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The lived experiences with paediatric hearing loss: medical doctors as parents of deaf children

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THE LIVED EXPERIENCES WITH PAEDIATRIC HEARING LOSS: MEDICAL DOCTORS AS PARENTS OF DEAF CHILDREN

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A research report submitted to the Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, in partial fulfilment of the requirements for the degree, MSc Med Child Health (Neurodevelopment).

Johannesburg, 2020

DECLARATION

I Bianca Caren Birdsey declare that this Research Report is my own, unaided work. It is being submitted for the Degree of MSc Med Child Health (Neurodevelopment) at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at any other University.

_____
(Signature of candidate)

_____day of_____20_____in_____

Name of Primary Supervisor: Dr Lavanithum (Neethie) Joseph

Signature of Primary Supervisor _____Date_____

Dedicated to Prof Lorna Jacklin, my initial co-supervisor, who inspired so many of us to give of our best, for the sake of children and families.

ABSTRACT

Paediatric hearing loss is an important aspect of neurodevelopment. Optimal management includes a holistic family-centered approach. In spite of knowing this, the field of paediatric hearing loss is largely influenced by a medical model view of disability. Exposure to the lived experience may be the catalyst for the necessary shift towards holistic family care. This study explored the lived experiences of South African medical doctors who are also parents of deaf children. The aim being to better understand the field of paediatric hearing loss through their insights gained as parents. Interpretative Phenomenological Analysis was the approach used for this qualitative enquiry. Five participants were selected using purposive sampling and an in-depth semi-structured interview used as the data instrument. Thereafter, three levels of thematic analysis were conducted. Four organizing themes emerged reflecting the complex journey of parenting deaf children, insights into the interactions and support received, as well as the reflections on the inadequate knowledge of doctors about paediatric deafness. Participants acknowledged the power of the lived experience in changing their own practice as both parents and practitioners.

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Finally, for my family who love and support me unconditionally. My three treasures – no words could express the gratitude I have for them and this journey they've guided me on.

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NOMENCLATURE

CI	Cochlear Implant
DALY	Disability Adjusted Life Years
dB	Decibels
D/HH	Deaf or Hard of Hearing
EHDI	Early Hearing Detection and Intervention
ENT	Ear Nose and Throat
FCEI	Family Centered Early Intervention
GP	General Practitioner
GPODHH	The Global Coalition of Parents of Children who are Deaf or Hard of Hearing
HPCSA	Health Professions Council of South Africa
HIV	Human Immunodeficiency Virus
ICF	International Classification of Functioning, Disability and Health
IPA	Interpretative Phenomenological Analysis
JCIH	Joint Committee on Infant Hearing
NHI	National Health Insurance
OAE	Otoacoustic Emission
SARS	South African Revenue Service
TB	Tuberculosis
UN	United Nations
WHO	World Health Organization

CHAPTER ONE

1 INTRODUCTION

1.1 Study Background and Literature Review

The World Report on Disability has estimated that 10-20% of the global population, translating to more than one billion people, are disabled, and that the prevalence of disability is increasing (1). Consequently, the World Health Organization (WHO) has identified disability as an important area in medicine warranting continued research (2).

The medical model, on which medical professions are founded, is primarily a disease-centered approach focusing on disease elimination and optimization of individual functioning (2). It has been said that medicine is thus dominated by those who are trying to identify causes and cures for diseases (3). This unipolar view of deviations from the norm (4), which has been referred to as "medical paternalism"(5), has been challenged over the past thirty years by reconceptualists who promote a foundational shift in social constructs towards disability (6). This is the social model of disability which views people affected by disability as living under the "shackles of overmedicalization"(7). The social model, also known as the "social oppression theory" (8), sees the social barriers, discrimination and prejudices towards disability as the overall disabling factors for a person, rather than the physical impairment per se (2).

