she will carry on with her work which is her responsibility. She had no sympathy and just told us to face it – not only by literally saying it, but also by her attitude. We were left alone to deal with this little baby by ourselves without any guidance as to how to do that. (-done by EH from transcripts from P8, p. 6, 9 – 7, 1 and P1, p. 9, 4)

4.1.4.4.3 Grateful. Thus, when participants felt like they were being guided and that a helping hand was offered them to help their child, they experienced a great sense of gratitude.

This gratitude was directed specifically towards the schools in which they enrolled their children that helped and supported them after the diagnosis. This gratitude was often felt shortly after a diagnosis was made as they enquired or were told by the audiologists about the possible options for schooling. This support was often given very soon after diagnosis and thus is part of the diagnostic experience. They felt that the schools provided them with support, information and hope. A vignette has been used to illustrate this:

Life became so much easier when we started at the school. They were fantastic. There was a renewed sense of hope, because finally my child was receiving help. I'm proud of my child for being in that school. I wouldn't want to exchange it for anything else. They do so much for the parents that are in the same position as us and we just say thank you. It is all thanks to the school that we could cope with the situation. (- done by EH from transcripts from P1, 12, 1; P7, p. 2, 5; P8, p. 4, 4; P9, p.8, 2; and P4, p 13, 4)

4.2 Theme 2: The good and the bad of professional interaction

In the previous theme it was evident that participants were on an emotional journey through the diagnostic process. This theme however relates to a very specific point in the diagnostic process, namely the moment of diagnosis itself where the audiologist is the bearer of the news of diagnosis. This theme thus reveals the second aim's objective to describe the experience of that interaction. This is the point where participants had direct interaction and contact with the bearer of the news. Thus, the person conveying the news becomes highly important in this respect. The quality of the professional interaction influenced the participants in two ways, namely the information they received and how it was conveyed. This interaction was then further experienced differently as good or bad quality, as illustrated in the table below.

Table 8: A summary of the caregivers' experiences of quality of the professionals' interaction in terms of the information that was given and the language use of the professionals during the interaction.

Quality of professional interaction		
TYPE OF INTERACTION	GOOD	POOR
Information	Participants felt comfort when they were included in the testing process. At the beginning of the appointment they need to know: - what testing will be done - what the test tests - what the results could potentially mean	Participants felt anxiety when professionals hid behind their machines
	Visual aids need to be used when explaining the audiogram.	Participants felt cheated and powerless when no options were given for schooling and different amplification technology.
	The information should include the following: What a normal audiogram looks like and how their child's compares and what that means Ear anatomy Aetiology Amplification options Contact details of schools and other parents i.e. a plan of action was in place	When little or no information was given the participants felt disregarded and extremely negative towards the professional.
Language use of professional	When the professional was positive the participants felt hope for their child.	When the professional was blunt the participants felt dropped, cold and alone .
	The participants valued gentleness as they then felt supported, less alone and that they could deal better with the news of diagnosis.	In some instances the professional was rude and disregarded the participant. The participants in turn then did not know how to stand up for their child in light of the professionals' treatment of them, i.e. they did not know how to support their child in light of the lack of support they got.

4.2.1 Good quality of information.

Quality in this context refers to the information that participants perceived as being valuable in this life-changing situation. They gave suggestions on what information should be given, in which format, how much of it and when it should be given. They also judged the professional on their knowledge and professionalism so as to gauge if the information given

could be completely trusted. Participants received information in an ongoing process throughout the diagnostic experience. The majority of participants could recall in detail how the testing procedure occurred.

Participants often spoke of the need to have options, be that options for amplification, communication mode or schools. The majority of participants emphasised the importance of being given a plan as well as having options ready for them to consider. When they were given options they felt empowered to make informed decisions for their children and less anxious on what they should do: "... because like they gave us the news, they comforted us, they gave us options, what to do and what not to do..." (P8 p. 13, 2)

Participants thus valued the options given and credited the guidance given by the professional for their now increased feeling of security and hope. However, participants also added a strong note of caution about the importance of the timing of when the information was provided so as to maximise the opportunity to make conscientious, non-emotional and well-thought-out decisions. It is important to note that a few of the participants also said that the professionals should then give the news in a nice way.

... someone's holding your hand and you hold your child's hand and they will just take you there.... We also had to go and decide about that. So towards her: I could say she was quite professional... I couldn't, she was also very supportive, because she didn't ask us to make decisions there and there... (P2 p. 6, 1-2)

Participants spoke of the comfort they felt at knowing that the professional they were dealing with knew what they were talking about and gave them solid, professional information. They acknowledged the professional's expertise and felt secure in their knowledge like they had come to the right place for help: "... it was mostly professional,

because the ladies they knew exactly what they were talking about. I mean you felt like you were in the right place. We were settled by what they were telling us.” (P2 p. 5, 1)

4.2.2 Bad quality of information.

If there weren't any options given, especially when it came to amplification options (hearing aids vs cochlea implants), as in a few cases, the participants felt cheated and powerless where they otherwise could have helped their child in a different way. A vignette has been used to illustrate this:

They didn't really give us any voice. I wish they had. I still think to this day it's just wrong if you don't give a person all the options, especially if they ask if there isn't anything else that can be done. It's like they put flaps next to our eyes so you don't see any other possibilities. It's wrong to tell a parent the cochlear implant is the only option, just as is it wrong to say that hearing aids and signing are the only option for your child. When professionals do this, they force us to make uninformed, rushed decisions taking away our right to choose for our child. (- done by EH from transcripts from P8 p. 4, 1; P1 p. 8, 5 and P3 p. 6, 1)

There were a few cases where professionals didn't provide any information regarding the hearing loss and only communicated the bare minimum with the participants. In these cases the participants felt disregarded and extremely negative towards the professionals, blaming them for their unprofessional behaviour.

... they were supposed to sit down with me and explain the procedure, you know. Sometimes I do blame them you know, because they were supposed to tell me what's going on: “What was this?” So, they didn't do that... (P5 p. 9, 2)

4.2.3 Language use of the professional.

How the news was presented carried a lot of importance in the minds of the participants. Just as they judged the professional according to their knowledge, they judged them according to their “bedside manner”. There are four interrelated categories that come into play in this sub-theme: positivity and gentleness vs bluntness, as well as acknowledgement vs disregard and rudeness. How the professional made the participants feel with their use of language had two sides: either the participant became more hopeful and confident or more lonely and lost, as illustrated in the figure below.

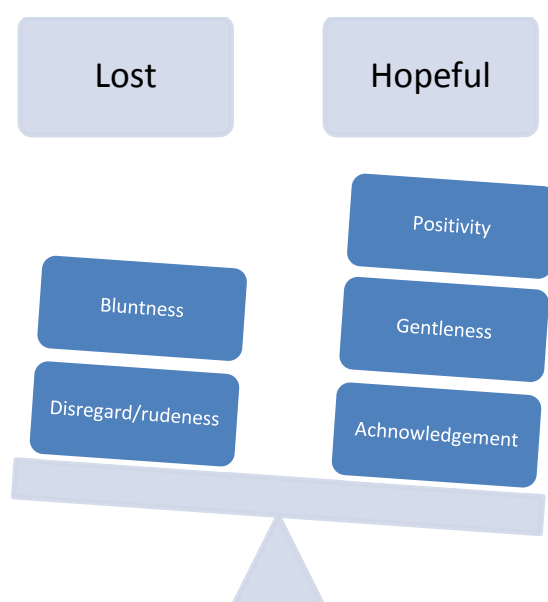


Figure 10: The language use of professional contributing to the participants' emotional reaction to the news

4.2.3.1 *The appreciation for positivity.*

A few participants felt that the professional's positivity and hope for their child inspired more hope in them for their child's future. It is interesting to note that these participants had a very strong conviction that their child should be verbal rather than use sign language and that the way the news was presented with such positivity and hope dispelled the worry they had about their child not being “normal”. One participant (herself being deaf)

explained that her goal for her child was to “be as normal as possible” (P3, p. 4, 9). The professional’s positive outlook supported this hope.

The audiologist was very positive about it and explained how we could go about everything. And immediately that fear and that uncertainty rolled out of the room, because now she went on about how the child will be able to hear. She believed he would be as normal as possible. It’s good that she didn’t start off by saying: “You know what I have got some bad news.” She had hope and emphasised that if we play quickly we could still catch up so much. (- done by EH from transcriptions from P2 p. 3, 2; P3 p. 4, 9 & 7, 4; and P10 p. 5, 6)

4.2.3.2 The request for gentleness.

When the news was further presented sympathetically, and with gentleness, participants felt supported by the professional. It helped them deal with the news and made them feel less alone.

... and they were very gentle. It wasn’t something like: “You know what you’re son’s deaf. Here are some hearing aids.” No. They sat us down and laid it to us...” (P4 p. 5, 4) “Well like I said they were so loving and so like you know subtle about everything.” (P4 p. 6, 6)

The conduct of the professional during the diagnosis mattered not only to hearing participants, but the deaf participants also placed special emphasis on professional conduct. Body language was viewed as important, even more so than the actual intonation of the professional’s voice. Deaf participants in particular highlighted that while news about deafness was important, the professional’s prejudices regarding Deaf people was a concern.

You have to work softly with Deaf individuals, because if you become cross they will immediately feel like you’re pointing blame at them and they will retreat from you. If

you are unkind they will pull back. Deaf people are very in tune to body language and will quickly notice if you talk down to them. (- translated by EH for P13 p. 11, 4-5)

4.2.3.3 Dislike of bluntness.

The blunt manner in which the diagnosis was sometimes presented induced an intense emotional reaction of “feeling dropped”, “cold” and “alone” for a few participants. They spoke of the need they had for the professional to have more sympathy, listen to them, and present the news more gently. Although they reported the professional to be very informative and knowledgeable, they felt that the professional should have treated the situation as a life-changing event, rather than just give the information so “correctly”.

And she said: “Uhm, ya, but with her hearing loss she won't benefit with hearing aids, so the only thing that I can tell you is that she must go sign. You have to sign; you have to do lessons now in sign language”. ... And she looked where we come from, and she said: ... she would really say School B is better and she will then be the audiologist and she will fit hearing aids, just if we want to and the next thing she said... And sho, that was also a hammer, oh! It was terrible...“Oh, and your home language I see is German.” And we said: “Yes, we're very German.” And she said: “Ok, you have to change your home language now.” ... “No, because all the therapists in South Africa are English and/or Afrikaans for that matter, which one would we prefer? And if you want to have German, then you must move back to Germany.” Just like that. It was harsh! That was really, really harsh. (P1, p. 7,3 & 4)

“There was never a comforting time where she could... I don't know, maybe I'm just a hugger, maybe it's my personality, she is a professional, she was absolutely professional: that's how you do it, it's correct and whatever. She was too correct for my liking. We had to deal with a child, a baby and there was no sympathy actually. “Face it. That's what it is. Face it”. And if you can make a survey or something ...

that can make audiologists more aware of how tender we are when we hear that and how gentle you have to go along and tell people about a baby that is deaf, I would be just so grateful if you can do that - If you can change the world in that way.” (P1 p. 9, 4)

4.2.3.4 The plea against disregard and rudeness.

A few participants felt that they weren't acknowledged during the testing and were treated with complete disregard. They did not receive answers from professionals when they asked questions. This power dynamic is interesting to note as they described the context to be typical of public health care in South Africa. These participants did not know how to support their child in light of the lack of information from the professional. This is vividly illustrated below:

So I tried to tell them to explain to me what was going on. You know this public hospital, they don't tell you anything. (P5 p. 2, 3) You know, if somebody has a problem, you sit them down, and then you talk with them. It doesn't matter if they are young, or old, but you sit down with the person and tell them the problem. Even if you don't know the problem, just explain whatever you know, the little you know...” (P5 p. 9, 3)

... they are so rude, and you are scared to go to ask him: “What can I do to do this or to reach this?” So to them I just want to tell them: they choose to be the doctors, no one choose for them, then they choose to be the sisters, no one just for them, so they have to be faithful, they have to be strong and then they have to be patient, each and every one who go inside the hospital, it's your sister or it's your brother, it's your child. Just feel free for them and then you can open them to come to you, to ask many questions... So I just want to tell them that please, let them try to be open for other people...” (P7 p. 11, 2)

4.3 Theme 3: Imbalanced relationships, strained resources and resulting identity threats

This theme covers sub-themes which highlight the extensive, pervasive and all-encompassing effect the diagnosis had on the participants following the diagnosis of hearing loss. These findings relate to the third aim where the caregivers' stories were analysed to understand how their roles and identities changed with this experience. Their roles were in most part shaped and changed by their relationships with themselves, their child and others. There were challenges and sources of support. This is valuable to note as the diagnosis lived on in a world outside the clinical moment of diagnosis. All of a sudden their identities were changed in relation to others and this was threatening to them.

The theme is divided into sub-themes that discuss the impact of the news on relationships to various members in their family, friends and the outside community, and describe what helped and what didn't help, and what resources were useful to them. It then delves deeper into the deeper meaning of what they were saying about their identity: asking why, talking about losing a dream and changing their worldview.

4.3.1 Impact of the news on relationships

This theme discusses the network of support for the participants, from the professional at diagnosis to the home and the community. It weighs up the relationships of the participants with all the people within this network, as well as the specific support they received and the challenges they faced.

4.3.1.1 Impact of news on relationship to spouse.

There are different factors that played into this relationship. On the one hand, some participants felt a deep sense of gratitude, tarnished somewhat by the way spouses dealt with the news. On the other hand some participants felt a deep sense of loneliness where they were left alone without a partner to help. A male participant expanded on this by stating that leaving a partner alone to deal with the diagnosis was common practice in his opinion of his

culture, giving the sub-themes another dimension of what moral obligations are felt to be essential by the participant.

Some participants spoke highly of their spouses, telling of how they grew together by being there for each other. They felt immense gratitude towards them for supporting them throughout this experience: "Really, my husband is so supportive! ... and then he takes us as a family on this ship and we ride this ship and then we get there. He's a real captain." (P2 p. 8, 4)

It presented a special bond. However, what is worthy to note here is that if the participant and his or her spouse reacted differently to and coped differently with the news of the diagnosis it caused tension within the relationship. So although it made them stronger, it was an unforeseen stress that put strain on their life and their relationship.

Blame was already mentioned in the first theme where the spouse's initial response was to blame the child, because he himself did not know how to deal with it otherwise. Being present at the diagnosis also seemed to play a role. One participant implied that if her spouse had been there it could have escalated the tension: "... I think it wasn't intentional, but my husband blames San-Marie* for many things." (P6 p. 4, 1). Another participant supported this feeling of blame and said:

... but he did say that if there was really something wrong, he would blame me for it. I know that it was also his reaction, because it was difficult for him to accept and to think that the test might confirm our suspicions – what would he do, how would he feel and how would he have reacted?" (P10 p. 3, 4)

Thus, how the news would be received by a parent or their spouse could not be predicted by the participant. However the importance of their spouse's support and their

presence at the diagnosis was emphasised regardless of their reaction: "Luckily Heinz* was there and we were waiting and she really did a very long test." (P1 p. 5, 5)

4.3.1.1.1 Facing the news alone or together. Single mothers literally stood to face the news and its implications alone. They told of how they felt an extra weight they had to carry even if they received support from other family members. They expressed their regret and loneliness at the absence of the father of their child. Although each participant's story regarding how they became a single parent was different; they all expressed that a father-figure and the support that a father-figure brings was missing after the diagnosis.

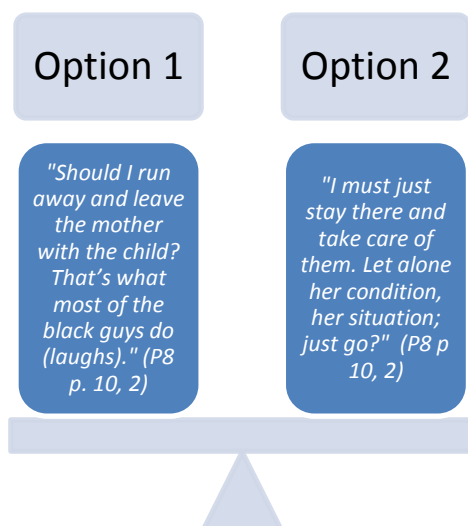
My mom is the one who supported me during this time, because the father left when I was pregnant. (P5 p. 3, 6) Researcher: So what would you say was missing? P5: The father, ya. The father-figure. But my father was there. My father was there all the way. (P5 p. 8, 4)

One of the male participants of the same ethnic and socio-economic group picked up on this theme by stating that he battled to come to terms with the news as well as having to face his wife's sadness. He thought of running away "like all the other black guys do". The breakdown of his quote below depicts his struggle and reasoning:

PROBLEM:

"For me like it was like dealing with the news and dealing with the wife ... It was like an explosive..." (P8 p. 8, 3)... How am I going to deal with this? My mind was blank. I didn't know where to go; I didn't know where to find help. (P8 p. 10, 2)

OPTIONS:



SOLUTION: OPTION 2

I thought no, that's not going to solve the problem. It will haunt me at the end of the day; it will come back to me... I can't just run away..." (P8 10, 2)

Figure 11: The internal struggle and reasoning behind the moral and relational dilemma between a participant and his spouse

This male participant emphasised how in his experience it was considered to be a legitimate option to leave his wife when faced with a problem. He attributed this to his culture. This was his experience however and is not to be generalised, but adds another possible complicated dimension to relationships when faced with disability.

4.3.1.2 Impact of relationships to family.

Majority of participants reported support and or challenges in their relationship with their families. These experiences were shaped mostly by the first people outside of their close family unit they told the news to. This sub-theme is categorised into two main categories:

support within specific family member relationships; and challenges that were comprised of the different dimensions of isolation.

4.3.1.2.1 Support. When participants reported support it was pointed out to be in relation to a specific member in the close family unit. The dynamic of the relationship was also very specific to the participants' background and situation.

4.3.1.2.1.1 Family unit. The single mothers reported how they had to rely on the help and acceptance of their child from their parents. They felt more acceptance of and peace with the situation if their parents approved of and accepted the child. As they relied on their parents for the support, this became of cardinal importance to them. This was mostly due to the fact that if it wasn't for their family, they would otherwise have no-one else to support them: "... as long as my parents accepted it I don't care about the other person. As long as my parents accepted him..." (P5 p. 5, 5)

A few participants, who had a family history of deafness, relied heavily on their own or their spouses' parents for their support, because of their apparent expertise with deafness. This was especially credited towards their mothers/mother-in-laws. They were the ones that could guide and give advice the best.