This shift in perspective can be further seen in the replacement of the biomedical model with the biopsychosocial model, a philosophy of clinical care introduced in the 1980s by the late George Engels (9). This movement acknowledged that there was a need to change the perspective of the health worker from one fully focused on pathology, to one holistically considering the biological, psychological, and social factors of the patient and the complex interactions of these factors (10). The biopsychosocial model also recognizes the centrality of relationships to healthcare, leading to increased self-awareness of the health practitioner and multidimensional satisfactory care of the patient (10).

These paradigm shifts have greatly impacted global influence from the WHO and the United Nations (UN). The UN Convention on the Rights of Persons with Disability in 2007 recognized that disability is an "evolving concept" which includes the interactions between people, attitudes, and environmental barriers (11). The WHO has produced the International Classification of Functioning, Disability and Health (ICF) which aside from producing a common language for health workers across the globe, serves to endorse the holistic management and consideration of a person living with a disability (12). These are all positive steps towards the holistic service provision for, and meaningful understanding of, the disabled.

In spite of this philosophical transitioning, the medical model of disability continues to be the bedrock of medical training (3). Juxtaposed messages from global health leaders continue to undermine the positive attitudinal changes promoted. An example of this is the Disability Adjusted Life Years (DALY) calculation; a burden of disease measurement. This was launched by the World Bank and WHO as a combined measure of morbidity and mortality. By virtue of definition, this assumes that people with disability live lives of subordinate value when compared to those without disability (13). Thus, while the need for change is acknowledged, the persistent impression is that of medical model dominance (3).

The field of hearing loss amplifies the complexity of the disability approach continuum. The polar ends which include cultural-linguistic and medical-audiological views to this disability are consistently held in contention (14). The typical understanding of a person who is deaf is from a medical model perspective (15) which underpins the way deaf people young and old, and their families, receive services. Typically, deafness continues to be constructed in a misinformed, negative manner (15).

WHO statistics reflect the significant contribution of deafness by rating it amongst the top 20 contributors to the global burden of disease (16), with 5% of the world population (466 million people inclusive of 34 million children), having a disabling hearing loss (17). Hearing loss is defined by the WHO as the inability to hear sounds below 25dB in both ears (17). There are different degrees of hearing loss including mild, moderate, severe, and profound hearing loss (17,18). The term hard of hearing tends to relate to a mild, moderate, or severe hearing loss, where spoken language is usually the primary mode of communication (17,18). People are often described as deaf rather than hard of hearing, when their hearing threshold shows a profound

loss. There is also an association with the use of a sign language for persons referred to as Deaf (17). The terminology can be an area of confusion as it may relate to an audiological classification for some, whilst a functional language classification for others. The WHO further defines hearing loss in terms of disability. Disabling hearing loss is a loss of more than 40dB in the better ear for adults and more than 30dB in the better ear for children, with up to 90% living in low or middle income countries (16,19) and 25% living in Sub-Saharan Africa (20). Statistically, for developing countries, this translates to a prevalence of 6 per 1000 infants utilizing pubic health services (21) and remains the most frequently occurring "birth defect" (16,22). In South Africa disabling hearing loss is rated as having the second highest prevalence for disability (22). The prevalence of hearing loss is even higher if one also included that which fell outside of the "disabling hearing loss" definition – including unilateral hearing loss, fluctuating hearing loss and minimal hearing loss (23). This is relevant, for if remained unmanaged as experience and research indicates, all hearing loss can have negative consequences (16). For the purposes of this study, the term "hearing loss" will be used to holistically encompass congenital deafness in keeping with the use of terminology by the WHO and Joint Committee on Infant Hearing (JCIH).

In considering the prevalence of deafness as a disability in a developing country such as South Africa, one needs to understand the relevance of this phenomenon to the neurodevelopment of children who are deaf or hard of hearing, as well as the socioemotional implications for their families. In spite of the relatively high prevalence in disability overall of paediatric hearing loss, it is a relatively low incidence phenomenon (24) which then competes with the more prevalent health burdens (25), such as HIV and TB, for the attention of medical professionals. Consequently, it may not be something medical professionals are particularly aware of or knowledgeable about.

The complexity of paediatric hearing loss is largely founded in the fact that between 92% and 95% of deaf babies are born to hearing parents who have no prior knowledge of hearing loss nor association with deafness (18,26). In the developing world, Universal Newborn Hearing Screening is not routine, so babies who are born with a hearing loss are usually identified late (27) when their language milestones are noted to be delayed (21). This is typically between the ages of two and three years, missing the critical period for optimal language development (21,25). South Africa performs within what is expected for the developing world. A recent study

by the University of the Witwatersrand's Centre for Deaf Studies revealed a mean age of identification of 28 months for the cohort studied (25). International best practices include Universal Newborn Hearing Screening and intervention which fulfill a "1-3-6" recommendation (28). This relates to the Joint Committee on Infant Hearing (JCIH) recommending that infant screening be done before the age of one month of life, diagnostic audiological testing by three months of age, and comprehensive intervention commenced by six months of age (28). When this is adhered to, deaf children typically develop language outcomes optimally, on par with their chronological age (29,30). The Health Professions Council of South Africa (HPCSA) has adopted these guidelines, recommending infant screening by one month of age (no later than six weeks), diagnostic and medical evaluation by three months of age (no later than four months) and appropriate intervention by six months (no later than eight months) (31). In spite of having national guidelines that mirror international best practices, South Africa is significantly falling short of implementing these effectively.

In South Africa, Universal Newborn Hearing Screening is not routinely observed (21). The vast majority of families would not have had newborn screening offered to them (21,23). The consequences of late identification and late intervention for deaf children are complex and have long term significance (29,32,33). These include impairments in language development, cognitive development, speech development, socioemotional development, and reasoning skills (29,30,34). These factors have further implications for academic, educational, vocational, and social opportunities as well as mental health and overall quality of life (16). These consequences are further exacerbated in poor socioeconomic settings such as South Africa (23), where those who are deaf or hard of hearing become the poorest of the poor since income earned is on average 45% less than that of the hearing population (31).

Paediatric deafness therefore is a disability of marked significance that warrants careful understanding and care to optimize outcomes for deaf and hard of hearing children. Early identification with appropriate early intervention significantly ameliorates these potential negative consequences (25,29,30). Research shows that the first six months of infant neurodevelopment are a specifically sensitive period and an optimal window of opportunity for language development (29–31). In countries where late identification is typical, this window of opportunity is being wasted.

Aside from the evident neurodevelopmental consequences to undermanaged hearing loss, families, on learning that their child is deaf, experience trauma and grief that can be likened to experiencing a death in the family (15). Raising a deaf child impacts the whole family (18,35), resulting in the deafness belonging to the family as a unit and not just the deaf child (18,35,36). Understanding the multidimensional impact of raising a deaf child and having insights into the relevant social support networks is critical to strategically implementing quality early intervention for that particular child (35,37).

What complicates the emotional rollercoaster for parents, is the extreme politics in the field for permanent childhood deafness. Those who hold a more social view of deafness as a disability, consider deafness as a linguistic minority group rather than pathology needing fixing. This is depicted by the use of the capital "D" Deaf, meaning those who culturally identify with deafness and use a signed language as a primary mode of communication (15,38,39). On the other end of the spectrum are those who are founded on the medical model of disability and focus on the need to "fix" the deafness through the use of surgical procedures such as cochlear implants, state of the art technology such as hearing aids and intensive Auditory Verbal Therapy (14,40). The deafness is considered an audiological disease, and much focus lies on making the deaf person as "hearing" as possible (14,38,39). Parents find themselves in the middle of this debate as they start their unique navigation of their parenting journey. A biopsychosocial approach, considering the holistic well-being and management of the child and family, would be considered a balance between the purist social and medical models of disability, and in this case, paediatric hearing loss (41).

International best practices promote informed choice as a vehicle to navigate the politics and debates in the field, allowing for decision making that bests suits the child and family (42). Informed choice principles aim to provide enough information about the spectrum of choice options allowing for parents to make careful considerations within the politically heated field of paediatric deafness (43). Informed choice challenges the medical model, viewing parents as important stakeholders in the intervention of their deaf child (42).