I think I was lucky enough; my mother-in-law was still around and she brought up Gwen*. She was the only child in her family that didn't have a hearing impairment, so I think it was a lot easier for us... (P11p. 3, 3)

Participants also leaned on their siblings for support as a few retold of the special bond they had with their sister(s) and how these seemed to understand much quicker what they required of them and also how they felt, giving emotional support. This alleviated the burdens of every day working with their child as well as coping with the pain that occurred at

diagnosis and also after diagnosis: "... although, my sisters are here, and they accepted it quite well. They knew what we wanted from them." (P4 p. 7, 2)

Participants seemed exceptionally grateful for the 'normal' treatment they received from their sisters. They did not engage in a pity partner, but rather helped and encouraged them: "They didn't feel sorry for me and pitied me, because that is not what I wanted. What I wanted was that we could get over that bridge and get her to talk." (P9 p.6, 4)

4.3.1.2.2 Challenges.

4.3.1.2.2.1 Isolation. The challenge that participants were mainly faced with was that of isolation. They were isolated from their families or their child was. Their isolation was due to labelling, ignorance and prejudice by family members.

4.3.1.2.2.2 Labelling. A painful experience was reported by a few participants whose in-laws had strong negative responses to their child's hearing loss just after the diagnosis. In these cases family members bluntly labelled and isolated the children in front of others in the participants' direct community, e.g. acquaintances or the pastor. This caused a lot of pain and hurt. Two quotes have been included to show the depth of emotion at their in-laws labelling of their child.

And I will never forget that. There it really struck me. It was harder than the blow of the audiologist, because there you somehow expect it; you're in a medical environment, but when Opa said that to Pastor: "Here's your first deaf congregation member". It was terrible... everything was just so sore, it was like this raw wound, and everything just scraped it open, anything that would say your child is deaf, your child can't hear... (P1 p. 10, 3)

4.3.1.2.2.3 *Ignorance*. One challenge unique to the Deaf couple is that they gave insight into the hearing and Deaf world and the difference in culture. They didn't expect a bridge of understanding and accommodation from people immersed within the hearing world. As a result they raised their child so as to become more acquainted and comfortable within the Deaf community. Their extended, hearing families were ignorant of them, never going out of their way to accommodate them or show any interest towards them as individuals. "We felt that the family neglected Renier*... So when they came to visit it mostly only an exchange of greetings, but nothing more than that as they would carry on talking among each other." (- translated from Afrikaans to English by ER for P13 p. 4, 8)

4.3.1.2.2.4 *Prejudices*. A few participants struggled to make their families understand what implications the hearing loss has for their child. Certain prejudices influence their families views on how the child should be treated differently. The participants had to advocate for their child and their capabilities, encouraging their family to treat the child 'normally'. A vignette has been used to illustrate which prejudices were held about the child with a hearing loss.

It was all new to the family. When we went to visit they would often shout at their own children saying: "No, leave that one, don't play rough with her." We would then have to explain: " She's not sick, you can play normally with her. She also jumps and climbs trees. She is no china doll that will get hurt at the smallest thing. Leave her, don't pity her or me for that matter." We appreciated their concern, but wished they could have treated her more normally. The elderly immediately assumed she would go signing as she would never be able to hear. (- done by EH from transcripts from P9 p. 9, 1; P4 p. 7, 2 and P2 p. 8, 4)

4.3.1.3 Impact on relationship with friends and community.

The support structures that were in place for caregivers included parent support groups as referred to by professionals and the Deaf community of which some participants were already a part of. The challenges that participants faced included one isolating factor, ignorance, which was similar as discussed with their relationship with their family, but also that of isolating cultural differences.

4.3.1.3.1 Support.

4.3.1.3.1.1 Parent support groups: A few participants specifically mentioned organised parent support groups that helped to cope and come to terms with the implications of the hearing loss. They expressed this to be of great help and promoted a feeling of community and togetherness. It also alleviated the feeling of being alone and they felt extreme gratitude towards having that support from others who are going through a similar experience.

... when you heard the news you think you're the only person who, on the whole planet, who has a deaf child, because where do you go? ... It was so fantastic, it was absolutely magnificent. And you start talking: "How did he become deaf?" etc. And suddenly you were part of the family and that made it work. (P1 p. 12, 3)

The need for a parent support group was furthermore expressed by a few other participants who did not receive that kind of support. Thus this is an important supportive link in the process of dealing with diagnosis of hearing loss so as to also gauge what future prospects for their child might be.

I would have liked that (P8 p. 6, 9) I would have liked more examples of children that went through this, that had an implant and how they were coping. Not just words on a page, I wanted to see it. That would have helped." (P8 p. 7, 2)

4.3.1.3.1.2 Deaf Community: Some participants expressed how they received support and courage from their friends. Both of these sets of friends were entrenched within the Deaf community and it was interesting to note that this group gave hope and advice that other, hearing people, could or would not be able to give. A vignette has been used to illustrate this more clearly.

It was our experience that our Deaf friends loved our child and that they accepted him completely as part of us and our Deaf world. They gave us advice, not the hearing people, probably because they weren't confident enough to share advice, because they didn't know how to handle a deaf baby. These friends of ours encouraged us, because they had made a success of their lives. They're all working and there's no real outcast. This gave us hope for the future." (- done by EH from transcripts from P13 p. 7, 4 & P11 p. 8, 1)

4.3.1.3.2 Challenges.

4.3.1.3.2.1 Ignorance and the need for more public and professional awareness: A few participants reported ignorance from the professionals as well as their community. They reported that there was too little information regarding hearing loss in their communities, as well as in the professional world where GP's did not know what cochlear implants and degrees of hearing loss meant and implied: "... there's very little information, because very few people from when it happen to my child know what it is... So I would say an increased awareness, because they don't understand. Even GP's."(- translated by ER from transcript from P8 p. 8, 7)

Other participants expanded on this sub-category and told of interaction with friends and the broader community where the participants' situation was turned into a pity party. Instead of providing the participants with possible solutions, they're ignorance forced them to return to their prejudiced viewpoint of disability and labelled the child as such.

Come here with some information. Say: "P8 there is this doctor; he/she gave me this information. Go and try these person, maybe she might help." Like coming here and holding the child and "Ag, shame, she's so cute, but she can't hear." I didn't take that, I didn't take that story. (P9 p. 9, 1)

4.3.1.3.2.2 Cultural differences. It was interesting to note that social and cultural context created different views on the diagnosis. This view created scripts which were very unique in nature and specific to a particular cultural group. A few participants from two different cultural groups shared the impact that cultural differences made on their experiences with their child(ren)'s hearing loss; especially after diagnosis.

One (couple counted as a unit) reflected on the difficulty that exists between the hearing and the Deaf world where they themselves experienced the difficulty of finding a job and feel accepted within both communities. They understood the differences, but were more comfortable with their own cultural group and projected that onto their child as well. They predicted that one of the challenges that he would face would be to struggle within the hearing world as it is essentially different to his culture.

The other participant actually chose to seek out help and support from another cultural group, He believed that his own (Black) community was too fatalistic and nonchalant to give their child the proper care. This participant was seeking something 'better' for the sake of his child; believing that this 'something' meant that he would not mind to integrate his child within the White community.

We accept and know the difference between the hearing and the deaf world and that a hearing child would default to the hearing world. For that reason Renier* was much closer to us... whereas our hearing daughter is more at home in the hearing world."(- translated from Afrikaans to English by ER for P13, p. 8, 5)

“... we went to a black doctor, I'm not trying to be racial, but then we said: “You know what, let's be realistic, in white communities they knows lots of stuff... We will find help.” (P9 3, 1-2)

4.3.1.4 Resources depleted and supportive

There were three types of resources that otherwise impacted on the time shortly after diagnosis by which participants could and did deal with the diagnosis itself. These include three categories: finances, technology and prayer/church.

4.3.1.4.1 Depleted or extra finances caused increased stress. Some participants told about the stress (in one case causing illness) they felt due to the financial implications that the hearing aids and/or cochlear implants brought with them. The decision between the two and the push for example the cochlear implant from professional teams, was also seen as stressful. Most of these participants spoke of funding they received from donors, professionals and family and how this alleviated their burden; however financing caused a lot of added anxiety above and beyond the actual hearing loss in their child.

It was very stressful to think how we we're going to get that kind of money to actually have that kind of operation done... So just before his operation I ended up with alopecia... and then Kobus Pretorius* approached us and said that he would like to be part of the fund and thereafter the fundraising went quite smoothly. (P4 p. 7, 3 – 8, 1)

4.3.1.4.2 Technological advances in amplification: These were seen as a great support. Some participants praised the technologically advanced amplification that was available to their children. A few of the participants could compare it to older technology, because of the contact to the deaf community and experience with hearing aids. Some other participants retold of their appreciation of the cochlear implant giving access to better hearing and improved language skills and development for their children: "Technology is so advanced these days that you will never fall behind. You will not have a deaf and dumb child, or whatever the case may be." (P11 p. 9, 1)

4.3.1.4.3 Spirituality provided strength during difficult times. A few participants spoke of how prayer helped them deal with the diagnosis and come to terms with it, a participant specifically referring to the church community that helped and supported her. This is important to note as an important link in the network of support needed for parents who are coming to terms with the diagnosis of a hearing loss in their child: "... that will help us... and we prayed a lot. I am not a church-goer, but I do believe in God. I pray a lot..." (P9 p. 12, 3)

4.3.2 Dramatic, disruptions, changes and shaping of participants' roles and identities.

This sub-theme tries to show how participant's interpreted and attached meaning to their experiences and how they constructed their world and identities from that. With the event of diagnosis their world changed. This is mostly represented in their question "why me?" This category is there to unpack some of the issues associated with this question and look deeper into where the search for meaning started and where it ended.

4.3.2.1 "Why?"

Majority of participants asked the question "why me?" or "why my child?" It represented an inherent search for answers and an attempt at coming to terms with the

diagnosis. Where the question came from is represented in the sub-themes “loss of a dream” and “identity”. How they dealt with it was intricately different and pertained to their specific belief system and where they would believe to find strength under “inherent beliefs” and “learnt attitudes”.

4.3.2.1.1 Loss of a dream. A few participants' stories started with hope and a certain expectation of life, a dream which had to change with diagnosis. They were confronted with an unexpected mind shift as some felt their own dreams crushed and their lives turned upside down; forcing a few to quit jobs, move, and/or earn less money. This ultimately ruined the dream they had for their futures and that of their children.

It's almost like when you have a dream and it's no longer that dream... Because she couldn't just go to any school... and all the therapies. It's bad, because a normal child wouldn't have had that.” (- translated by EH from Afrikaans to English for P8 p. 6+8)

Participants were confronted with the idea of possibly leading another, unfamiliar life where they would have to change to function in another world, such as signing. Thus there was an existential fear of their child not being a part of their own, ‘normal’ hearing world. Participants thought that their children would become strangers to them thus threatening their roles and identities as parents.

So they explained to us that it's not too late because we were really panicking: it's too late for speech! Maybe she should go into deaf speech, you know, go to a deaf school, and do signing. (P2 p. 6, 1)

A deaf participant emphasised the differences between the hearing and Deaf world and sympathised with hearing parents recognising and highlighting the fact that there

different experiences and expectations of deafness exist in these worlds. She explained that a hearing parent would react with more disbelief as they are confronted with a new idea and not knowing how to navigate through this uncertainty: "... Normal hearing mom, like my mom... Because getting a baby that is deaf is very unexpected." (P3 p. 5, 7+8)

4.3.2.1.2 Identity. Participants asked the question of "why me?" as it did not only change their circumstances and dreams for their future, but rocked the boat in terms of their own language which ultimately encompassed change for their culture and identity. Due to the diagnosis the implication for a few participants' children was that they would not speak the same home language as their parents (as schooling and therapy in South Africa is done either in Afrikaans or English). One illustrative participant told of the critical self-questioning she underwent on who she was as she was confronted with changing her home language:

... you actually change your whole culture; your whole being; you change your whole self." (P1 p. 8, 4) "Why? Don't make a God out of this. It's just a language." And he took it, weeps, away with a child that doesn't speak German, because the therapy in South Africa was in English... That was then a real, real mirror that He held in front of you and asked: "Who are you actually? (P1 p. 11, 4)

Changing the home language sometimes evoked pride and glee at being able to speak another language that other grown-ups cannot speak, the initial feeling of hurt was not missed as it changed participants' worlds.

... she gave me the courage to learn a lot of new things... at least now she is learning English as well and she is trying to learn our language as well, of which is Tswana, but it was hurting, but it opened our eyes in a way. (P9 p. 3, 1)

Although both of these participants came to terms with their changed identities, they both still had to grapple with the question of “why me?” and “why my language?” depicting the life-changing effects that the diagnosis can have on parent’s lives.

4.3.2.2 Dealing with the question.

4.3.2.2.1 Inherent beliefs. Some participants came to deal with the question “why me?” by relying on their religion. They turned to God and asked Him why this happened to them and/or their child. A few participants started to cope with it as they felt that God was trying to teach them a new perspective and lesson be that on a practical level like learning a new language or on a more reflective level.

... so why can I say: “God, why you give me this kind of child? Maybe you just want to give me just another experience.” Because at the moment I now know sign language and there’s a lot of people that don’t know it.” (P7 p. 6, 1)

We’re very structured, very organised, and that’s how it was, our lives: we will get married, then we will have children, then we will have that, then we will build the house, and then, then, then. Like that. And it was as if God said: “Hey, listen, where I am?” And He said: “I’m going to give you this child and I will show you that it’s not about you at all.” (P1 p. 11 4)

4.3.2.2.2 Learnt attitude. A few participants dealt with the question by adopting an attitude to remain strong and have courage. Grievance over deafness did not seem to trespass into pity over the deaf child: parents seemed to separate the “what” of deafness from the “who” of their existential-relational child (Wever, 2002): “Why? Why? Why? Why my child? ... Just find a way to do something. Just find a way to do something and help this child.” (P8 p. 9, 2) “And we had the courage to see those people...” (P9 p. 12, 2)

4.3.2.3 Altering worldviews.

Participants told of how they grew personally through this major life incident and how that experience changed them as individuals as well as change how they saw their world and their child in that world, integrating their child into that worldview. Two sub-categories emerged where participants told of how they started viewing disability differently from this experience and how they finally had the courage to disclose information to their community and become advocates for the disability and their child.

4.3.2.3.1 Coming out of hiding. Some participants spoke about being open about the diagnosis within their community. A few told of how in this way they found the school for their child and that being open and honest not hiding the child, got them to find help.

A few participants explained this attitude of “being open”, “not hiding their children’s disability” to be difficult in their communities as they live in a world where their children are laughed at and that some people in communities would even get violent if you confront them with a new reality. This makes the task of being an advocate and creating awareness very difficult, thus highlighting the importance of educating lay people regarding children with a hearing loss.

No, they hide the problem... They don’t want their child to be seen; because if there is paraplegic in the house, most of the people they don’t go out, they hide that person. They fear that other people will laugh at them. Yes, they will laugh, but at the end, they’ll laugh (parents of disabled child – added by EH) – their laugh will no longer be there (community – added by EH). They will know that this person is like that; it’s how God made that person. Going out openly you are not hiding the fact that you’ve got a deaf person in the house.”(P9 p. 12, 1+4)

4.3.2.3.1.1 Rethinking disability and altering world views: A few participants told of how they viewed disability in a different light since having a child with a hearing loss. They were more sympathetic and hopeful for children with hearing loss and encouraged that there is help to be found so that they can lead a “normal” life. One of the deaf participants echoed this sentiment stating that her child changed her world as she can show him off to the world as being able to achieve and be like a normal child:

It made me look at people with disabilities from a whole new point of view and that there is hope out there and you should never look at them differently from others. That's the one thing that I've learnt. (P4 p. 11, 1)

He's definitely changed my life. I think he changed my life, because he's a deaf child he is something that I can be proud of. I don't want to compare him, but when other people say: “Oh, look at that deaf child. He can talk normally, he can hear like a normal child. (P3 p. 8, 6)

4.4 Summary

This chapter show-cased an in-depth set of results depicting a deep and emotional journey that impacted the lives of parents of deaf children to the core. Although there were many role-players involved in the process it remained a story intrinsically unique to the experience of the participants facing a new reality. This shows that the qualitative analysis yielded nuanced, in-depth results which otherwise would not have been depicted in a quantitative survey. The impact was not restricted to their own lives, but those around them as well, be that close family and friends, or their community, and even further than that their identity within that community. Whether they had previous exposure to hearing loss or not it remained a challenge to navigate through this new reality and find a place in a world that initially only sees a disabled child. The next chapter will discuss what implications these

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results hold for the audiologist in terms of his/her interaction with and service for these parents, and the awareness these results generate for the context in which parents receive this life-changing news.

CHAPTER FIVE

DISCUSSION

5.1 Overview of the Chapter

In this chapter the results will be discussed and contextualised within the literature.

5.2 Theme 1: Diagnosis is a catastrophic and emotional experience

As is evident from the results, participants experienced diagnosis with predominantly negative emotions. Participants described shock, worry and hurt as the predominant emotions at the time of the diagnosis, and often felt overwhelmed by them. The emotional strain they experienced was often described as cataclysmic and catastrophic (Wever, 2002).

Participants also described the moment of diagnosis vividly, almost as still movies or pictures, and could go back and relive the emotions very quickly in recall. However, although recall was vivid, they often had difficulty putting it into words succinctly. Either participants succumbed to the emotion felt at the time of diagnosis and described it in overwhelming, emotive terms, or they described it superficially and logically, without the emotive language you would expect, although they would openly cry while retelling the story (see 4.1.3 Hurt in 4.1 Theme 1: The catastrophic emotional impact of diagnosis in Chapter 4). These traumatic memories also remained central to the participants' stories throughout their life.

The emotions appeared unresolved even until the point of data collection, which indicates how these emotions remain a huge part of their coming to terms with the news of diagnosis. Some participants were aware that they were acting out emotionally and were trying desperately, even during the interview, to reason out the situation without succumbing to emotion (see 4.1.3.2 Grief in 4.1 Theme 1 in Results Chapter).

The results illuminate that participants' emotive responses included worry, acute shock followed by hurt, which resulted in fear and confusion. The data shows that how participants tried to cope with the news was greatly influenced by their fear of the unknown and the resulting confusion that the new situation brought (see 4.1.4 Emotions associated with the steps to coping in 4.1 Theme 1). This is why there were so many emotions evoked during the diagnostic process and by and in the relationships affected by the diagnosis. The challenges participants now faced were complex and held completely new implications for their lives and the life of their child, implications that they feared and did not know how to navigate.