If deafness is a significant contributor to global disability, and the consequences of mismanaged child deafness dire, the need to explore and understand the factors that optimize outcomes warrants prioritization. Yoshinaga-Itano and Moeller have explored these predictive factors; their

research is the most renowned on this subject to date. Both found that early identification with appropriate intervention before the age of six months, had the best predictive value for language development and reading skills (29,30). A second important predictive factor for good academic outcomes identified by both, was active parent involvement in the intervention process (29,30). Further exploration into what contributes and what determines "active involvement" is still necessary to fully understand this interesting phenomenon. Acceptance and inclusion are key underpinning factors that see parents able to confidently engage in their child's intervention (26). Parent to parent support has been identified as an important form of support to illicit the parent's acknowledgement of "sameness" in being able to identify with the lived experience of fellow parents (44–46). Informed choice promotes parent inclusion, and a move from patient-centered care to family-centered care, thus considering the entire family in intervention strategies while critically involving the parents as key stakeholders (43).

Family-centeredness has thus been endorsed in best practice principles globally to maximize parental participation because of its important predictive factor for deaf child outcomes. Family-centered care advocates that the parents are ultimately in control of the decision making, offering a parent-professional partnership as the cornerstone of caregiving (28,42,47). The goal becomes holistic progress with a focus on family strengths, enjoyment of parenting, emotional availability, self-efficacy, joyful interaction and communication, and active engagement and participation (42). Parent-professional partnerships are meant to be supportive, respectful, and empowering (47). Research appraising family-centered care has shown this holistic approach to be a strong predictor of parents' emotional well-being and service satisfaction (47).

The evolution of the philosophy of care can be appreciated as a gradual shift from an isolated curative focus with the medical provider as the sole decision maker, to one of holistic care considering the family-professional partnership as the decision-making unit. Typically, research indicates that medical professionals still struggle with this new world approach (48–51). Studies investigating the attitudes of professionals and experiences of families across disability show that communication with doctors are at times, dissatisfactory for more that 50% of families (51). The general impression is that doctors do not respect the intelligence of those living with disability nor do doctors value the participation of people in their own healthcare (48). Parents of children with disability at times feel judged by doctors while not being engaged with in a respectful, appropriate manner (49). Parents seldom enjoy an equal relationship with professionals (52)

which is of significance, as the attitudes of health professionals has an important role to play in determining the quality of services that the disabled and their families receive (50).

The language used by professionals is an important factor to consider. Typically healthcare workers relate to disability with language that emphasizes dysfunction and pathology (52), underestimating the significance of the impact of this "naming" (53). One needs to appreciate the impact of parent-professional engagement in order to understand the need for and value of attitudinal and behavioral change. It has been seen that the initial interactions with health professionals are significant, having a lasting impact on a parent's capacity to cope with their child's disability and diagnosis (51).

If one zooms into paediatric deafness as a disability, it is evident that this field is one where the ideal professional-parent relationship has far to go. Deaf people have shared insights expressing how doctors underestimate the complexity of their communication needs (48). Informed choice is also not actioned regularly in the field of paediatric deafness (43). Knowledge about paediatric deafness among physicians in general is lacking, with significant underappreciation of the purpose of early identification and its significance to language and cognitive development (54,55). Physicians may appreciate the need for hearing tests for high risk groups, however this targeted screening will miss more than 50% of hearing loss (54,56). Parents consult primary care physicians frequently during the first two years of a child's life for various problems including a spectrum of child development queries (55). Research has shown that doctors tend to minimize the impact of a failed hearing test and the relevance it has to child development (55). Research in developing world settings has suggested that doctors are often the reasons for the delays in identification and initiation of intervention for paediatric hearing loss (54).

Considering the prevalence and impact of paediatric deafness, as well as the resistance to change from a medical model approach to patient care, one cannot help questioning what may be necessary to influence change. Theories concerning in-build reasoning, decision making and heuristics provide interesting food for thought (57). Kahneman and Tversky, both cognitive psychologists, explored how heuristics and biases tend to frame the way we perceive the world and new situations we may encounter (58). When thinking about disability and the cognitive dissonance (59) that is experienced in the disability attitude evolution, it is evident that deep seated attitudes and perspectives are difficult to influence. This would remain true for health

workers who persist to view disability through a medical model lens alone. Since individual perceptions and realities are rooted in cultural and social views, one also needs to consider the impact to the individual, when those closest to them - their family and friends - are also subject to the same societal constructs that influence medicine (15). Medicine itself is an influential field. Thus, positive change here would have a significant ripple effect on society at large. How therefore does one begin to try and influence for positive change? What exposure would shift a perspective?

Experiments dealing with perspective shifts identify that change is indeed possible (59). Teaching people about flawed reasoning and exposing them to alternative possibilities has shown to influence biases seen in medicine. Kahneman's WYSIATI rule, "what you see is all there is" is a cognitive bias that explains the gaps in knowledge and understanding that we all have due to a limitation in experience and exposure (58). Another famous psychology experiment further demonstrates this. The "Invisible Gorilla" experiment showed how people do not see what they are not expecting to see (60). In this experiment, college students were tasked with passing a ball between team members while counting their team's number of passes. While they were engaged with keeping count, a person dressed in a life-sized gorilla suit walked slowly across their ball court. No one noticed the gorilla. A parallel can be drawn here with medicine. This inattentional blindness (60) may explain the resistance to view disability differently. In this experiment with the gorilla, the researchers determined that most people missed the gorilla completely, simply because they were not looking for it. The experiment also revealed that knowing to expect the gorilla, then made it visible to those who previously missed it (60). How then can we make the "invisible gorillas" such as the broader views of disability, more visible to health workers?

Actively equipping health workers with a richer understanding of disability would be beneficial if coupled with exposing them to their own medical model founded biases and cognitive processes that typically dominate their gaze (59,60). Having health workers understand the value of certain interventions and ways of practicing medicine may result in attitudinal changes. These in turn would cause an intentional behavior shift. This move from attitude change to action is known as the "theory of reasoned action," a health communication model used to motion change in clinical care (55). There is an imminent need to change the clinician's stance from one of objective detachment to a wider gaze that includes reflective participation (9).

Exposing health workers to the daily lived experiences of those with disabilities, allowing one to learn from those with experiential expertise (61,62), would be a useful tool to developing empathy and a greater understanding (63,64). Understanding the family perspective allows for the health worker to engage in the meaning-making of the experience with the family (65). Perspectives undergo reconstruction as health workers learn alongside those with the lived experience (5,65,66) and this engagement creates a sense of "sameness". This makes this "new normal" more relatable and may very well influence attitudinal changes (67). If medical doctors were those sharing their lived experience - the dual professional "providers of care" insights and "receivers of care" insights - these experiences would be especially relatable for fellow professionals sharing in their colleagues' experiential expertise through this research. Indeed, this would serve as an invaluable form of knowledge transfer.

1.2 Study Rationale

Paediatric deafness is a growing field of global relevance. My research resonates with the dire consequence of this neurodevelopmental emergency. All research emphasizes that parent involvement and active family participation is key to a deaf child thriving. The approach that best facilitates this is family-centeredness, which is why international best practices endorse this whole heartedly. Family-centeredness is a significant step away from the medical model which still remains the bedrock for healthcare training and consequent behavior. As a result, this approach is not being implemented as desired; seeing families unsupported, disempowered, and uninvolved. This bears a catastrophic consequence to the deaf child. Finding those lived experiences to influence deep rooted medical model perspectives would be a worthwhile exposure to health workers in this field. Lived experiences would have a greater impact in unveiling the "invisible gorillas" of preconceived ideas if they were to be particularly relatable. This in turn, facilitating a better understanding of the need for holistic patient care, which in the case of children, encompasses the framework of family-centeredness.