They found that choosing an amplification device (whether hearing aid and/or cochlear implant) and mode of communication (spoken vs manual) was especially challenging at the time of diagnosis (see 4.1.1 Worry in 4.1 Theme 1). As participants explained, their worry over these clinical decisions became intertwined with their concern over how their children would participate in all spheres of life: communication, education and work. In addition, the diagnosis presented further challenging questions about schooling, their relationships with their spouse, with their family and wider community (see 4.3 Theme 3: Imbalanced relationships, strained resources and resulting identity threats in the Results Chapter). Participants soon realised that the hearing loss threatened their child's complete participation in life. As a result, participants worried about what steps were best to take next and wanted guidance on these steps, even while they could not look past their own feelings of shock and hurt.

Hearing participants often worried about the language they should use with their child, i.e. manual vs spoken language (see 4.1.1). They expressed a wish to form a child- and relational centred, meaningful relationship (Wever, 2002), and often felt that this was to be acquired through use of their "normal" language. They had a deep fear that now they would

not be able to connect with their child. They also worried that it was already too late and that they might have lost some connection with their child, for example when they realised that they could not soothe their baby because it could not hear them (see 4.1 Theme 1: The catastrophic emotional impact of diagnosis in Chapter 4). Hearing participants also worried about whether wider society would be able to accept their child. They started to perceive their child as different, and were thus reluctant to choose a language that further showcased this “difference”. Here the practitioner played a vital role in guiding and reassuring the participants to come to terms with their worries and fears, a role which will be discussed in the next theme.

The Deaf participants on the other hand worried about their child’s opportunities for the future on the basis of their own challenging vocational experience (see 4.1.1). They emphasised that because the societal norm is spoken language, they needed to be shown options that enabled their children to cope in the “hearing” world.

Parents thus generated very complex concerns as they discovered they had a child with a hearing loss. The Deaf participants’ experience with deafness allowed them to view it very differently to the hearing participants. They favoured a de-stigmatizing view of the disability, emphasising that their child was ‘normal’. Yet, Deaf participants, like their “hearing” counterparts, feared that their children would not be able to lead fulfilled, meaningful lives within the society at large.

Participants’ experiences with shock, worry and hurt, as revealed in this study, support the findings by Gittins, Patterson and Sharpe (2006), whose participants also described their experiences with a traumatic event as tragically shocking and life-changing. Narrative research studies indicate that those events which impact deeply on one’s life are imprinted into experience (Frank, 1998; Frank, 2013). This is because during these traumatic

experiences the body prepares for survival and the limbic system becomes more active in processing information than the frontal cortex – the part that does the understanding, thinking and reasoning (Burke, 2008) - which indicates that the emotive response transcends a reasoned response. The literature thus concurs with the results of this study.

Literature on emotional intelligence (EQ) illuminates the importance of understanding emotions when faced by a new, stressful and life-altering environment – in this instance a diagnosis of hearing impairment. An individual's capacity for self-control and persistence enhances one's ability to reason. However, it is at the point of diagnosis that a heightened emotional response and zeal surfaces and inhibits one's capacity for self-control, persistence and thus reasoning (Goleman, 1995). The flood of emotions prevents the person from processing additional information – which explains why patients often do not process additional technical information from professionals at the moment of diagnosis (Goleman, 1995).

This study has shown the effects of hearing loss on the parents to be deeply emotional due to their anxiety over their child's participation in society. This anxiety extended far beyond the typical audiological scope of practice. The field of audiology has often been more focused on the body's anatomy and physiology and consequent functioning, and so sought to find medical treatments and solutions for that functioning. But, it is anxiety over the broader contextual and personal concepts falling under the activity and participation of the child within their family and society (Naudé & Bornman, 2014) that causes parents most concern and anguish, and that they feel the most need to have addressed.

The International Classification of Functioning (ICF) recognised that the experience of disability is complex as it describes the impairment and its consequences (WHO, 2001). This study highlights that the news of diagnosis is experienced as a personal, emotional

response which is intrinsically linked to the social and contextual challenges which will be faced. It also highlights that while the ICF typically focuses on the individual with the impairment, the caregivers have a central role to play in the process which begins with the experience of the diagnosis. When the patient/client and his/her family are recognised in a holistic way there exists, among other things, a real opportunity to lessen or worsen this sense of tragedy. This holds certain implications for the practitioner in the field of audiology and is further discussed under the implications of this study.

5.3 Theme 2: The audiologist is central to the growth and recovery of the caregivers' emotional equilibrium

The audiologist was the main practitioner involved in the experience of diagnosis, although some participants also dealt with other professionals, for example ENT's, who also broke the news of diagnosis to them. In their first encounter with hearing loss in their child, participants felt dependent on the practitioners' guidance to assist with the decisions that they now had to make in terms of amplification, communication and schooling. Although the audiologist was a gateway to information, he/she was also a witness to the emotional impact of the diagnosis on participants, as well as their attempt at coping with these emotions.

The emotions the participants described remained for life and interplayed with their perception of how well the practitioners handled the whole experience of diagnosis. This study's results show that the interaction with the practitioner could mediate the sense of tragedy (see 4.2 Theme 2: The good and the bad of professional interaction in Results Chapter). That means, the experience and consequent feeling of shock was dynamic and open to change when the practitioner responded to parents' pain with empathy, positivity and a listening ear. However, Participants had varied experiences with the practitioner from good

encounters to bad encounters as seen in the results (see 4.2 Theme 2: The good and the bad of professional interaction).

The relationship with the practitioner was seen as positive when the practitioner was gentle and included parents in the testing procedures. When the practitioner did so the participants started to hope again. Moving out of the shock state was aided when the practitioner showed the following traits or behaviours (see 4.2 Theme 2: The good and the bad of professional interactions in the results chapter for illustrative quotes): the practitioner gave an element of hope by remaining positive about the participants' children; was forthcoming with a lot of information that was set out and illustrated clearly; was collaborative in sharing knowledge; and shared in the participants' experience by showing empathy, offering options of support and was gentle in the delivery of the news.

Being gentle can be defined simply as an attitude of care. The participants could pick up very quickly by a practitioners' language use whether they seemed to care for them and their child's well-being or not. Thus, It was not so much an inflection of the voice or an extra show of affection, but rather a caring attitude that was important (see 4.2.3.1 and 4.2.3.2 in 4.2 Theme 2: The good and the bad of professional interactions in Chapter 4). At this point it needs to be emphasised that a majority of the participants were female and the results mostly relate to what they said. It is likely that males may prefer different interactions.

Literature however supports the focus on a gentle engagement with parents since, regardless of a practitioner's theoretical and experiential knowledge and intervention approach, the working relationship within the context of that initial interaction remains critical to the building of rapport and the consequent successful intervention outcome (Duchan & Kovarsky, 2011; Sharpley, Halat, Rabinowicz, Weiland & Stafford, 2001). It is, however, important to note that "body language" plays a vital role in achieving this Gentle

engagement and effective rapport with the client, as suggested by the Deaf participants in this study (see 4.2.3. The request for gentleness). They told of how they relied heavily on visual cues to gauge what was happening in a given interaction with others. Thus, they could easily pick up if an individual was cross or impatient, and were particularly sensitive to this sense. This perception of impatience in the practitioner could then be interpreted as blaming the Deaf parent for the child being deaf, and thus cause the participant to retreat further from the practitioner. Being gentle thus incorporates an attitude of caring when delivering the news verbally as well as manually through body language.

Participants felt comfort when they were included in the testing process. At the beginning of the appointment they needed to know the following: what testing would be done, what the test tested and what the results could potentially mean. Visual aids needed to be used when explaining the audiogram. The information had to include the following: What a normal audiogram looks like and how their child's compared and what that meant, as well as ear anatomy, aetiology, amplification options and contact details of schools and other parents (see 4.2.1 Good quality of information in 4.2 Theme 2).

Yet, it was noticeable in parents' stories that, despite the great importance they gave to the information itself, they emphasised even more how important a gentle and caring attitude in the practitioner was when giving the news and the information (see 4.2.3.2). So rather than only seeing the practitioner within the professions conceptual framework as a solution provider whose expert opinion, guidance and knowledge has been sought out to habilitate a communication problem, a more successful approach by the practitioner was to facilitate and engage with the clients' families and coach them on what recommendations meant (Clark, 2014).

This is clearly seen in the results under good quality of interactions (see 4.2.1) where participants asked for illustrative examples and information on what results and options for amplification and communication modes meant. However, this meaning-making was not only focussed on explanations and a list of information, but rather meaning-making ensued from the negotiations between practitioner and patient, where interpersonal and emotional relationships started playing a role within the interaction. That means good quality relationships considered the emotion that the participant was going through. When the practitioner did not miss the emotionally laden signal by the parent and responded gently, the participant felt more empowered to face the problem. They could deal better with the diagnosis and the information that followed.

This is also supported in the literature by Clark (2014) and Duchan & Kovarsky (2011). They both argue that on-going meaning-making is important as it determines the success of the intervention. However, meaning-making is further influenced and determined by practitioners as they are often guided by their own personal compasses of compassion, respect, fairness, and honesty which in turn are also influenced by personal factors such as friends, family, peers, educators and experiences (Clark, 2014). As an example, in this study there was the practitioner who believed that a child with a severe hearing loss needed to sign and that consequently the family needed to change their home language. She could possibly have given this information in what she believed to be an honest, factual assessment of the child's intervention needs, although it was experienced as extremely harsh and blunt (see P1's quote under 4.2.3.3 Dislike of bluntness in 4.2 Theme 2 of Chapter 4). Thus this set of results refers back to the practitioner's and the participant's differing backgrounds and worldviews. There was a need by participants for practitioners to acknowledge them and their background and show recognition for the complexity of their concerns for their child.

Strong negative emotions at diagnosis were also influenced by parents' interaction with the practitioner and exacerbated by the following factors (see 4.2.2 Bad quality of interaction, 4.2.3.3 Dislike of bluntness and 4.2.3.4 The plea against rudeness in "4.2 Theme 2 in Results Chapter): a feeling of being abandoned in terms of information; receiving no further guidelines on intervention options, schooling and other support; receiving news that was given bluntly; feeling forced to choose for a particular amplification device (e.g. CI); and receiving news given in an unsympathetic way with a superfluous amount of technical and clinical terms.

These strong negative emotions, including anger, blame, loneliness and shock (see 4.1.2, 4.1.4.3 and 4.1.4.4), could have been avoided by practitioners. The participants spoke of a sense of hope when the practitioner showed: empathy by using a gentle tone of voice and recognizing that they must be going through a hard time now, while also reassuring them that they are there to help and guide the parent (see especially P1's quotes in 4.2.3.2 The request for gentleness in Theme 2: The good and the bad of professional interaction of Chapter 4).

The following practical guidelines were suggested by participants to achieve a better interaction (see Theme 2: The good and the bad of professional interaction in Chapter 4): Provide guidance with decision-making by being clinically competent and be honest yet unbiased regarding informational counselling and the possible options of habilitation, i.e. manual vs spoken, hearing aids vs cochlear implants etc. At the same time, as is reported by Leach (2005) and Kovacs (2013) identifying, respecting and reflecting on parents' outlook and expectation for their child's future helped them deal with the diagnosis better (Kovacs, 2013; Leach, 2005). In this study it was mostly reported as a sense of hope for their child's future and for them to find a place in the society.

A strong point of emphasis from the data is that a sense of awareness is to be created among professionals to be sensitive to and respect caregivers' decisions when it comes to amplification and intervention. The contempt that hearing participants for example showed for SASL illuminated their entrenched societal view on disability, i.e. the societal norm of the dominant hearing culture still is a taboo against the use of a manual mode of communication. Thus, hearing participants feared to a greater degree than their Deaf counterparts that in the hearing world their child was now labelled as "the other" child who might be excluded (see 4.3.1.3 Impact on relationships with friends and community in Theme 3: Imbalanced relationships, strained resources and resulting identity threats in Chapter 4).

This set of results from this study thus supports research that states that Deaf individuals' fears of exclusion are still present and valid within our country's societal context and although there has been progress in the last 20 years the norms of equality still need to be redressed by looking at educational access for those with specifically a hearing disability (Kritzinger, Schneider, Swartz & Braathen, 2014). An added awareness of the societal implications needs to exist with the practitioner when giving (unbiased) information on different habilitation options (including amplification and communication mode).

As shown above, showing empathy and understanding has a lot to do with the way one interacts as a practitioner with the parent. Practitioners who acknowledge that they recognise parents' feelings and fears within the context they live in, and speaking in a gentler tone, help to address parents' initial and acute sense of shock and fear and potentially reduce the sense of confusion as parents are now able to listen to the information that is given to them. The participants spoke of a sense of coming home and being able to absorb information if it was given in a positive fashion (see 4.2.3.1 The appreciation for positivity in Theme 2 in Chapter 4). This process is supported by the idea of addressing the EQ before the IQ for the intake of information, as described by Goleman (1995).

The point of emphasis with these results is that when the practitioner is facilitative, he/she is inevitably aware of the parents' emotional state, and the participants experienced this as positive. The literature supports this finding as a listening, empathetic ear renders a sense of collaboration, reciprocity, parity and growth in clients' emotional development and coping with their loss of a dream (Leach, 2005). An environment where the caregivers feel listened to create a space where they can grow and become independent, empowered collaborators for the "treatment" of their child (Kovacs, 2012). Thus the findings from this data set is in keeping with the literature that states that a practitioner who is warm, friendly, affirming and understanding creates a greater alliance with the parent and creates the space for collaboration and effective treatment of their child (Leach, 2005; Ackerman & Hilsenroth, 2003).

5.3 Theme 3: Diagnosis has extensive, pervasive and disruptive effects on identity

This discussion highlights the deep personal impact of a diagnosis on participants' identity. The news of the diagnosis disrupted their sense of self and affected every facet of their life, far beyond the clinical interaction with the practitioner. Thus it answers the third aims objective to analyse how their experiences shaped their roles and identities.

All participants expressed the wish for their child to be 'normal'. For most of them this "normality" meant the ability to have oral communication, which was seen as key for the child's ability to connect with their family and their peers, to go to school and to have a self-sufficient job one day. Participants essentially wanted their child to be like them and to belong to a hearing world – the world most participants were a part of and where they knew the rules of engagement. However, with the onset of the diagnosis parents began to question how their children would grow up and integrate into society when they did not fit in with this, traditional, conception of normality. As a result participants struggled with their role to

parent: they did not know if they could continue to care for their child (4.3.1.1 in the Results Chapter), they asked why it happened to them (4.3.2.1), they were at a loss how to carry on (4.3.2.1), or how they would be able to help their child communicate (4.1.3 & 4.1.4), get a job or find a partner (4.1.1) or care for themselves when they are no longer with the parents (4.1.1). Participants knew hearing impairment to be invisible and yet to pose challenges their child was likely to face - challenges produced and fuelled at a level of societal expectations and judgements.

The societal implications of their child's hearing loss continued to live on in a real world outside of the experience of the actual event of diagnosis. Participants spoke about how they were scared to reveal the disability to others at first (see 4.3.2.2 Dealing with the question in 4.3 Imbalanced relationships, strained resources and resulting identity threats). They told of their fear that their society might get angry when confronted with something they were unfamiliar with. They even experienced how their children were laughed at. They essentially felt like they had to come out of hiding (see 4.3.2.3 Altering worldviews in 4.3 Theme 3: Imbalanced relationships, strained resources and identity threats in the Results Chapter).

The emotional pain participants spoke of is thus in part created by the culture, society and historical context in which they live. These influences were not absolute but varied for participants. However, it was evident that dealing with differences was challenging for participants because they lived in communities where difference and disability was seen as a problem. When addressing these difficult issues, the importance of a more open conversation between practitioner and parent was highlighted as so vividly described by P7 in the results chapter under 4.2.3.4. Literature supports this conclusion. Pillay (2003), for example, emphasises the importance of a conversation where the practitioner is knowledgeable on

issues of disability in relation to opportunity, participation, prejudice, stigma, inclusion and society (Pillay, 2003).

Thus, these results also caution the practitioner not to make assumptions in the post-diagnostic conversation with parents about their idea of “normal” as the practitioner is part of a societal norm with his/her own background where “normal” might mean something different to what it means to the parent. For example, the practitioner might find it erroneous of the parent to label their child as “normal”, as was emphasised by the Deaf participant (in 4.1.4.1 in the Results Chapter). It is advisable therefore, for the practitioner to keep on asking the question what ‘normal’ really means. That is why collaboration is emphasised in these results by the participants. Collaboration opens up communication about where one could meet on the expectations one has for the child and how one can best serve the parents who are grappling with decisions for their child at that point.

The study has also shown how a visibly different language like SASL, or an eye-catching amplification device, or even another spoken language to that of your community, signified to the participants’ world a “disabled”, and so different and abnormal, body. The overwhelming choice for spoken language in this cohort was situated in participants’ hopes of equipping their child with the skills to belong to the dominant group: the ‘hearing’ world where spoken language is the dominant language, as this group holds political, cultural and economic power in South Africa (Ige, 2010). Thus, their choice of language was perhaps less driven by language options that were unfamiliar to them, but rather by a kind of knee jerk fear that their child might not ‘belong’. Participants chose what they knew - thus they wanted their child to be normal as seen in their eyes. The further away from this identity that the child had to be, the more participants’ struggle with their identity ensued.

This was further complicated when the participant had decided to use spoken language as a mode of communication but had to choose a different spoken language to his/her mother-tongue (see 4.3.2.1). South Africa's practitioners are predominantly white, English and/or Afrikaans-speaking females (Pillay, 1997; Pillay 2003) and therefore professional intervention and scholastic education is also provided predominantly in these two languages. This meant that participants with different home languages struggled with the reality of not being able to raise their child in their own home language. This enforced change of language then posed an identity challenge where participants did not know how their child would fit in to the parental culture as spoken language comprised such a big part of who they felt they were.

Identity is shaped by language and the language choices we make conversely relate to our identity (Ige, 2010). When participants did not have access to intervention and education opportunities that accommodated their home language, they faced a dilemma with regard to their personal and social identity. They either had to give up their identity or give their child the opportunity to communicate with their peers and achieve academically in the language of general instruction. This is supported in literature: how parents understand themselves in relation to others, understand what makes them unique and how they view and want others to view their past, present and future is embedded in language use. As participants made clear in their wish for their children - how you employ language makes you 'belong' to a certain culture and world-view. It is the symbol of individual and group identity and becomes even more relevant when considering South Africa's multi-faceted society (Ige, 2010). Therefore, coaching parents and clarifying the perceptions that they and the general public might hold about the use of manual vs oral communication, or even another spoken language, becomes very important in the relationship of practitioner to parent. Participants struggled with this issue at the point of diagnosis as they struggled to understand why they had to change their

language and felt their culture and identity threatened by it (see 4.3.2.1 Why? in 4.3.2 Dramatic, disruptive changes and shaping of participants' roles and identities). They wanted to belong.

Societal norms make it difficult for anyone with a difference to be included (Pillay, 1997). This is referred to in the literature as viewing the “other” as a body without value (Edwards & Imrie, 2003). As explained in this study, disabilities of any form have often been hidden from public view, with families choosing to keep their children at home rather than risk having them exposed to public scrutiny and even ridicule, since a disabled person is often viewed as worth less and as less able in all facets of life be that mental, emotional or intellectual. In South Africa this still rings true as could be seen in the participants' talk of “coming out” and “being strong” (see 4.3.2.2 Dealing with the question in Theme 4 of Chapter 4), not hiding their children but rather being proud of them as “normal” children even in public view among friends and family (Swanepoel & Almec, 2008).

Literature argues that the way disability is understood is influenced by paradigms of thinking. In a society, individuals are influenced by these paradigms to understand disability in certain ways. In this study's results this became evident in how others around the direct family reacted to a diagnosis: for example in the assumption that the child would go straight to signing because few people understood that a cochlear implant might enable the child to communicate verbally (see 4.3.1.2). Another instance is provided by the pleading of the participants that the terms used to describe their children did not mean that they were dysfunctional or not able to interact with others, even when signing (see 4.3.1.3 Impact on Relationship to Family, Friends and Community in Results Chapter), indicating that participants often faced this assumption from people in their wider circle of family and acquaintances. Thus, although participants started to come to terms with the “normality” of

their child, they had to fight against the societal norm still present in their surroundings that labelled their child as abnormal.

They showed a struggle that came from their own sense of identity that was shaped by society, i.e. as being part of a normal hearing world. Participants not only had to fight against society's norms as expressed by people around them, but against society's norms as it had shaped their own perceptions inside them, too. Thus, although these are factors outside of their control, the societal norm had a deep personal impact on them. Who they were and how they struggled with their "new" identity was influenced by the relationships they had with others and the identity they had formed by being part of those relationships with others, belonging to a certain group (see 4.3 Imbalanced relationships, strained resources and resulting identity threats). With this point the purpose of clinical intervention is highlighted where the question arises if intervention is meant to make individual people "normal" again in the way wider society would define and recognise "normality", or if intervention is meant to empower people to live happy, productive lives that might not look "normal" according to wider social standards.

The participants' sense of belonging changed over time as they changed their own worldview about disability. They no longer judged others' disabilities anymore or perceived disabled people as mentally inferior or less valuable as a result of disability. They essentially shed the idea that a disabled person was not "capable" of being part of "normal" society (see 4.3.2.3 Altering worldviews in 4.3 Theme 3 in the Results Chapter).

Parents of children with hearing loss ultimately want their children to be independent, happy and self-sufficient adults one day (Kovacs, 2012; Wever, 2003). In the literature, and in the wider profession of audiology, however, there still exists a notion that the impairment as such is located entirely in the individual body. It is thus up to the individual with the

impairment, or in the case of this research project, the parent of the disabled child, to address and resolve the problem of their disability, otherwise they may be justifiably excluded from education, employment and the general public sphere (Couser, 2005). This worked against the participants' wish for their children to become independent, happy and self-sufficient adults (Kovacs, 2012) yet some still found themselves at war with the wishes and dreams they had for their child.

Hearing impairment raises precisely the issue of what is “normal” communication, and to what extent parents and professionals should aim to return the hearing impaired child to “normality” as perceived in society, or should focus on empowering them to live happy productive lives, whether they look “normal” or not. . Being faced with the possible choice for SASL worried participants, yet even choosing verbal communication was not as simple as it meant for some that they had to speak a whole different oral language and thereby change their identity (4.3.2.1). They all struggled with this identity threat while knowing that spoken and written English or Afrikaans gave access to opportunities in South Africa (4.3.2). The message participants were bringing across is that this reaction challenges who they were and who their children were in a society that already marginalises persons with a disability. Practitioners are to be aware of these issues of belonging, identity struggles and inclusion and explore opportunities of empowerment by prioritising care management and wellness rather than trying to “cure” the person with the disability (Hayes & Hannold, 2007). This is a difficult journey for parents.

To cope with this difficult journey, participants reverted to a sense of safety as a strategy to deal with this tragedy from the diagnostic process. The resources they tapped into most were a combination of spiritual, economic and technological resources (see “4.3.1.4 Resources depleted and supportive” in “4.3 Theme 3”). Most participants' reaction to the news urged them to respond to it with a new-found determination to carry on, mostly

expressed as a feeling of having to be “strong” for their child (see “4.3.2.2 Dealing with the question” in “4.3 Theme 3”). Participants thus exhibited a strong problem-orientated way of dealing with the news, rather than staying in this sense of despair and hurt, i.e. it was dynamic.

Their expectation of their child and that of their community and environment changed as they would ‘shove aside the future’ so to speak and focussed on who the child was rather than letting the child be defined by the disability it had (Wever, 2002). Although grief was said to not necessarily subside, participants felt a need to control it (see 4.1.1). This increased awareness of responsibility for their child was prevalent with all participants and revealed a lot about their belief systems, namely to act urgently so as to establish communication – any form of communication.

Participants began to shift their focus from their challenges with communication to finding ways for how they could bond with their children. Yet, their child and they themselves were still part of a minority group in a society that did not understand them. That is why friends, family and society labelling their child as ‘deaf’ hurt them (see 4.3.1.3). It perpetuated the idea that the disability was solely embedded in the body of the child and that they and their parent held sole responsibility for it (Couser, 2005). Ignorance, prejudices and subsequent isolation from their friends and even family angered them and made them ‘stronger’ so as to advocate their child’s needs to the community at large. Their hurt was tangible and they channeled this pain into becoming advocates.

Further study is needed to understand more deeply how they constructed their personal identity, yet their initial reaction to the diagnosis of hearing loss showed that they struggled with the perceptions of society and they drew on their resources to help them cope with that. However, their social identity in the position they took towards disability as an idea

and the beliefs they held later on about disability within society was clearly stated: They wanted to come out of hiding and no longer feel shame for their child for being different. In actual fact they showcased their children as being not much different to other children and in all regards just as “normal”. They wanted to disclose information about disability and wanted their voices to be heard. They stepped in as advocates for their children and wanted this new revelation of being “normal” with a disability to be integrated into society.

5.4 Conclusion.

The participants told of a multi-faceted problem when faced with hearing loss in their child. At diagnosis they had to consider things they were mostly unfamiliar with: how would their child learn to communicate, how would they socialise, learn and play, be happy and independent one day? It left them feeling shocked, worried and hurt. They were shocked that it had happened to them and their child, worried about what it meant for them and their child's future in the hearing world, and hurt at the thought of diminished opportunities for their child. At diagnosis they faced unknown implications which held personal, social, vocational and political ramifications for their children. Their parental role was challenged as they had to make decisions very early on in their child's life on their behalf. The participants were aware of the potential problems yet did not know how to navigate through them.

The audiologist however played a vital role in their coping with these emotions and the intake of information by being gentle and collaborative in their approach to guiding the participant. This was an overwhelming new world to navigate through as they started to change their own attitudes and beliefs, and negotiated a new and emergent identity. They no longer felt part of the hearing world and felt the pressures of society to be ‘normal’. It however changed their societal, “normative” worldview on disability to make them realise that their child was first and foremost a child and became strong advocates of hearing loss

and the normalcy of their children. Yet, the diagnosis is a cataclysmic event and the emotional ramifications continued indefinitely. The audiologist was central in the navigation, growth and recovery of the initial emotions they felt.

In light of this description of the nature and the consequent actions and change that caregivers underwent upon hearing the diagnosis of hearing loss in their child, as well as the crucial role that the professionals play in parents' regaining a sense of emotional equilibrium, the profession would benefit from better understanding and acknowledging the emotional pain that parents go through at diagnosis. Practitioners' better understanding of what parents' emotional needs are in the first instance, and then finding a way to meet those needs within the constraints of their role, scope of practise and own emotions, is central to the growth and recovery of the parents' emotional well-being and subsequent success of intervention. Realising that the diagnosis of hearing loss lives outside in a real world with prejudice and stigma was hard to navigate for participants and thus a need exists for this to be addressed by the professional at diagnosis. In short, at stake is the professional's recognition of another person who has a child that has a hearing loss. It's about respect and providing a service – not the perfect service, but the best service one can provide at that point. Thus the recommendation from this study is for a more humanistic, family-centred paediatric audiology practice.

“Our prime purpose in life is to help others and if you can't help them, at least don't hurt them.” – Dalai Lama

CHAPTER 6

CONCLUSION

The following chapter wants to succinctly summarise the main results and themes as related to the aims.

6.1 Aim 1:

The first aim of this research project was to describe the nature of the caregivers' experiences of the unfolding diagnostic process. The nature of the participants experience of diagnosis with predominantly negative emotions and described shock, worry and hurt as the predominant, overwhelming emotions. The emotional responses were intense, varied yet far-reaching and all-encompassing. Although the emotions can be viewed as non-pathological with most participants being able to resolve their emotional conflicts and achieving some form of acceptance, an awareness of the distressful feelings at diagnosis were highlighted (Kricos, 2000 in Alpiner & McCarthy, 2000).

6.2 Aim 2:

The second aim wanted to describe caregivers' experiences of their interactions with the audiologist. This study showed that the audiologist could mediate the sense of loss felt by the participants. When the audiologist was cognisant to the range of emotions that the participant felt by reacting emphatically and sensitively to their emotional reactions the participants were better able to deal with the news of diagnosis (Kricos, 2000 in Alpiner & McCarthy, 2000).

6.3 Aim3:

This aim analysed how caregivers' experiences shaped their roles and identities. The news of the diagnosis disrupted their sense of self and affected every facet of their life, far

beyond the clinical interaction with the practitioner. Not only did the effects reach into areas of their life including social status, relationships with their spouse and other family members, but also their personality, coping strategies and attitudes (Kricos, 2000 in Alpiner & McCarthy, 2000).

6.4 Strengths and limitations of the study

One of the biggest strengths of this study was that the qualitative nature of this study created an opportunity of in-depth enquiry. This allowed expression to caregivers' thoughts, feelings and experiences which provided valuable and powerful information that may improve services that caregivers receive in the future.

Another strength is that it had a great variety and diversity of participants which rendered rich, nuanced transcriptions which indicated very clearly the universal truths that caregivers go through at the time of diagnosis of hearing loss in their child.

One limitation of the study was the few participants that took part in the study. This means that the results cannot to be standardized. However, this is not the aim of qualitative research, but rather to decipher the nuanced, in-depth data that would otherwise be lost with a standardized set of tools for enquiry.

6.5 Implications for further research and clinical practice

In the discussion it was discussed how practitioners are to become collaborators and work on gaining rapport with the parent. However, the toll on practitioners needs to be considered in this instance; specifically the impact of being the messenger of bad news. Role-overload may thus be worth exploring in future research. Practitioners that work with hearing impaired individuals face stress and frustration on a daily basis (Nemes, 2004 and Pichler,

2008) and role-overload is a very real factor of compassion fatigue which mostly stems from being exposed to and intimately knowing of other people's emotional reactions (Severn, Searchfield & Huggard, 2012).

From the discussion themes the point to note was that the parental experience was emotional and the practitioner can worsen or lessen the burden on the parent with the hearing impaired child. However, practitioners in this study as well as the researcher were not prepared to deal with the strong emotion that came with the diagnosis. This deserves attention in research and professional education. The practitioner is to balance the emotional needs of the parents, an area where many practitioners failed in this study, as well as not fall prey to role overload. The importance of how to coach parents is thus again emphasised at this point: training of practitioners, peer support and supervision are some of the suggestions to support practitioners to take over the role as coaches (Severn et al., 2012)

The literature shows that practitioners who are schooled within a medical model promote "normalisation" and therefore provide a bias and one-sided approach which creates further strains for parents/clients (Pillay, 2003). To assist, practitioners can foster links between parents of children who have followed a different communication mode so that they can make informed decisions about the type of intervention for their child.. In doing this the practitioner facilitates parents in reviewing their values and beliefs as they make the transition to seeing their child with his/her own set of unique abilities and personality (Wever, 2002) .

There was a plea by participants for a platform to be created within the clinical interaction of equality, authenticity and rapport. Yet one needs to keep in mind that the practitioner enters the room with his/her own set of values and biases and yet the ideal would be to have these align with the parent/client for true collaboration to happen. Thus a

practitioner risks to be “seen” by the parent, not just as a professional who gives guidance and coaching, but as another human with his/her own views who wishes to journey on the road with them and their child.

This implies a true paradigm shift away from the practitioner only as the expert whose knowledge and skill has been sought out to habilitate the hearing loss. However, the lack of a supervisory model and support structure on a tertiary level as well as in the field causes practitioners to rather revert to their knowledge based expertise as a place of safety due to the high demands set for them on an emotional level for which they are not adequately trained for. Yet, hiding behind expertise is harming the interaction (English, 2008; Cokely & DePlacido, 2012; Severn, Searchfield & Huggard, 2012; Fixsen & Ridge, 2012). Thus further research needs to be conducted in the training, supervision and implementation of programmes that acknowledge and support families' emotional and other needs whilst still facilitating identification, diagnosis and intervention of younger and younger children as UNHS is implemented more and more (van der Spuy & Pottas, 2008).

The study also supports the United Nations Convention on rights of persons with disability to acknowledge the full scope of experience of impairments which are experienced as disabling. The medicalization of disability confines our understanding to the bodily aspects of the hearing problem. The participants stories however highlights the deep personal impact of diagnosis on caregivers. So although there is a framework in place to provide the opportunity to service patients and their family in a more holistic manner and according to what they actually need our training bias as professional people has been more on activity and function. Also, there is a gap between participation and the emotions evidently felt, where without training professionals do not know where it fits in (Danermark, Cieza, Gangé, Gimigliano, Granberg, Hickson, Kramer, McPherson, Möller, Russo, Strömngren, Stucki &

Swanepoel, 2010). Further study is also needed to understand more deeply how parents construct their personal identity.

REFERENCES

- Ackerman, S. J., & Hilsenroth, M. J. (2003). A review of therapist characteristics and techniques positively impacting the therapeutic alliance. *Clinical Psychology Review, 23*, 1-33.
- Adams, B. G., Van de Vijver, F. J. R., de Bruin, G. P., & Torres, C. B. (2014). Identity in descriptions of others across ethnic groups in South Africa. *Journal of Cross-Cultural Psychology, 45*(9), 1411-1433. doi:10.1177/0022022114542466
- Advanced Bionics. (n.d.). *Getting a cochlear implant*. Retrieved from http://www.advancedbionics.com/com/en/your_journey/getting_a_cochlearimplant.html
- AFA. (n.d.). *This is autism*. Retrieved from <http://www.afa.org.za/thisisautism>
- American Academy of Audiology. (2003). Pediatric amplification protocol. *Audiology Today, 16*(2), 46-53.
- Andersson, G. W., Miniscalco, C., & Gillberg, C. (2014). Preschoolers assessed for autism: Parent and teacher experiences of the diagnostic process . *Research in Developmental Disabilities 35*, 3392–3402. doi: 10.1016/j.ridd.2014.08.027
- Aras, I., Stevanovic, R., Vlahovic, S., Stevanovic, S., Kolaric, B., & Kondic, L. (2014). Health related quality of life in parents of children with speech and hearing impairment. *International Journal of Pediatric Otorhinolaryngology, 78*, 323–329. doi:[http:10.1016/j.ijporl.2013.12.001](http://10.1016/j.ijporl.2013.12.001)
- Artières, F., Vieu, A., Mondain, M., Uziel, A., & Venail, F. (2009). Impact of early cochlear implantation on the linguistic development of the deaf child. *Otology & Neurotology, 30*(6), 736-742.

ASHA. (n.d.). Retrieved February 2015 from <http://search.asha.org/>

Bosteels, S., Van Hove, G., & Vandebroek, M. (2012) The rollercoaster of experiences: becoming the parent of a deaf child. *Disability & Society*, 27(7), 983-996, doi:10.1080/09687599.2012.705059

Bowe, F. G. (2004). Economics and adults identified as low-functioning deaf. *Journal of Disability Policy Studies*, 15(1), 43-49.

Bowe, F. G., McMahon, B. T., Chang, T., & Louvi, I. (2005). *Workplace discrimination, deafness and hearing impairment: The national EEOC ADA research project*. Retrieved from Research Gate:
http://www.researchgate.net/publication/7737228_Workplace_discrimination_deafness_and_hearing_impairment_the_national_EEOC_ADA_research_project

Brinton, J. (2012). Review of Foundations of aural rehabilitation: Children, adults, and their family members. *Deafness & Education International*, 14(3), 178-179. doi: 10.1179/1464315412Z.00000000018

Burger, T., Spahn, C., Richter, B., Eissele, S., Lohle, E., & Bengel, J. (2005). Parental distress: The initial phase of hearing aid and cochlear implant fitting. *American Annals of the Deaf*, 5 – 10.

Burke, T. (2008). *How Trauma impacts the brain* [PDF document]. Retrieved from <http://www.rachelsvineyard.org/Downloads/Canada%20Conference%2008/TextOfBrainPP.pdf>

Cadoni, G., Agostino, S., Scipione, S., Ippolito, S., Caselli, A., Marchese, R., & Paludetti, G. (2005). Sudden sensorineural hearing loss: our experience in diagnosis, treatment, and outcome. *The Journal Of Otolaryngology*, 34(6), 395-401.

CAREGIVERS' EXPERIENCES OF THE DIAGNOSIS OF HEARING LOSS

Capella, M. E. (2003). Evaluating differences in demographics, services, and outcomes for vocational rehabilitation consumers with hearing loss versus consumers with other disabilities. *Journal of Rehabilitation*, 69(3), 39-46.

Carel du Toit Trust Pretoria (n.d.) *Charity SA*. Retrieved October 2011, from:

<http://www.charitysa.co.za/carel-du-toit-trust-pretoria.html>

The Carel du Toit Centre Pretoria (2009). *Business Plan for BEE Comp Short Jan 09*.

Retrieved October 2011, from:

www.givengain.com/.../Business_plan_For_BEE_Comp_Short_Jan_09.pdf.