This research is of personal interest to me because of my own transitional journey through disability. As a medical doctor, I managed patients with care, yet with large medical model-sized blind spots towards differences. My lived experience as a parent to three deaf children taught me more about patient needs and holistic management than I could ever have learned from a textbook. I also found myself in a field which was previously of no interest to me. The field of

paediatric deafness was not one that I considered to be particularly important. This was largely due to the complex context and burden of developing world medicine, which is a reality for South African doctors. On reaping the personal consequences of such ignorance, my journey has led me to deeply appreciate the neurocognitive significance of early language deprivation, and the socioemotional consequences of mismanaged paediatric deafness. As a mother, I have new found insight into the realities of families journeying similarly.

Being in a unique position of both parent and medical doctor, I now have insights into both sides through switching roles and perspectives, unlike my former unipolar view. For my research I wanted to recruit similar participants to myself. Participants who too share a dual experience as parent and practitioner in this field. I wanted to explore the reciprocal relationship between parenting and doctoring and see what experiences could be shared that may lead to new insights gained for colleagues in the field. This unique positioning would provide invaluable "insider information" for those working with families reflecting a dual appreciation of medical model "deafness" whilst sharing fresh insights into the lived experience of what "being deaf" might mean for children and their families (68). The stance of shared sameness, both with the medical world and the lived experience in paediatric deafness, would hope to bring an interesting relatability to colleagues reading my research. The goal, to influence positive change in the way that families are understood and managed, in the hope of seeing true family-centeredness practiced. The fruit of this practice would be enjoyed by both family and professional alike. As an overflow, raising the awareness of the management and approach to this particular disability, should lead to attitude changes towards disability in general (69).

Therefore, the question that I aim to answer is exploratory:

How do medical doctors experience being parents of deaf children, and what reflections on the process and the services do they consequently have?

1.3 Summary of Chapter

In spite of a global acceptance for the need to manage disability holistically, moving away from a medical model to a more biopsychosocial model, medical professionals persist to view disability through a medical model lens. The field of paediatric deafness also sees this to be true.

In this field, the framework of family-centeredness is recommended to promote holistic family care. Considering the evidence that shows that a child's optimal outcomes are largely dependent on the family's active participation, adopting a holistic family-centered approach to care would be in the best interest of the deaf child.

How does one facilitate a change of practice within medical professionals? Research suggests that exposing professionals to a lived experience is an effective catalyst for change. Through my research I hope to initiate change in the way paediatric deafness is viewed and managed, through exposing the lived experience of parents of deaf children who are also medical doctors. Through creating a sense of sameness with other professionals in the medical field, I hope to have their lived experiences as parents be considered as trustworthy experiential expertise.

In the following chapter my aim and objectives will be defined, and the methodology I have used to achieve these will be introduced. Thereafter, the results will be presented and later discussed. This will be followed by conclusions drawn through this study, together with recommendations to the broader medical world - specifically hearing health professionals and medical doctors.

CHAPTER TWO

2 METHODOLOGY

2.1 Aim and Objectives

The aim of this study was to explore the experiences of medical doctors in South Africa as parents of deaf children, examining how the field of paediatric hearing loss can be better understood, by medical professionals' insights gained as parents.

The objectives were:

1. To describe the parenting journey when parenting one or more deaf children in the context of South Africa, while having a professional background in medicine.
2. To explore reflections that medical doctors might have on the medical interactions, services, and support that they have accessed during their parenting journey.
3. To analyse the plurality of perspective that both medical doctor and parent might have, specifically focusing on the influence that one may have had on the other.

2.2 Study Design

A qualitative research approach was considered best to achieve the aim and objectives of the study. Whilst qualitative research is not as prominent as quantitative research in medicine, this approach allows for a good exploration of experiential data which could serve to equip this field in medicine with a richer understanding of the phenomenon being explored. Qualitative research is gaining favour in the medical field, especially when unique experience is in question (65). Qualitative research can serve as a relevant tool in understanding the actions, beliefs, experiences, and perceptions of others (70). This approach is person-centered, exploring the contribution of the whole human being to the experience. The researcher themselves serves as a core research instrument, as they explore phenomena, problems, or puzzles that they may have encountered in the field (70). There is debate with regards to the value of an "insider" or "outsider" researcher (68). Young proposes that in fact all researchers are "insiders" as

researchers opt for subject matter that is of particular interest to them as their own experiences influence what they choose to look at (68). My unique position as medical doctor and then parent to deaf children, allows me to be uniquely matched to my study population. While one would need to be acutely aware of preventing bias, my position as researcher also allows me to be in a trusted position by participants to share freely, knowing that they have an extremely unique common ground.