Chamak, B., & Bonniau, B. (2013). Changes in the diagnosis of autism: How parents and professionals act and react in France. *Cult Med Psychiatry*, 37, 405-426. doi:

10.1007/s11013-013-9323-1

City of Tshwane Metropolitan Municipality (2008). *City of Tshwane Municipality Household Survey of 2008*. Retrieved in October 2011, from:

www.tshwane.gov.za/.../CoT_HouseholdSurvey2008.pdf

Clandinin, D. J., & Connelly, F. M. (2000). *Narrative inquiry: Experience and story in qualitative research*. San Francisco: Jossey-Bass.

Clark, J. G. (2014). Patient-centred practice: Aligning professional ethics with patient goals.

Retrieved from <http://www.mm3admin.co.za/cms/cpd/articles/patientcentredpractice.html>

Cone-Wesson, B. (2003). Electrophysiologic assessment of hearing in infants: Compound nerve action potential, auditory brainstem response, and auditory state response. *The Volta Review*, 103 (4), 253-275.

CAREGIVERS' EXPERIENCES OF THE DIAGNOSIS OF HEARING LOSS

Coogle, C. G., Guerette, A. R., & Hanline, M. F. (2013). Early intervention experiences of families of children with an autism spectrum disorder: a qualitative pilot study. *Early Childhood Research & Practice, 15*(1), Retrieved from <http://www.ecrp.uiuc.edu/>

CSO Dominican School for Deaf Children (n.d.) *Dominican School for Deaf Children Hammanskraal*. Retrieved in October 2011, from: <http://www.cso.za.org/domdeafhmnskrl.htm>

Clark, J. G., & English, K. A. (2004). *Counseling in Audiologic Practice*. Boston: Pearson Education, Inc.

Cokely, C.G., & DePlacido, C.G. (2012). Fostering reflective skills in audiology practice and education. *Seminars in Hearing, 33*, 65-77.

Cole, D. (1953). Communication and rapport in clinical testing. *Journal of Consulting Psychology, 17*(2), 132-134.

Coughlin, S.S. & Beauchamp, T. L. (1992). Ethics, scientific validity, and the design of epidemiological studies. *Epidemiology. (3)*, 343-347.

Couser, G. T. (2005). Disability as diversity: A difference with a difference. *Ilha Do Desterro, 48*, 95-113.

Danermark, B., Cieza, A., Gangé, J., Gimigliano, F., Granberg, S., Hickson, ... L., Swanepoel, D. (2010). International classification of functioning, disability, and health core sets for hearing loss: A discussion paper and invitation. *International Journal of Audiology, 49*, 256-262. doi:10.3109/14992020903410110

DEAFSA. (n.d.). Retrieved 2015, from <http://www.deafsa.co.za/>

CAREGIVERS' EXPERIENCES OF THE DIAGNOSIS OF HEARING LOSS

Dictionary.com. (n.d.). *dictionary.com*. Retrieved June 2011, from

<http://dictionary.reference.com> Eduplex (2009). *Eduplex Pre-, Primary and High School & Training Centre*. Retrieved in October, from: <http://www.eduplex.co.za>

DiLollo, L. D., DiLollo, A., Mendel, L. L., English, K., & McCarthy, P. (2006). Facilitating ownership of acquired hearing loss: A narrative therapy approach. *JARA*, 49-67.

Duchn, J. F. , & Kovarsky, D. (2011). Rapport and relationships in clinical interactions. *Topics in Language Disorders*, 31(4), 297-299. doi: 10.1097/TLD.0b013e31823baf91

Duchan, J. F. (2011). How conceptual frameworks influence discovery and depictions of emotions in clinical relationships. *Topics in Language Disorder*, 31(4), 300-309.
doi:10.1097/TLD.0b013e318234ef15

Edwards, C., & Imrie, R. (2003). Disability and bodies as bearers of value. *BSA Publications*, 37 (2), 239-256. doi: 0038-0385(200305)37:2

English, K., Naeve-Velguth, S., Rall, E., Uyehara-Isono, J., & Pittman, A. (2007). Development of an instrument to evaluate audiologic counseling skills. *Journal of the American Academy of Audiology*, 675-687.

English, K. (2008). Case Study: Patient's Perspective. Retrieved August 2011 from http://www.google.co.za/url?sa=t&source=web&cd=1&ved=0CB4QFjAA&url=http%3A%2F%2Fidainstitute.com%2Fmeetings%2Fseminars%2Fspeakers%2Fkristina_english%2Ffiledownload

English, K. (2009). *Handbook of Clinical Audiology* (6th ed.). (J. Katz, L. Medwetsky, R. Burkard, & L. J. Hood, Eds.) Philadelphia: Wolters Kluwer Health/Lippincott Williams & Wilkins.\

CAREGIVERS' EXPERIENCES OF THE DIAGNOSIS OF HEARING LOSS

Fixen, A., & Ridge, D. (2012). Performance, emotion work, and transition: Challenging experiences of complementary therapy student practitioners commencing clinical practice.

Qualitative Health Research, 22(9), 1163-1175. doi:10.1177/1049732312449213

Fourie, R., Crowley, N., & Oliviera, A. (2011). A qualitative exploration of therapeutic relationships from the perspective of six children receiving speech–language therapy. *Top Lang Disorders, 31(4), 310–324.* doi:10.1097/TLD.0b013e3182353f00

Frijda, N. H. (1988). The Laws of Emotion. *American Psychologist, 43, 349-358.*

Frank, A. W. (2013). From sick role to practices of health and illness. *Medical Education, 47, 18-25.*

doi:10.1111/j.1365-2923.2012.04298.x

Frank, A. W. (2000). Illness and autobiographical work: Dialogue as narrative destabilization. *Qualitative Sociology, 23 (1), 135-156.*

Frank, A. W. (1998). Just Listening: Narrative and Deep Illness. *Families, Systems & Health, 16, 197-212.*

Fulcher, A., Purcell, A. A., Baker, E., & Munro, M. (2012). Listen up: Children with early identified hearing loss achieve age-appropriate speech/language outcomes by 3 years-of-age.

International Journal of Pediatric Otorhinolaryngology, 1785-1794.

Gauteng Provincial Government (2011). *Socio-economic review and outlook 2011 .*

Retrieved December 2014 from

<http://www.tshwane.gov.za/AboutTshwane/CityManagement/CityDepartments/EconomicDevelopment/Local%20Economic%20Development%20%28LED%29/Documents/Socio-Economic%20Review%20and%20Outlook.pdf>

geda (2010). *Gauteng Economic Opportunity Atlas*. Retrieved October 2011, from Gauteng Economic Development Agency:

http://www.geda.co.za/G_Atlas/index.php?option=com_content&view=section&id=8&Itemid=37

Gilbey, P. (2010). Qualitative analysis of parents' experience with receiving the news of the detection of their child's hearing loss. *International Journal of Pediatric Otorhinolaryngology*, 265-270.

Gittins, C. B., Paterson, H. M., & Sharpe, L. (2014). How does immediate recall of a stressful event affect psychological response to it?. *Journal of Behavior Therapy and Experimental Psychiatry*, 46, 19-26. doi: 10.1016/j.jbtep.2014.07.006

Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. Chicago: Aldine Pub.

Godsell, M., Shaban, & R. Z., Gamble, J. (2013). "Recognizing rapport": Health professionals' lived experience of caring for patients under transmission-based precautions in an Australian health care setting. *American Journal of Infection Control*, 41, 971-975.

Goleman, D. (1995). *Emotional intelligence: Why it can matter more than IQ*. Bantam Books.

Graungaard, A. H., & Skov, L. (2006). Why do we need a diagnosis? A qualitative study of parents' experiences, coping and needs, when the newborn child is severely disabled. *Child: care, health and development*, 33(3), 296–307. doi:10.1111/j.1365-2214.2006.00666.x

Gray, D. E. (2004). *Doing research in the real world*. SAGE Publications.

CAREGIVERS' EXPERIENCES OF THE DIAGNOSIS OF HEARING LOSS

Grennes, C., Hickson, L., Laplante-Lévesque, A., & Davidson, B. (2014). Patient-centred care: A review for rehabilitative audiologists. *International Journal of Audiology*, *53*, 60-67. doi: 10.3109/14992027.2013.847286

Grennes, C., Hickson, L., Laplante-Lévesque, A., Meyer, C., & Davidson, B. (2015). The nature of communication throughout diagnosis and management planning in initial audiologic rehabilitation consultations. *Journal of the American Academy of Audiology*, *26*(1), 36-50. doi:10.3766/jaaa.26.1.5.

Groenewald, T. (2004). A Phenomenological Research Design Illustrated. *International Journal of Qualitative Methods*, *3*(1). Retrieved from from http://www.ualberta.ca/~iiqm/backissues/3_1/pdf/groenewald.pdf

Hall, J. W. III (2010). Aural immitance measures are more useful now than ever. *The Hearing Journal*, *63*(4), 10-15.

Hall, J. W. III, & Mueller, H. G. III (1997). *Audiologist desk reference. Volume 1: Diagnostic principles, procedures, and practices*. London, Singular Publishing Group.

Hannan, G. (2013). *Taking the 'hard' out of hearing on the job: Working with hearing loss*. Retrieved from IOS Press: <http://iospress.metapress.com/content/y187137822024j82/>

Hayes, J., & Hannold, E.M. (2007). The road to empowerment: A historical perspective on the medicalization of disability. *JHSA*, 352-377.

Hayes, N. (1997). *Doing qualitative analysis in psychology*. Erlbaum.

Hayes, S. A., & Watson, S. L. (2013). The impact of parenting stress: A meta-analysis of studies comparing the experience of parenting stress in parents of children with and without

autism spectrum disorder. *J Autism Dev Disord*, 43, 629–642. doi: 10.1007/s10803-012-1604-y

Hewson, D. (1997). Coping with loss of ability: 'Good grief or episodic stress response?'. *Social Science and Medicine*, 1129-1139.

Hewetson, R., & Singh, S. (2009). The lived experience of mothers of children with chronic feeding and/or swallowing difficulties. *Dysphagia*, 24, 322–332. doi:10.1007/s00455-009-9210-7

Hintermair, M. (2006). Parental resources, parental stress, and socioemotional development of deaf and hard of hearing children. *Journal of Deaf Studies and Deaf Education*, 493-513.

Hintermair, M. (2004). Sense of coherence: A relevant resource in the coping process of mothers of deaf and hard-of-hearing children? *Journal of Deaf Studies and Deaf Education*, 15-26.

Ho, V. (2013). Managing rapport through evaluation in grounder - A qualitative study. *Journal of Pragmatics*, 61, 63-77. doi:10.1016/j.pragma.2013.11.019

Holzinger, D., Fellingner, J., & Beitel, C. (2011). Early onset of family centred intervention predicts language outcomes in children with hearing loss. *International Journal of Pediatric Otorhinolaryngology*, 256-260.

HPCSA. (2007). *Early hearing detection and intervention programmes in South Africa – Position statement* [PDF document]. Retrieved from http://www.hpcsa.co.za/Uploads/editor/UserFiles/downloads/speech/early_hearing_detection_statement.pdf

Ratanjee, H.R. (2014). *Counselling of adults who need amplification: Practices of South African Audiologists* (Unpublished Masters dissertation). University of KwaZulu-Natal, KZN.

Ige, B. (2010). Identity and language choice: 'We equals I'. *Journal of Pragmatics*, 42, 3047-3054. doi:10.1016/j.pragma.2010.04.018

Jacobs, P. G., Brown, P. M., & Paatsch, L. (2012). Social and professional participation of individuals who are deaf: Utilizing the psychosocial potential maximization framework. *The Volta Review*, 112(1), 37-62.

Jones, B., & Ficklin, L. (2012). To walk in their shoes: Recognising the expression of empathy as a research reality. *Emotion, Space and Society*, 5, 103-112.
doi:10.1016/j.emospa.2010.10.007

Kathard, H. (2001). Sharing stories: Life history narratives in stuttering research. *International Journal of Language and Communication Disorders*, 36, 52-56.

Katz, J. (2009). *Handbook of Clinical Audiology* (6th ed.). (R. B. Larry Medwetsky, Ed.) Philadelphia: Wolters Kluwer Health/Lippincott Williams & Wilkins.

Keenan, M., Dillenburger, K., Doherty, A., Byrne, T., & Gallagher, S. (2010). The experiences of parents during diagnosis and forward planning for children with autism spectrum disorder. *Journal of Applied Research in Intellectual Disabilities*, 23, 390–397.
doi:10.1111/j.1468-3148.2010.00555.x

Kemmerly, M. A., & Compton, M. V. (2014). Are you deaf or hard of hearing? Which do you go by: Perceptions of identity in families of students with hearing loss. *The Volta Review*, 114(2).157-192.

King, K. A. (2013). A tale of three sisters: Language ideologies, identities, and negotiations in a bilingual, transnational family. *International Multilingual Research Journal*, 7, 49-65.

doi:10.1080/19313152.2013.746800

Koroleva, I.V., Lantsov, A.A., & Podosinnikova, G.A. (2000). Experience in the early diagnosis and habilitation of children with hearing loss in St. Petersburg. *Vestnik Otorinolaringologii*, 3, 23-27.

Kovacs, L. (2012). Partnering with parents to enhance habilitation: a parent's perspective. *Seminars in Speech and Language*, 33(4), 259-263. doi:10.1055/s-0032-1326915

Knudsen, L. V., Laplante-Lévesque, A., Jones, L., Preminger, J. E., Nielsen, C., Lunner, T., Hickson, L., Naylor, G., & Kramer, S.E. (2012). Conducting qualitative research in audiology: A tutorial. *International Journal of Audiology*, 51, 83-92.

doi:10.3109/14992027.2011.606283

Knutson, J. F. (1997). Observational assessment of the interaction of implant recipients with family and peers: Preliminary findings. *Otolaryngology - Head and Neck Surgery*, 117.

Kricos, P.B. (2000). *Family counselling for children with hearing loss* (3rd ed.). In G. J. Alpinier & P. A. McCarthy (Eds.), *Rehabilitative Audiology* (3rd ed.). Baltimore: Lippincott, Williams & Wilkins.

Kritzinger, J., Schneider, M., Swartz, L., & Braathen, S. H. (2014). "I just answer yes" to everything they say": Access to health care for deaf people in Worcester, South Africa and the politics of exclusion. *Patient Education and Counseling*, 94, 379-383.

<http://dx.doi.org/10.1016/j.pec.2013.12.006>

Kruijssen-Terpstra, A. J., Ketelaar, M., Boeije, H., Jongmans, M. J., Gorter, J. W., Verheijden, J., . . . Verschuren, O. (2013). Parents' experiences with physical and

occupational therapy for their young child with cerebral palsy: A mixed studies review.

Child: Care, health and development, 40 (6), 787-796. doi:10.1111/cch.12097

Kubler-Ross, E. (1969). *On death and dying*. NY : MacMillan.

Kurtzer-White, E., & Luterman, D. (2001). *Early Childhood Deafness*. York Press.

Landsman, G. H. (1998). Reconstructing motherhood in the age of perfect babies: Mothers of infants and toddlers with disabilities. *Journal of Women Culture and Society*, 24(1). 69-99.

Laplante-Lévesque, A., Hickson, L., & Grenness, C. (2014). An Australian survey of audiologists' preferences for patient-centredness. *International Journal of Audiology*, 53, 76-82. doi: 10.3109/14992027.2013.832418

Lasisi, A. O., Onakoya, P. A., Lasisi, T. J., Akinola, M.D., & Tongo, O. (2014). Neonatal hearing screening in a rural/sub-urban community in Nigeria, sub-Saharan Africa - A preliminary report. *International Journal of Pediatric Otorhinolaryngology*, 78, 1452-1455. doi:10.1016/j.ijporl.2014.06.003

Leach, M. J. (2005). Rapport: A key to treatment success. *Complementary Therapies in Clinical Practice*, 11, 262–265. doi:10.1016/j.ctcp.2005.05.005

Lederberg, A. R., & Golbach, T. (2002). Parenting stress and social support in hearing mothers of deaf and hearing children: A longitudinal study. *Journal of Deaf Studies and Deaf Education*, 330-345.

Lee, D.T.F., Woo, J., & Mackenzie, A.E. (2002). The cultural context of adjusting to nursing home life: Chinese elders' perspectives. *The Gerontologist*, 42(5), 667-675.

Leigh, G. (2011). The changing context for education of the deaf: New imperatives for teacher education. *Unpublished*.

Leigh, G. (2010) The changing context for education of the deaf in Australia: New imperative for teacher education. *Japanese Journal of Special Education*, 47(6), 427-441.

Lench, H. C., Flores, S. A., & Bench, S. W. (2011). Discrete emotions predict changes in cognition, judgment, experience, behavior, and physiology: A meta-analysis of experimental emotion elicitation. *Psychological Bulletin*, 137, 834-855.

Le Roux, T., Swanepoel, D., Louw, A., Vinck, B., & Tshifularo, M. (2015). Profound childhood hearing loss in a South Africa cohort: Risk profile, diagnosis and age of intervention. *International Journal of Pediatric Otorhinolaryngology*, 79, 8-14.

Lincoln, Y.S., & Guba, E.G. (1985). *Naturalistic Inquiry*. Newbury Park, CA: Sage Publications.

Lukyanchenko, N. V. (2013). Creating positive parent identity in parents of children with disabilities in the context of escort service. *Psychological Science and Education*, 1, 57-64.

Luterman, D., Kurtzer-White, E., & Seewald, R. C. (1999). *The Young Deaf Child*. York Press.

Luterman, D. (2002). *When your child is deaf: a guide for parents*. Baltimore: York Press.

Majdalani, M. N., Doumit, M. A. A., Rahi, A. C. (2014). The lived experience of parents of children admitted to the pediatric intensive care unit in Lebanon. *International Journal of Nursing Studies*, 51, 217-225. doi:10.1016/j.ijnurstu.2013.06.001

Margolis, R. H. (2004). What do your patients remember? *Hearing Journal*, 10, 16-17.

Mast, M. S., Kindlimann, A., & Langewitz, W. (2005). Recipient's perception on breaking bad news: How you put it really makes a difference. *Patient Education and Counseling*, 244-251.

CAREGIVERS' EXPERIENCES OF THE DIAGNOSIS OF HEARING LOSS

Mappery.com (2007). *Tshwane City Maps*. Retrieved October 2011, from mappery:

<http://mappery.com/map-of/Tshwane-City-Map>

Mason, M. (2010). Sample size and saturation in PhD studies using qualitative interviews.

Forum Qualitative Sozialforschung / Forum: Qualitative Social Research, 11(3), Art. 8,

<http://nbn-resolving.de/urn:nbn:de:0114-fqs100387>.

McGavin, C. (2013). Colleen's Story: Reflections on the Concept of "Patient and Family

Centered Care". *Journal of Family Nursing*, 19(4), 418-430. doi:10.1177/1074840713496114

Meadow-Orlans, K. (1994). Stress, support, and deafness: Perceptions of infants' mothers and fathers. *Journal of Early Intervention*, 91-102.

Meadow-Orlans, K., Dyssegaard, S., & Smith-Gray, B. (1995). Infants who are deaf or hard of hearing, with and without physical/cognitive disabilities. *American Annals of the Deaf*, 279-286.

Meinzen-Derr, J., Lim, L. H., Choo, D. I., Buyniski, S., & Wiley, S. (2008). Pediatric hearing impairment caregiver experience: Impact of duration of hearing loss on parental stress.

International Journal of Pediatric Otorhinolaryngology, 1693-1703.

Merriam, S. B. (2009). *Qualitative Research: A Guide to Design and Implementation*. John-Wiley & Sons, Inc.

metrofile.com (n.d.) *The Transoranje Institute*. Retrieved October 2011, from:

www.metrofile.com/AboutUs/.../TheTransoranjeInstitute/

Meyer, M. E., Swanepoel D., le Roux, T., & van der Linde, M. (2012). Early detection of infant hearing loss in the private health care sector of South Africa. *International Journal of Pediatric Otorhinolaryngology*, 76, 698-703.

CAREGIVERS' EXPERIENCES OF THE DIAGNOSIS OF HEARING LOSS

- Mitchell, C., & Holdt, N. (2014) The search for a timely diagnosis: Parents' experiences of their child being diagnosed with an Autistic Spectrum Disorder. *Journal of Child & Adolescent Mental Health*, 26(1), 49-62. doi:10.2989/17280583.2013.849606
- Mitchell, J. T. (2008). A short guide to giving bad news. *International Journal of Emergency Mental Health* , 197-201.
- Moeller, M. P. (2000). Early intervention and language development in children who are deaf and hard of hearing. *Pediatrics* , 1-9.
- Mohr, P. E., Feldman, J. J., Dunbar, J. L., McConkey-Robbins, A., Niparko, J. K., Rittenhouse, R. K., & Skinner, M. W. (2000). The societal costs of severe to profound hearing loss in the United States. *International Journal of Technology Assessment in Health Care*, 16(4), 1120-1135.
- Moodie-Dyer, A., Joyce, H. D., Anderson-Butcher, D., & Hoffman, J. (2014). Parent-caregiver experiences with the autism spectrum disorder service delivery system. *Journal of Family Social Work*, 17(4), 344-362, doi: 10.1080/10522158.2014.903581
- Mount Sinai Hospital, Toronto, Ontario (2005). *Infant hearing program: Audiologic assessment protocol and support documentation*.
- Munoz, K., Blaiser, K., & Barwick, K. (2013). Parent hearing aid experiences in the United States. *Journal of the American Academy of Audiology*, 24(1), 5-16. doi:10.3766/jaaa.24.1.2
- Naudé, A. M. , & Bornman, J. (2014). A Systematic Review of Ethics Knowledge in Audiology (1980-2010). *American Journal of Audiology*, 23, 151-157. Retrieved from <http://aja.pubs.asha.org/>

Nemes, J. (2004). [Professional burnout: How to stop it from happening to you. The Hearing Journal, 57\(1\), 21-26. doi: 10.1097/01.HJ.0000292398.79310.26](#)

Northern, J. L., & Downs, M. P. (2002). *Hearing in children. Fifth edition.* Lippincott Williams & Wilkins.

O'Gorman, F. (2015). Worrying - *A literary and cultural history.* Retrieved from <http://www.bloomsbury.com/uk/worrying-9781441143600/>

Olusanya, B. O., Neumann, K. J., & Saunders, J. E. (2014). The global burden of disabling hearing impairment: A call to action. *Bull World Health Organ, 92*, 367-373.
doi:<http://dx.doi.org/10.2471/BLT.13.128728>

Olusanya, B. O., Wirz, S. L., & Luxon, L. M. (2008). Hospital-based universal newborn hearing screening for early detection of permanent congenital hearing loss in Lagos, Nigeria. *International Journal of Pediatric Otorhinolaryngology* , 991-1001.

Patton, M. Q. (2002). *Qualitative Research and Evaluation Methods.* SAGE Publications.

Perloff, R. (1997). Book review: Daniel Goleman's emotional intelligence: Why it can matter more than IQ. *The Psychologist-Manager Journal, 1*, 21-22.

Picard, M. (2004). Children with permanent hearing loss and associated disabilities: Revisiting current epidemiological data and causes of deafness. *Volta Review*, 221-236.

Pichler, L. (2008). Improving communication and counseling for pediatric audiology evaluations. *Audiologyonline*, October 3, 2008.

Pillay, M. (1997). *Speech-language therapy and audiology: Practice with a black African first language clientele* (Masters Dissertation). University of Durban-Westville, South Africa.

CAREGIVERS' EXPERIENCES OF THE DIAGNOSIS OF HEARING LOSS

Pipp-Siegel, S., Yoshinaga-Itano, A. L., & Sedey, C. (2002). Predictors of parental stress in mothers of young children with hearing loss. *Journal of Deaf Studies and Deaf Education*, 1-17.

Polit, D. F. & Hungler, B.P. (1993). *Essentials of Nursing Research: Methods, Appraisals, and Utilization*. J.B. Lippincott Company.

Popper, K. R. (1992). *Conjectures and refutations: The growth of scientific knowledge*. Routledge.

Rankin, D., Harden, J., Waugh, N., Noyes, K., Barnard, K. D., Stephen, J., . . . Lawton, J. (2014). Pathways to diagnosis: a qualitative study of the experiences and emotional reactions of parents of children diagnosed with type 1 diabetes. *Pediatric Diabetes*, 15, 591-598. doi:10.1111/pedi.12124

Reid, D. K., & Knight, M. G. (2006). Disability justifies exclusion of minority students: A critical history grounded in disability studies. *Educational Researcher*, 35(6), 18-23. doi: 10.3102/0013189X035006018

Reyes, R. (2008). Early intervention for hearing impairment: Appropriate, accessible and affordable. *Ann Acad Med Singapore*, 55-62.

Robinson, J. A. (1996). Perspective, meaning and remembering. In Rub, D. C. (Ed.), *Remembering our past*. Cambridge University Press.

Rossetti, L. M. (2001). *Communication intervention: Birth to three* (2nd ed.). Albany: Delmar Publishing.

Rothschild, B., & Rand, M. (2006). *Help for the helper: The psychology of compassion fatigue and vicarious trauma*. New York, London: W.W. Norton and Company.

CAREGIVERS' EXPERIENCES OF THE DIAGNOSIS OF HEARING LOSS

Rothschild, B. (2002). The body remembers. *The body remembers: The psychophysiology of trauma and trauma treatment*. W.W. Norton and Company.

Rubin, H.J., & Rubin, I.S. (2005). *Qualitative interviewing: The art of hearing data* (2nd ed.). Sage Publications, Inc.

Sampson, H. (2004). Navigating the waves: the usefulness of a pilot in qualitative research. *Qualitative Research*, 4(3), 383-402.

Saunders, J., & Barrs, D. (2011). Cochlear implantation in developing countries as humanitarian service: Physician attitudes and recommendations for best practice. *Otolaryngology - Head and Neck Surgery*, 145(1), 74-79. doi:10.1177/0194599811401343

Scheepers, L. J., Swanepoel, D., & le Roux, T. (2014). Why parents refuse newborn hearing screening and default on follow-up rescreening - A South African perspective. *International Journal of Pediatric Otorhinolaryngology*, 78, 652-658. doi:10.1016/j.ijporl.2014.01.026

Lucia Jane Scheepers *International Journal of Pediatric Otorhinolaryngology*, 78 (2014) 652-658. doi:10.1016/j.ijporl.2014.01.026

Severn, M. S., Searchfield, G. D., & Huggard, P. (2012). Occupational stress amongst audiologists: Compassion satisfaction, compassion fatigue, and burnout. *International Journal of Audiology*, 51, 3-9. doi: 10.3109/14992027.2011.602366

Sharpley, C. F., Halat, J., Rabinowicz, T., Weiland, B., & Stafford, J. (2001). Standard posture, postural mirroring and client-perceived rapport. *Counselling Psychology Quarterly*, 14, 267-280. doi: 10.1080/09515070110088843

sonitus.co.za (n.d.) *Sonitusskool vor Gehoorgestremde Leerders*. Retrieved October 2011, from: <http://www.sonitus.co.za>

CAREGIVERS' EXPERIENCES OF THE DIAGNOSIS OF HEARING LOSS

Statistics South Africa. (2012). *Census 2011* [PDF document]. Retrieved from <http://www.statssa.gov.za/publications/p03014/p030142011.pdf>

Stroebel, D., & Swanepoel, D. (2014). Does parental experience of the diagnosis and intervention process differ for children with auditory neuropathy?. *International Journal of Pediatric Otorhinolaryngology*, 1-6. doi:10.1016/j.ijporl.2014.10.015

Strunk, J. A., Pickler, R., McCain, N. L., Ameringer, S., & Myers, B. J. (2014). Managing the health care needs of adolescents with autism spectrum disorder: The parents' experience. *Families, Systems, & Health*, 32 (3), 328–337.

Suter, W. N. (2012). *Introduction to educational research: A critical thinking approach* (2nd ed.). Sage Publications, Inc.

Swanepoel, D. (2006). Audiology in South Africa. *International Journal of Audiology*, 45, 262–266. doi:10.1080/14992020500485650

Swanepoel, D., Störbeck, C., & Friedland, P. (2009). Early hearing detection and intervention in South Africa. *International Journal of Pediatric Otorhinolaryngology*, 73, 783–786.

Swanepoel, D., Hugo, R., & Louw, B. (2006). Infant hearing screening at immunization clinics in South Africa. *International Journal of Pediatric Otorhinolaryngology*, 70, 1241–1249.

Swanepoel, D., Almec, N. (2008). Maternal views on infant hearing loss and early intervention in a South African community. *International Journal of Audiology*, 47, 44–48. doi:10.1080/14992020802252279

CAREGIVERS' EXPERIENCES OF THE DIAGNOSIS OF HEARING LOSS

Theunissen, M., & Swanepoel, D. (2008). Early hearing detection and intervention services in the public health sector in South Africa. *International Journal of Audiology, 47*, 23-29.

doi:10.1080/14992020802294032

Thomas, C. (2010). Negotiating the contested terrain of narrative methods in illness contexts. *Sociology of Health & Illness, 32*, 647–660. doi:10.1111/j.1467-9566.2010.01239.x

Tomblin, J. B., Oleson, J. J., Ambrose, S. E., Walker, E., & Moeller, M. P. (2014). The influence of hearing aids on the speech and language development of children with hearing loss. *JAMA Otolaryngol Head Neck Surg, 140*(5), 403-409. doi:10.1001/jamaoto.2014.267

transoranje.webs.com (n.d.) *Transoranje School for the Deaf*. Retrieved October 2011, from: <http://transoranje.webs.com/>

www.tshwane.gov.za (2009-2010). *City of Tshwane*. Retrieved October 2011, from: <http://www.tshwane.gov.za>

Tshwane General and Regional Overview (2013). Retrieved December 2014, from: <http://www.parliament.gov.za>

Tye-Murray, N. (2009). *Foundations of aural rehabilitation. Children, adults and their families* (3rd ed.). Clifton Park, NY: Delmar Cengage Learning.

United Nations - Convention on the rights of persons with disabilities and optional Protocol. (n. d.). Retrieved from <http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>

Van der Pal, S. M., Alpay, L. L., van Steenbrugge, G., & Detmar, S. B. (2014). An exploration of parents' experiences and empowerment in the care for preterm born children. *J Child Fam Stud, 23*, 1081–1089. doi:10.1007/s10826-013-9765-7

CAREGIVERS' EXPERIENCES OF THE DIAGNOSIS OF HEARING LOSS

Van der Spuy, T., & Pottas, L. (2008). Infant hearing loss in South Africa: Age of intervention and parental needs for support. *International Journal of Audiology*, 30-35.

Van Teijlingen, E., & Hundley, V. (2001). The importance of pilot studies. *Social Research Update*, 1-4.

VAANI. (n.d.). *VAANI, Deaf Childrens Foundation*. Retrieved May 2011, from Modes of Communication: <http://vaani.in/deafness/communication/>

Waterhouse, G. J., & Strupp, H. H. (1984). The patient-therapist relationship: Research from the psychodynamic perspective. *Clinical Psychology Review*, 4, 77-92.

Watermeyer, J. Kanji, A., & Cohen, A. (2012). Caregiver recall and understanding of paediatric diagnostic information and assessment feedback. *International Journal of Audiology*, 51, 864-869. doi:10.3109/14992027.2012.721014

Watt, L., Dix, D., Gulati, S., Sung, L., Klaassen, R. J., Shaw, N. T., & Klassen, A. F. (2011). Family-centred care: a qualitative study of Chinese and South Asian immigrant parents' experiences of care in paediatric oncology. *Child: Care, Health and Development*, 39(2), 185-193. doi:10.1111/j.1365-2214.2011.01342.x

Welsh, D. (2009). *The rise and fall of Apartheid*. Jeppestown: Jonathan Ball.

Wever, C. C. (2002). *Parenting deaf children in the era of cochlear implantation: A narrative-ethical analysis* (Doctoral dissertation). Retrieved from the UCT Health Sciences Library. (ISBN: 9090158391)

WHO. (2001). *ICF: International classification of functioning, disability and health*. Geneva: World Health Organisation.

CAREGIVERS' EXPERIENCES OF THE DIAGNOSIS OF HEARING LOSS

WHO. (2013). *Prevention of blindness and deafness. Grades of hearing impairment.*

Retrieved from http://www.who.int/pbd/deafness/hearing_impairment_grades/en/

WHO. (n.d.). *About WHO.* Retrieved from <http://www.who.int/about/en/>

WMA. (2008). *World Medical Association declaration of Helsinki: Ethical principles for medical research involving human subjects.* Retrieved from

<http://www.wma.net/en/30publications/10policies/b3/>

Woodbridge, S., Buys, L., & Miller, E. (2011). My grandchild has a disability: Impact on grandparenting identity, roles and relationships. *Journal of Aging Studies, 25*, 355-363.

doi:10.1016/j.jaging.2011.01.002

Yoshinago-Itano, C., & Sedey, A. (1999). Early speech development in children who are deaf or hard of hearing: Interrelationships with language and hearing. *Volta Review, 181-211.*

Yoshinago-Itano, C. (2004). Levels of evidence: Universal newborn hearing screening (UNHS) and early detection and intervention (EHDI) systems. *Journal of Communication Disorders, 451-465*

APPENDICES

Please note that all appendices make reference to the researcher by her maiden name as this is how participant received the information.

Appendix A

Appendix Aa: Information letter to the institutions

Research Ethics Committee

E53 Room 44.1. Old Main Building

Grootte Schuur Hospital

Observatory

Tel: (021) 406 6592



INFORMATION REGARDING A RESEARCH STUDY

Title

Caregivers' experiences of the diagnosis of hearing loss

Researcher

Elfriede Röhrs

Dear Sir/Madam,

I am a speech-therapist/audiologist and a masters' student at the University of Cape Town. I would like to invite you to take part in my study by identifying caregivers willing to share their experience of the diagnosis of hearing loss in their child. This study has been approved by the University of Cape Town, Faculty of Health Sciences, Human Research, Ethics Committee (HREC REF: 416/2011).

Aim of the research:

I would like to tell the caregivers' stories. This study is important as it will allow caregivers to tell of their thoughts, feelings and experiences, so that professionals learn and come to understand the challenges facing caregivers and professionals as well, when coming to terms with the diagnosis of hearing loss in their child. To be able to do this I am interested in their recollections of their child's hearing diagnosis and would like to gain access to it by having a conversation with them. The study will consist of two interviews (together with an interpreter if the need arises):

The first interview will involve standard questions with a larger group of caregivers such as: what, when and how the diagnosis happened; what language was used by the person giving the diagnosis; what things did or did not help the caregiver to cope with the message of diagnosis, and beyond this?

The second interview will ask those who are willing to carry on with the study and share in more detail of their experience with the diagnosis of hearing loss in their child.

CAREGIVERS' EXPERIENCES OF THE DIAGNOSIS OF HEARING LOSS

Time and venue:

Eligible caregivers include those who were present when hearing loss was suspected; were present during the period of diagnosis; were involved in their child's life from that point on up until when the interview will be conducted; and can state that they have some memory or recollection of this time/event. Ideally I would like to speak to those caregivers whose children's primary disability is a hearing loss.

Upon having identified these participants and gaining access by word of mouth, news letters or mentioning the research to the caregiver/s at a parents meeting; the caregiver will be given an information letter similar to this one. If they agree to participate in this study, the caregivers will be contacted regarding a time and place that is most suitable for them to schedule an interview appointment of about one and a half hours in length.

After the interview they will be contacted again regarding a short summary that I will have made of their interview so as to make sure that I understood their story correctly. Upon finishing the first set of interviews with all of the caregivers, I will identify caregivers who's interview gave some richly descriptive stories of the experience and who are willing to carry on to the second phase and another interview of about an hour and a half at a venue of their choice.

Confidentiality:

Please note that consenting to putting the researcher into contact with suitable caregivers is completely up to you and that I will only use participant's recorded and written interviews in ways that they agreed to. In all of the records, caregivers will remain anonymous or have a pseudo-name. Only me and my reviewers will have access to audio recordings and will be kept on my personal computer under a password name. Some verbatim quotations may appear in the final research text, but will be included in such a way so as not to make known the caregiver's or child's name.

Your rights:

Your institution's participation in this research study is completely voluntary. You have the right to withdraw from participation in this study at any time with no negative consequences.

Risks and discomfort:

Your institution will be exposed to minimal or no risks; i.e. the research will not influence your institution in any way that is not a common day occurrence. The following risks are however involved for the caregivers who participate in this study: they may be burdened by the loss of privacy and time spent conversing in interviews; and they may (re-)experience emotional distress due to sensitive questions being asked. However, great care has been implemented to make sure that caregiver rights

CAREGIVERS' EXPERIENCES OF THE DIAGNOSIS OF HEARING LOSS

and feelings are respected by formulating an ethically sound research procedure and if participants get upset a referral to an accessible psychologist is in place for management of the emotional distress experienced.