In qualitative research, the understanding of both the underlying ontology and epistemology of the phenomenon being explored is important (68,70). Ontology refers to the study of being and looks at the nature of the reality. In this study it would include the nature of being a medical doctor, or the nature of being a parent of a deaf child. The next step that would enrich this further would be to unpack how being a doctor-parent can extend our understanding of the field of paediatric audiology from a parent's perspective as well as the medical profession's view on disability as a whole. Epistemology refers to the study of knowing. This is expanded by Young and Ackerman as "how reality can be known, who is or should be a knower, what the relationship is between the knower and the knowable, and on what grounds his or her knowledge should be trusted" (71). Epistemology is fundamental to the qualitative research design chosen, that being Interpretative Phenomenological Analysis (IPA).

IPA originated in psychology and is a rapidly growing entity in qualitative enquiry especially in health psychology (72,73). This research approach looks at how people reason or make sense of life experiences, and this is becoming more popular in health research as we appreciate that there is more to understanding the perceptions and experiences of others, than simply the biomedical parameters that are usually studied (73). When significant events are experienced by individuals, they start reflecting on the significance of the event consciously or subconsciously. IPA serves to engage with these reflections (72). IPA is said to quadruple the advantages known to qualitative research due to the unique bonding between researcher and participant (74). There are three core theoretical frameworks of IPA (72). The first is phenomenology. This is a philosophical approach to understanding and studying experiences, allowing for a detailed examination of the participant's lifeworld (62,72). The experience in my research is twofold; that of being a medical doctor and that of parenting a deaf child. The second theoretical framework comes from hermeneutics. This is the theory of interpretation and sense-making, and in IPA is said to be a double hermeneutic as the researcher is trying to tap into the "insider perspective" of participants

whilst simultaneously trying to make sense of the participants making sense of their experience (62). This is both an empathetic and questioning process (62). This is the process where one may consider my unique position of sameness with the participants as potentially biasing the hermeneutic circle. I propose that my epistemological position would be a unique stance in understanding and empathizing with the experiences and sense-making process of participants, through my wide exposure and understanding of the phenomenon of paediatric deafness, both personally and professionally. Another protective factor against bias is that IPA is a bottom up approach (75). There is no assumption from the researcher that is being questioned through participants, but rather an opportunity to give a voice to the unique experiences of participants (75,76). The commitment is not to assume a certain truth to be unveiled but rather to understand the perspective of each participant, noting where they may converge or diverge (72). The third theoretical underpinning of IPA is idiography (72). This is a concern with the particular details of the experience as well as the depth of analysis (72). Through meticulous attention to detail, the researcher attempts to enter as far as possible, the social and psychological worlds of the participant (62), which with my personal rationale, seems an appropriate methodological fit. Analysis in IPA mirrors analysis in qualitative research as a whole in that it is not simple and quick but rather labour-intensive, rigorous, time consuming, and systematic. This all in the effort to reflect the truth of the phenomenon (70,72).

A small sample size may be seen as a limitation in this study, but it is appropriate to use such small numbers for IPA as the analysis is very in-depth. Every effort is made to reduce researcher bias especially during the process of selecting themes for analysis. The methodology itself is somewhat protective against bias in that as Smith and Osborn state, “there is no attempt to test a pre-determined hypothesis of the researcher; rather the aim is to explore, flexibly and in detail, and area of concern” (73).