Implications:

You will help to create a greater sense of understanding and possibly open up development of added counselling techniques and considerations, thereby helping audiologists in better serving families coming to terms with the news of a hearing loss in their child. Caregivers will be acknowledged for what they have been through and thereby become advocates to assist others who have gone through a similar experience.

If you are willing to take part I will ask you to sign a consent form to say that the aims and nature of this study were explained to you. Your identity at signing will be held strictly confidential and will be collected and delivered, by myself, for proof to the University of Cape Town, Faculty of Health Sciences, Human Research, Ethics Committee.

Please feel free to contact me if you need any further information.

Kind Regards

Elfriede Röhrs

E-mail: elfriede.rohrs@uct.ac.za

Cellphone: 079 5221185

Name of supervisor: Dr. Dunay Taljaard

E-mail: dunay.taljaard@uct.ac.za

Name of co-supervisor: Prof Harsha Kathard

E-mail: harsha.kathard@uct.ac.za

Appendix Ab: Information letter to the participants



CAREGIVERS' EXPERIENCES OF THE DIAGNOSIS OF HEARING LOSS

Research Ethics Committee
E53 Room 44.1. Old Main Building
Grootte Schuur Hospital
Observatory
Tel: (021) 406 6592

INFORMATION REGARDING A RESEARCH STUDY

Title

Caregivers' experiences of the diagnosis of hearing loss

Researcher

Elfriede Röhrs

Dear Caregiver,

I am a speech-therapist and audiologist who is a masters' student at the University of Cape Town. I would like to invite you to take part in my study. This study has been approved by the University of Cape Town, Faculty of Health Sciences, Human Research, Ethics Committee (HREC REF: 416/2011).

Aim of the research:

I would like to tell the stories of caregivers who have received news of a hearing loss in their child a few years ago. This study is important as it will allow you to tell of your thoughts, feelings and experiences, so that professionals learn and come to understand the challenges facing you and professionals as well, when coming to terms with the diagnosis of hearing loss in their child. To be able to do this I am interested in your remembrance of this event and would like to gain access to it by interviewing you. The study will consist of two interviews (together with an interpreter, when the need arises):

The first interview will involve standard questions with a larger group of caregivers such as: what, when and how the diagnosis happened; what language was used by the person giving you the diagnosis; what things did or did not help you to cope with the message of diagnosis, and beyond this? In the second interview I will ask those who are willing to carry on with the study and share in more detail of their experience with the diagnosis of hearing loss in their child.

Time and venue:

CAREGIVERS' EXPERIENCES OF THE DIAGNOSIS OF HEARING LOSS

The institution/school with which your child is currently associated will have been contacted first. If you agree to take part in this study, you will be contacted by me regarding a time that is most suitable to you to schedule an interview appointment. I will need about one and a half hours of your time to do the interview.

After the interview you will receive a summary of your interview to make sure that I understood your experience correctly. After the first set of interviews, I will identify caregivers who's interview showed detailed descriptions of the experience and who are willing to carry on to the second phase. If you are one of them, a similar procedure as described above will take place.

Confidentiality:

I will be audio taping the interview and transcribing it verbatim. Please note that consenting to this is completely up to you and that I will only use it in ways that you agreed to it. In cases where you are comfortable with speaking South African Sign Language the researcher will audio record the interpreters utterances, with your permission. In all of the records, you will remain anonymous or with a pseudo-name. Only me and my reviewers will have access to the audio recordings and will be kept on my personal computer under a password name. Some verbatim quotations may appear in the final research text, but will be included in such a way that your or your child's name remains private.

Your rights:

Your participation in this research study is completely voluntary. You have the right to withdraw from taking part in this study at any time with no negative consequences.

Risks and discomfort:

The following risks are involved by participating in this study: you may be burdened by the loss of privacy and time spent being interviewed; and you may (re-)experience emotional distress due to sensitive questions being asked. However, great care has been taken to make sure that your rights and feelings are respected by formulating an ethically sound research procedure. If the conversation or if revisiting that time of your life is too upsetting a referral to an accessible psychologist is in place for management of the emotional distress you may experience when remembering the day of diagnosis.

Implications:

You will help to create a greater sense of understanding and possibly open up development of added counselling techniques and considerations. Thereby you will help audiologists in better serving families coming to terms with the news of a hearing a loss in their child. You will also be acknowledged for what you have been through and thereby become advocates to assist others who have gone through a similar experience.

If you are willing to participate, I will contact you regarding a time and place that will suit you for the interview. I will then also send and ask you to sign a consent form by which you agree that the aims and nature of this study were explained to you. Your identity at signing will be held strictly confidential and will be collected and delivered, by myself, for proof to the ethics committee at the University of Cape Town.

Please feel free to contact me if you need any further information.

Kind Regards

Elfriede Röhrs

E-mail: elfriede.rohrs@uct.ac.za

Cellphone: 079 5221185

Name of supervisor: Dr. Dunay Taljaard

E-mail: dunay.taljaard@uct.ac.za

Name of co-supervisor: Prof Harsha Kathard

E-mail: harsha.kathard@uct.ac.za

CAREGIVERS' EXPERIENCES OF THE DIAGNOSIS OF HEARING LOSS

Appendix Ac: Information letter to the pilot study participant

Research Ethics Committee
E53 Room 44.1. Old Main Building
Grootte Schuur Hospital
Observatory
Tel: (021) 406 6592



INFORMATION REGARDING A RESEARCH STUDY

Title

Caregivers' experiences of the diagnosis of hearing loss

Researcher

Elfriede Röhrs

Dear Caregiver,

I am a speech-therapist and audiologist who is a masters' student at the University of Cape Town. I would like to invite you to take part in my pilot study. This study has been approved by the University of Cape Town, Faculty of Health Sciences, Human Research, Ethics Committee (HREC REF: 416/2011).

Aim of the research:

I would like to tell the stories of caregivers who have received news of a hearing loss in their child a few years ago. This study is important as it will allow them to tell of their thoughts, feelings and experiences, so that professionals learn and come to understand the challenges facing you and professionals as well, when coming to terms with the diagnosis of hearing loss in their child. Before I can do this however I need to conduct a pilot study so as to make sure that my interview questions and skills are suitable, so that I can identify possible gaps in my information collection procedure.

To be able to do this I am interested in your remembrance of this event and would like to gain access to it by interviewing you. The study will consist of one interview:

The interview will involve standard questions such as: what, when and how the diagnosis happened; what language was used by the person giving you the diagnosis; what things did or did not help you to cope with the message of diagnosis, and beyond this?

CAREGIVERS' EXPERIENCES OF THE DIAGNOSIS OF HEARING LOSS

Time and venue:

If you agree to take part in this study, you will be contacted by me regarding a time that is most suitable to you to schedule an interview appointment. I will need about one and a half hours of your time to do the interview.

After the interview you will receive a summary of your interview to make sure that I understood your experience correctly.

Confidentiality:

I will be audio taping the interview and transcribing it verbatim. Please note that consenting to this is completely up to you and that I will only use it in ways that you agreed to it. In all of the records, you will remain anonymous or with a pseudo-name. Only me and my reviewers will have access to the audio recordings and will be kept on my personal computer under a password name.

Your rights:

Your participation in this research study is completely voluntary. You have the right to withdraw from taking part in this study at any time with no negative consequences.

Risks and discomfort:

The following risks are involved by participating in this study: you may be burdened by the loss of privacy and time spent being interviewed; and you may (re-)experience emotional distress due to sensitive questions being asked. However, great care has been taken to make sure that your rights and feelings are respected by formulating an ethically sound research procedure. If the conversation or if revisiting that time of your life is too upsetting a referral to an accessible psychologist is in place for management of the emotional distress you may experience when remembering the day of diagnosis.

Implications:

You will help to create a greater sense of understanding and possibly open up development of added counselling techniques and considerations. Thereby you will help audiologists in better serving families coming to terms with the news of a hearing a loss in their child. You will also be acknowledged for what you have been through and thereby become an advocate to assist others who have gone through a similar experience.

If you are willing to participate, I will contact you regarding a time and place that will suit you for the interview. I will then also send and ask you to sign a consent form by which you agree that the aims

CAREGIVERS' EXPERIENCES OF THE DIAGNOSIS OF HEARING LOSS

and nature of this study were explained to you. Your identity at signing will be held strictly confidential and will be collected and delivered, by myself, for proof to the ethics committee at the University of Cape Town.

Please feel free to contact me if you need any further information.

Kind Regards

Elfriede Röhrs

E-mail: elfriede.rohrs@uct.ac.za

Cellphone: 079 5221185

Name of supervisor: Dr. Dunay Taljaard

E-mail: dunay.taljaard@uct.ac.za

Name of co-supervisor: Prof Harsha Kathard

E-mail: harsha.kathard@uct.ac.za

Appendix Ba

Research Ethics Committee
 E53 Room 44.1, Old Main Building
 Groote Schuur Hospital
 Observatory
 Tel: (021) 406 6592



Date: 16 November 2011

This study has been approved by the University of Cape Town, Faculty of Health Sciences, Human Research Ethics Committee (Reference number: #16/2011).

Research Consent Form

Title

Caregiver's experiences of the diagnosis of hearing loss

Researcher

Elfriede Röhrs

I, J J DE GOEDE hereby consent to participate in this research study:

	tick
The aim and nature of the study has been explained to me.	✓
I understand that my school/institution will have to act as a platform to recruit participants.	✓
I understand that the interview that participants partake in will be audio taped and transcribed.	✓
I also understand that when SASI, or another language which the researcher does not speak is used, the interpreter's translations will be transcribed.	✓
I understand that participants will be asked to evaluate the accuracy of their represented experiences by commenting and amending the summary that the researcher will make of the interview, so that they may be understood correctly.	✓
I know that all have the right to participation and withdrawal from the study at any time, without any penalty or without having to make the reason for doing so, known.	✓

J J DE GOEDE

Name of principal/head

Elfriede Röhrs

Name of researcher

E-mail:

elfriede.rohrs@uct.ac.za

Cell number:

079 522 1785

JJdeGoede

Signature

Signature

Research Ethics Committee
 E53 Room 44.1, Old Main Building
 Groote Schuur Hospital
 Observatory
 Tel: (021) 406 6592



Date: 21/11/16

This study has been approved by the University of Cape Town, Faculty of Health Sciences, Human Research Ethics Committee (Reference number: 416/2011).

Research Consent Form

Title

Caregiver's experiences of the diagnosis of hearing loss

Researcher

Elisde Röhrs

I _____ hereby consent to participate in this research study.

	tick
The aim and nature of the study has been explained to me.	<input checked="" type="checkbox"/>
I understand that my school/institution will have to act as a platform to recruit participants.	<input checked="" type="checkbox"/>
I understand that the interview that participants partake in will be audio taped and transcribed.	<input checked="" type="checkbox"/>
I also understand that when SASL or another language which the researcher does not speak is used, the interpreter's translations will be transcribed.	<input checked="" type="checkbox"/>
I understand that participants will be asked to evaluate the accuracy of their represented experiences by commenting and amending the summary that the researcher will make of the interview, so that they may be understood correctly.	<input checked="" type="checkbox"/>
I know that all have the right to participation and withdrawal from the study at any time, without any penalty or without having to make the reason for doing so, known.	<input checked="" type="checkbox"/>

Name of principal/head

Signature

Elisde Röhrs

Signature

Name of researcher

E-mail:

elisde.rohrs@uct.ac.za

Cellphone:

079 5221185

CAREGIVERS' EXPERIENCES OF THE DIAGNOSIS OF HEARING LOSS

Research Ethics Committee
 E53 Room 44, F. Old Main Building
 Groote-Schuur Hospital
 Observatory
 Tel: (021) 406 6972



Date: 16 November 2011

This study has been approved by the University of Cape Town, Faculty of Health Sciences, Human Research Ethics Committee (Reference number: 414/2011)

Research Consent Form

Title

Caregivers' experiences of the diagnosis of hearing loss

Researcher

Elisde Rólv

I, J J DE GOEDE hereby consent to participate in this research study:

	Yes
The aim and nature of the study has been explained to me.	<input checked="" type="checkbox"/>
I understand that my school/institution will have to act as a platform to recruit participants.	<input checked="" type="checkbox"/>
I understand that the interview that participants partake in will be audio taped and transcribed.	<input checked="" type="checkbox"/>
I also understand that when SAS, or another language which the researcher does not speak is used, the interpreter's translation will be transcribed.	<input checked="" type="checkbox"/>
I understand that participants will be asked to evaluate the accuracy of their represented experiences by commenting and amending the summary that the researcher will make of the interview, so that they may be understood correctly.	<input checked="" type="checkbox"/>
I know that all have the right to participate and withdrawal from the study at any time, without any penalty or without having to make the reason for doing so known.	<input checked="" type="checkbox"/>

J J DE GOEDE

Name of principal/head

Elisde Rólv

Name of researcher

CAREGIVERS' EXPERIENCES OF THE DIAGNOSIS OF HEARING LOSS

Research Ethics Committee
 E53 Room 44.1, Old Main Building
 Groote Schuur Hospital
 Observatory
 Tel: (021) 406 6592



Date: 7/12/2011

This study has been approved by the University of Cape Town Faculty of Health Sciences, Human Research Ethics Committee (Reference number 416/2011).

Research Consent Form

Title

Caregiver's experiences of the diagnosis of hearing loss

Researcher

Eiliede Röhrs

CE Oosthuizen hereby consent to participate in the research study.

	tick
The aim and nature of the study has been explained to me.	✓
I understand that my school/institution will have to act as a platform to recruit participants.	✓
I understand that the interview that participants partake in will be audio-taped and transcribed.	✓
I also understand that when SASL or another language which the researcher does not speak is used, the interpreter's translations will be transcribed.	✓
I understand that participants will be asked to evaluate the accuracy of their represented experiences, by commenting and amending the summary that the researcher will make of the interview, so that they may be understood correctly.	✓
I know that all have the right to participation and withdrawal from the study at any time, without any penalty or without having to make the reason for doing so, known.	✓

Christna Oosthuizen
 Name of principal/head

Signature

Eiliede Röhrs
 Name of researcher

Signature

E-mail: eiliederohrs@uct.ac.za
 Cellphone: 079 5221185

Appendix Bb

Brief Description of the participating schools

To showcase the methodological diversity and to ensure that the dimensions for maximum variation were possible with these sites, brief descriptions of the schools that took part are added below. Please note that the descriptions date from data that was gained shortly before data collection commenced and thus does not include the most recent figures. Sites included: “The Eduplex”, “Sonitusskool vir Gehoorgestremde Leerders”, and “Transoranje School for the Deaf”. The “Carel du Toit Centre” in Pretoria agreed to partake, but no caregivers replied and notified the researcher to be a participant, and the “Dominican School for the Deaf” in Hammanskraal opted not to partake as they have very little contact with their students’ caregivers (see Appendix Ba for letters of participation).

“The Eduplex” is a private school, focusing on inclusive education for the hard of hearing children. Of a group of 85 deaf/hard of hearing children, out of 451 pupils from Grade 0000 to Grade 8, more than 50% are receiving bursaries - which include sponsorship for hearing aids and cochlear implants. Total deaf/hard of hearing children can be grouped into 27.6% black, 40% white, 6.5% Indian and 13% coloured children, all coming from a range of socio-economic backgrounds. “The Eduplex” follows a natural auditory oral approach with a strong focus on parental guidance (www.eduplex.co.za, 2009 and The Eduplex Annual Report, 2010).

“Sonitusskool vir Gehoorgestremde Leerders” is a state school with 37 hard of hearing, and 76 deaf children, with majority coming from a low socio-economic background. “Sonitus” has 321 pupils from Pre-grade R to Grade 12, with special, aid, and pre-vocational classes included. The school also has a boarding establishment. Totals for population groups of hard of hearing/deaf children include 46.9% white, 46.9% black, 4.4% coloured, and 1.7% children from population group named ‘other’. “Sonitus” follows an oral approach, although some teachers are well-versed in SASL and total communication (www.sonitus.co.za, 2010 and Sonitusskool Annual Report, 2010).

“Transoranje School for the Deaf” is a state school which, together with “Sonitusskool”, was the first specialised school to be established as part of the “Transoranje Institute for Special Education”. The

CAREGIVERS' EXPERIENCES OF THE DIAGNOSIS OF HEARING LOSS

“Transoranje Institute for Special Education”, established in 1947, operates on a national level for children with disabilities from all regions. Based in Pretoria-West, the school educates 194 learners with profound hearing loss of which 115 are boarders. The school focuses on learning language and formal communication skills with the help from specialist educators and therapists. Lipreading and total communication is taught from a young age. Of the different population groups enrolled in the school, 68% are black, 27.3% are white and 4.6% are coloured (www.transoranje.webs.com, 2011; www.metrofile.com, 2011; and Transoranje Annual Report 2010).

Appendix C



This study has been approved by the University of Cape Town, Faculty of Health Sciences, Human Research, Ethics Committee (HREC REF: 416/2011).

Checklist for participant selection

Tick the appropriate box:

<i>Caregiver:</i>	<i>tick</i>
was present when hearing loss was suspected	
was present during the period of diagnosis	
was involved in his/her child's life from that point on up until the interview will be conducted	
can state they can recollect the time/event of diagnosis	

The following boxes need to be ticked:

<i>Caregiver's:</i>	<i>tick</i>
child is currently enrolled in primary school, high school or older	
child's primary disability is not hearing loss	

Appendix D



This study has been approved by the University of Cape Town, Faculty of Health Sciences, Human Research, Ethics Committee (HREC REF: 416/2011).

THE IN-DEPYH INTERVIEW SCHEDULE

Main Questions and Probes for Phase One

Parents/caregivers who have gone through your experience with hearing loss all have a story to tell. You were the person there, right from the start of this journey. I believe your story is worth sharing. This is why I would really like to know more about what it was like to have gone through the experience.

So first of all, could you tell me about the time when you first suspected a hearing loss?

Where did you go to from there?

Which (other) people were involved?

How did you find out about _____'s hearing?

Could you share your memory of the actual event of diagnosis?

What plan was discussed after the diagnosis?

Who supported you with this decision?

Having gone through that experience in the order you just told me, it must have been done in a certain way... brought up some emotions...

Describe how the news was given to you.

What were your feelings towards the audiologist and/or other professionals giving the news?

How did you go about dealing with the news of the diagnosis?

How did the news influence your interaction with others?

What were your feelings on how other professionals went about dealing with the diagnosis?

What was especially difficult for you at the time of diagnosis?

All these things must have been influenced by the people and resources available to you during the time of diagnosis...

CAREGIVERS' EXPERIENCES OF THE DIAGNOSIS OF HEARING LOSS

What role did the _____ (title of professional) play that first confirmed your suspicion of hearing loss?

What role did the audiologist play during this process?

What helped you?

What did not help you?

What was missing?

What would you have done differently?

What would you have liked to have been done differently?

To close off the interview I would like to ask one last question:

Are there people/places/activities that stand out as important during your time of having to come to grips with the news?

Probes to be used intermittently, throughout, as deemed appropriate (Rubin & Rubin, 2005):

Probes:	Examples:
Continuation probes	<ul style="list-style-type: none"> - Mmm hmm. So? - Then what? And...? - What did you mean...? - Could you tell me about what happened when...?
Elaboration probes	<ul style="list-style-type: none"> - That sounds interesting. Could you tell me more about...? - Hmm, sounds like there is a story there. - Maybe something else was going on...? - Such as...? - Can you give me an example? - What can you tell me about...?
Attention probes	<ul style="list-style-type: none"> - Ok, I understand. - That is interesting. - Can I quote you on that?
Clarification probes	<ul style="list-style-type: none"> - Can you run that by me again? I'm afraid I didn't follow.
Steering probes	<ul style="list-style-type: none"> - Sorry, I distracted you with that question. You were talking about...(go back to topic)?

Appendix E



This study has been approved by the University of Cape Town, Faculty of Health Sciences, Human Research, Ethics Committee (HREC REF: 416/2011).

Biographical Questionnaire

Please complete the following questionnaire. Neither your, nor your child's name will be reported in the research.

Caregiver and family information:

Please tick next to the box where your age fits in:

25-30	30-35	35-40	40-45	45-50
-------	-------	-------	-------	-------

Please tick next to the box to which population group you belong:

Black	White	Indian	Coloured	Other
-------	-------	--------	----------	-------

Please tick what language you speak at home:

English	SASL	Afrikaans	seTswana	Other
---------	------	-----------	----------	-------

How long has it been since the diagnosis of your child's hearing loss?

What is your relationship to the child?

Child information:

At what age was your child diagnosed with a hearing loss?

CAREGIVERS' EXPERIENCES OF THE DIAGNOSIS OF HEARING LOSS

Please tick what your primary way of communicating is with your child?

Way of communicating:	TICK
Spoken language	<input type="checkbox"/>
Signed language	<input type="checkbox"/>
Combination of spoken and manual communication	<input type="checkbox"/>

What type of therapy has your child had before and what is your child currently receiving?

Type of therapy:	TICK
Physiotherapy	<input type="checkbox"/>
Occupational therapy	<input type="checkbox"/>
Speech-language therapy	<input type="checkbox"/>
Other:	<input type="checkbox"/>

Thank you for completing the questionnaire.

Appendix F



Research Ethics Committee
E53 Room 44.1. Old Main Building
Grootte Schuur Hospital
Observatory
Tel: (021) 406 6592

Date: _____

This study has been approved by the *University of Cape Town, Faculty of Health Sciences, Human Research, Ethics Committee* (HREC REF: 416/2011).

Agreement Letter

Title

Caregiver's experiences of the diagnosis of hearing loss

Researcher

Elfriede Röhrs

I _____ (interpreter) hereby state that I have read and understand the aim and nature of this study, that I will adhere to the ethical principles as outlined in the Declaration of Helsinki (Seoul version, 2008) and will adhere to the principles as stipulated in the proposal of this study in all areas of beneficence, non-malificence, justice and autonomy. I also promise to not fabricate, misinterpret or leave out any information stated by the participant/s and to try and translate utterances as verbatim as possible.

Name of translator

Signature

Elfriede Röhrs

Name of researcher

Signature

E-mail: elfriede.rohrs@uct.ac.za

Cellphone: 079 52211

Appendix G



UNIVERSITY OF CAPE TOWN

Faculty of Health Sciences
Faculty of Health Sciences Research Ethics Committee
Room E52-24 G roote Schuur Hospital Old Main Building
Observatory 7925
Telephone [021] 406 6338 • Facsimile [021] 406 6411
e-mail: sumayah.ariefeldien@uct.ac.za

28 October 2011

HREC REF: 416/2011

Miss E Röhrs
Health & Rehab
Communication Sciences
F-Floor
OMB

Dear Ms Röhrs

PROJECT TITLE: CAREGIVERS' EXPERIENCES WITH THE DIAGNOSIS OF HEARING LOSS

Thank you for addressing the concerns raised by the ethics committee.

It is a pleasure to inform you that the Ethics Committee has formally approved the above-mentioned study.

Approval is granted for one year till the 30 October 2012.

Please submit a progress form, using the standardised Annual Report Form (FHS016), if the study continues beyond the approval period. Please submit a Standard Closure form (FHS010) if the study is completed within the approval period.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please quote the REC. REF in all your correspondence.

Yours sincerely

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PROFESSOR M BLOCKMAN
CHAIRPERSON, HSF HUMAN ETHICS

Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number: IRB00001938

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Appendix H

Pilot Study Data Collection:

This pilot study followed the procedures as detailed in the approved proposal (HREC Ref: 416/2011, see Appendix G), with a few alterations according to interview situation or turn of events, as stipulated in the steps below:

A pilot participant who met the selection criteria and who was familiar and known to the researcher was phoned regarding the study on the 31/10/2011. The details of the study were explained and the individual was invited to participate. Thereafter the information was sent electronically (see Appendix Ac). The only difference in the information letter to the pilot study participant compared to main study participants was that together with an audio recorder, a video recorder was to be used. This was used so that the researcher's supervisors could assess the researcher's approach and interviewing technique. This was also mentioned in the phone call and again in the information letter. The researcher also sent the in-depth interview to the participant, electronically. This schedule served the function of giving her the opportunity to gather her thoughts and relive the event/s in her memory before the interview even started.

Upon giving telephonic consent, a date was decided on, telephonically, and the researcher travelled to meet the participant at her convenience on the 05/11/2011. At the venue for the interview, which was the participant's home, the video recorder was switched on to record the interview taking place. The researcher also used the audio recorder so as to become accustomed to the device. The interview was conducted in English. Although the participant's first language is German she is well versed and comfortable using English thus the interview was conducted in English so as to not have to translate it.

Whilst the researcher conducted the interview she was supposed to note on a piece of paper all descriptive and reflective observations that were seen and heard during the interview. However, this was only done after the interview, as the interview was an extension of a conversation and the note pad felt too bulky and thus distracting and formal (Rubin & Rubin, 2005 and Groenewald,

2004). The interview was conducted using the in-depth interview schedule as a guide. The participant was well-prepared; had already mentally prepared her story and the researcher therefore did not have to follow the schedule as strictly. The interviewing approach was found to be effective for highly personal data (Rubin & Rubin, 2005). It was also flexible enough to have allowed the participant to tell her story without the researcher imposing her personal assumptions.

The researcher assigned a code to the recording specified by date of the interview which then read PILOT 05/11/11 INTERVIEW TRANSCRIPTION. The interview was electronically recorded and saved under a password for confidentiality in a folder on the researcher's personal computer. The researcher then transcribed the pilot study interview verbatim on her personal computer as PILOT 05-11-11 INTERVIEW TRANSCRIPTION in a folder protected by a password, to ensure confidentiality.

Listening to the recording and making of notes occurred straight after the interview was fully transcribed, where the researcher engaged in transcription of key words, phrases and statements by immersing herself into the transcription (Groenewald, 2004). This resulted in a summary saved in the protected folder on the researcher's PC as PILOT SUMMARY 05-11-11. The researcher then verified the transcription and summary with the participant at which was supposed to be a follow-up meeting about the correctness of the field texts made. However, due to distance and travelling issues, all comments and suggested alterations were done electronically and per cell-phone. Any comments, additions and critiques were welcomed by the researcher from the participant (Rubin & Rubin, 2005). The participant agreed with and approved all that was written and how it was represented.

An analysis of the interview was then conducted by the researcher to identify narrative threads in and among the interview so as to write up a research text. The researcher also then sent off the video recording to her supervisors for perusal.

Pilot Data Analysis

The analysis process for the pilot study, written up as themes, is discussed below (Rubin & Rubin, 2005):

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Coding and categorising:

The researcher synthesised different versions of concepts, events and topical markers so as to understand the overall narrative picture. Labelling/coding of each concept, theme, event and topical marker by giving it a letter such as C for concept together with a suitable name took place so as to readily retrieve and examine all data units that occurred or referred to the same subject. The codes/data units were then grouped into a single computer file so as to see how the concept was seen overall; examine nuances, differences, similarities, and what events had different meanings to people.

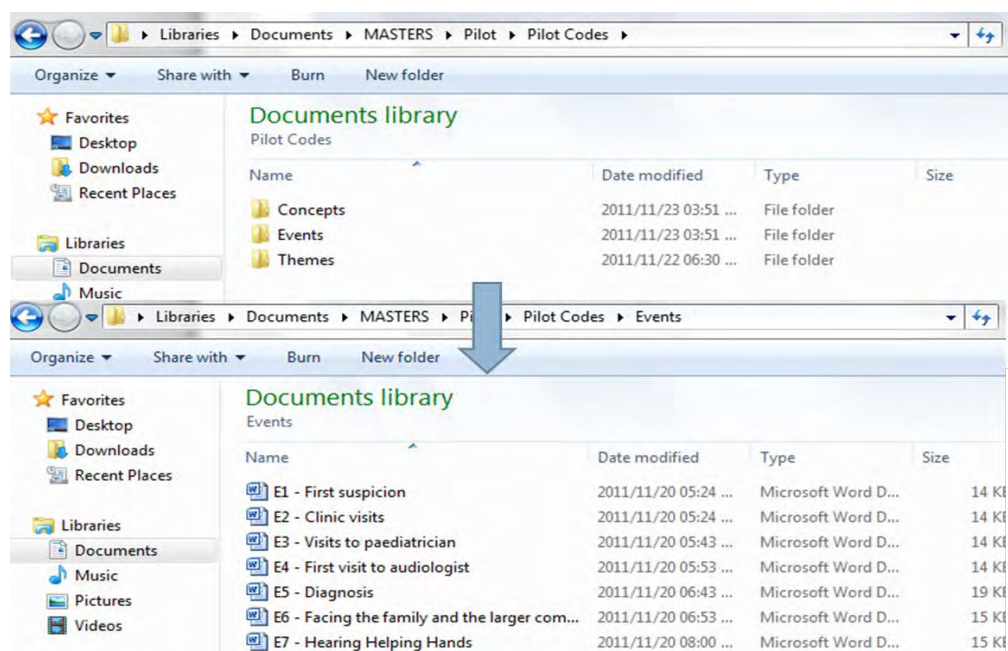


Figure a: Figure showing how codes were grouped and put into separate files

Synthesis into themes and representation.

The final synthesis of data was a detailed description of events and an attempt at an explanation of the how and why by the researcher, in the form of a narrative as represented in the figure below:

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Summary of Pilot Study

Events

Participant's first suspicion came from when the dogs barked under the babies cradle and she did not wake up.

Participant went to the clinic for follow-ups at 3 and 6 weeks after birth, and asked to test both times. The baby was tested with the bell and each time she was responsive, but saw instead of heard the bell.

The participant went to the paediatrician first at three months, with the request to have her babies ears tested as she suspected a hearing loss. The paediatrician said that an assessment by an audiologist could only be done between six to nine months old. At six months she went again and had a growing suspicion of a possible hearing loss. At eight months she went to the paediatrician again and could make an appointment with an audiologist from the number the paediatrician gave her. She got an appointment at nine months.

Participant went to the audiologist when the baby was nine months old. The audiologist did a hearing test with headphones and noted a very probable hearing problem. She booked them for a brainstem in another month.

The participant and her husband went to [redacted] for the brainstem when the participant was nine months old. The audiologist redid the test with the headphones to check for a better response, but the response was the same as the last visit. She then prepared the parents for the brainstem by explaining that they had to sedate their baby with this pink fluid, as she had to sleep during testing. The baby was however allergic to any red colorants, which they didn't know, and whilst walking around St Augustine's Hospital in [redacted], for the baby to fall asleep: the baby was getting wilder, instead of calming down. When she did fall asleep, she always woke up when they put her down on the bed in the ABR room. They did manage to get the electrodes on, but she always woke up and they could not do the test. The parents were however adamant to have the test done, and they gave the baby another dose of the sedation. Eventually after two hours, the baby fell asleep and they put her in the room to be tested. This was a long test. Once throughout testing the audiologist came to check the connection point of the electrodes on the baby's head as she was unsure if her computer was working properly. The audiologist never made eye contact throughout testing through the window, but kept on shaking her head, putting her pen in her mouth and pressing the buttons. After a long while she came out, tapped her pen on the desk, and said that there was bad news and that their child had a profoundly hearing loss. After explaining that profoundly meant that there was no hearing, and explaining how hearing works, the audiologist asked if there were any problems during pregnancy and if there was any deafness in the family. The audiologist then left them alone a little bit. When the audiologist came back she advised them to go for signing lesson, seek help at a signing school in [redacted], called [redacted] and that it would be best to move to [redacted] and that they should change their home language from German to English. The parents insisted that they would like to have hearing aids fitted, and the audiologist did the ear impression whilst the baby was sleeping. The audiologist then explained that she will order strong hearing aids, and that it would take about two weeks for the hearing aids to be collected. When the parents left, the

participant still felt restless and went back to ask if there isn't anything else they could school their baby, as they would do anything to help her hear. The audiologist then told them that there was a place in [redacted] called the [redacted] where they make deaf children hear. When asked by the participant why she hadn't told them before she responded by saying that she didn't believe they'd take it, as it's far and expensive. The participant then received a contact number from the audiologist for the [redacted]

The participant and her husband then drove back home to Margate after the diagnosis. They had to fetch their eldest daughter from the participant's in-laws. The Pastor from their church was coincidentally visiting at the time of their arrival. They arrived at the home, the grandmother asked them what happened, the father said that their baby had a hearing loss, and the grandmother started crying, joining the participant. The grandfather came out as well and said he was sorry to hear the news. When they went into the home the grandfather announced to the Pastor that he now had his first deaf congregation member. This was difficult for the participant and they left.

The participant contacted the [redacted] as soon as she heard that the hearing aids were soon to arrive [redacted] was a big help and guidance for the participant and her family from then on. It felt to her like she was part of a team and a larger family when she met other parents at Carel du Toit who had children who were also deaf and who were talking with their children. She told of the drive there, the difficulties, but ultimately the hope that she felt and the guidance, therapy and material that she got from them and the contacts they gave her. She also then told of the cochlear implant and that whole experience.

Themes

Aetiology/causes

The concept of aetiology was mentioned frequently throughout the interview. The question: "what was the cause?" has stayed with the participant. During the time of diagnosis, she once asked of the strawberry markings/stork marks, present at birth, left a marking on her child's brain that affected her hearing. This was however dismissed by facts given from the doctor at that time. The other factors include exposure to German measles during pregnancy, malaria pills before knowledge of the pregnancy, as well as family history, meaning that there could be a congenital factor of hearing loss. This still concerns the participant as that would mean that her child would maybe have her own children who are deaf. She emphasised that when being given the diagnosis the audiologist should have possible causes of hearing loss ready as: *if you have that small little baby in your hand, you want answers: you want to know what it could be.*

Hope and reality

The participant always felt a growing suspicion that there may be a hearing loss, but there was always a glimmer of hope - even until the news was delivered that the hearing loss was then at least only a 50% loss. Others also expressed hope or denied that there was a problem, by stating that the child was placid, very alert or very attentive to visual stimuli. The news of diagnosis was devastating to the participant and her family. She dealt with it by crying and distancing herself from those who did not deal with the news gently. There was a continuation of suspicion, hope, realisation, shock and again hope, as a plan began to unfold of what to do.

Figure b: A picture of the ensuing representative research text

Quality Evaluation:

The researcher had a look at the interview and the questioning itself by watching the video recording twice and making notes whilst watching and also stopping the recording. As soon as the interview was transcribed some more notes also surfaced.

The participant was well-prepared and knew what she wanted to say. This made it easier for the researcher as she never had to prompt. Some specific continuation and clarification probes were used. Here are some examples: "Mmm hmm. ... So? What exactly are those? Just like little splotches? So what kind of tests did the paediatrician do? So the touch and the visual... Did she sound the same as (name of sister)? So, was she fighting it? So was the cause very important to you? To what? Do you mean the news and...?"

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A lot of attention probes were used throughout the interview including non-verbal as well as verbal, for example: nodding as well as shaking of the head, leaning forward and looking directly into the eye, saying: "Ok, I understand.... That is interesting."

One single probe that could maybe be described as a steering probe, because the participant is not a first language English user, was when the researcher finished the sentences for her. For example when she couldn't find the word for measles again, or when the researcher finished her sentences for her. Although she knew what she wanted to say, it looked like she was fumbling. Rather the researcher should ask: "What word are you looking for? Describe it to me." because this leaves it open, and the researcher does not put words into the participant's mouth – even if they were the ones the participant was looking for.

One question that had bad timing was the: "Can I ask if she had a little speech banana with her?" That was used to soften or stall the blow of emotion that the researcher knew was coming, and also to check on the audio recorder that it was taping, especially because the interview was approaching such a critical, emotional part. The researcher learnt through this experience to trust in the equipment and be sure to have her undivided attention on the participant. Strategies to help with this could maybe include:

- Check that all equipment is working beforehand (as was done this time as well)
- Have a small notepad that you can just flip out if the participant (as this one) just starts the interview without you being quite ready yet.
- Make sure in the beginning and make a mental note that the recorder is indeed on. Don't be shy to wait a few minutes and then put it aside and forget about it.
- Note: if you're at ease, the participant is as well.

A lot of leading questions surfaced as the interview went on. This was due to a familiarity that was felt towards the participant after we had the break and also, because it was a long visit and the researcher was losing concentration. Leading questions and how they should have been asked, follow:

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- And if you change your home language, I'm assuming you are changing more than just your home language...?
- And if you change your home language that would mean...?
- So if you say it hurt you a lot, is it because it was said out loud, or it was like a label?
- Why would you say did it hurt you so much?
- Did it feel like: this is just how it's going to be, there's no hope?
- How did this "face it", make you feel?
- Would you say that was the most difficult to deal with?
- So what was the most difficult thing to deal with?
- Would you have liked ... Ok, the audiologist, we would have liked for her to have done things much differently?
- Would you have liked the audiologist to have done anything differently?
- So you would have liked her to have been a little bit more kind in her approach to giving the news?
- So how would you have liked this news to have been given to you?

Although all these leading questions were born out of something that the participant had already said, the researcher should remain consistent in her questioning, by having open-ended, non-leading questions.