2.3 Participants

2.3.1 Selection criteria

The selection criteria for participants in the study included:

- South African parents of deaf children. This specific target population allows a focus on both the South African medical support services as well as contextually - the reality of raising a deaf child in this country. Important variables that differ between countries include newborn hearing screening access and consequent early intervention.
- Participants need to be qualified medical doctors who were in clinical practice before and after the identification of their child's hearing loss, in order to enable the reflection on the reciprocal impact of their medical training and experience as well as their parenting journey. Participants needed to have received their undergraduate training and qualification in South Africa in order to accurately reflect the undergraduate experience in South African medical schools, with regards to information about and exposure to paediatric deafness.
- The participants needed to have children who met the "deafness" definition of "disabling hearing loss" as per WHO definition of having bilateral hearing loss of more than 30dB loss in the better ear (17).
- Doctors with adult deaf children were not included for the risk of recall bias for a much older child. Also, some choice options, would not have been freely available for such parents to opt into, which may have also created some selection bias.
- Doctors whose deaf children had other significant special needs were also not included, as I wanted the experiential focus to be on the deafness and not deviated to the significance of different medical challenges.

2.3.2 Sampling

IPA studies are usually conducted on small sample sizes with a relatively homogenous sample (72). Homogenous samples allow for better comparison of divergence and convergence of experiences (72). The recommended sample size is between three and six participants (62). Five

participants were recruited in total. This excludes the matched doctor-parent who was used for my pilot interview. I am part of a number of networks in the field of paediatric hearing loss, including having founded a national parent support programme for families with deaf children. Consequently, potential participants were accessible. I know of 12 South African medical doctors with children who have a hearing loss, but only five of them met the inclusion criteria, and one served as most appropriate for a pilot interview. All five doctors agreed to be participants in the study. Participants were not all from the same geographical area, warranting some travel for face to face interviews. In addition, participants were from different fields in clinical medicine. Purposive non-probability sampling was most appropriate for this research to ensure a reasonably homogenous sample population from such a unique target population (72,77). Participants were sourced through chain referral methods (77) and recruited by invitation. All participants were fluent users of English and confirmed that they indeed were comfortable to conduct the interviews in English. All consent forms and information letters were presented in written English.

2.4 Ethical Considerations

Ethical clearance was obtained from the University of the Witwatersrand Human Research Ethics Committee (Medical) – ethics clearance number M180720 (Appendix A). Because of the nature of the sample population, special effort has been made to preserve anonymity as a means of upholding confidentiality since with this very specific group of participants, simple anonymity would not be synonymous with confidentiality (68). As far as possible, participant quotes and references have been de-identified. This includes the omission of the field of medicine the participant may be involved in, where in South Africa they may work, where in South Africa they studied, how many deaf children they have, as well as the sex of the child. This effort is an attempt to uphold the ethical principle of nonmaleficence. A detailed description of the study (Appendix B) with declarations of its challenges, such as the non-guaranteed anonymity, was given to invited participants prior to signing informed consent for both participation (Appendix C) and recording of their interview (Appendix D). Participants were reassured that at any point during, or directly after the interviews, they would still be able to withdraw their data from the study, had they wished to do so.

Due to the nature of the interviews as well as my positioning as researcher and experience in supporting families with deaf children, the interviews can also be considered as somewhat therapeutic. For most of the participants, this would have been the first time they were able to share their story in totality in the detail that they felt comfortable sharing. Being truly heard can be considered an aspect of ethical beneficence. Where appropriate, participants were asked whether they had a need for further counselling and support. In these circumstances, participants acknowledged having support systems in place, should they feel the need to explore this further.

All interview recordings, notes, and transcriptions were stored securely to maintain privacy and confidentiality and will be erased/destroyed within 2 years of the publication of the research findings or 6 years after the study if no publications arise.

2.5 Data Collection Instrument

An in-depth semi-structured interview was chosen as the tool for primary data collection (72). In-depth interviews are the preferred tool for data collection in IPA studies (72). They best facilitate the sharing of thoughts, stories, and feelings about the chosen phenomenon. These interview questions were constructed under subheadings which aligned with the research aims and objectives. The questions were typically open-ended to allow for free and expansive sharing of perspective and information from participants. Questions were structured to be reflective in nature, giving participants the freedom to disclose thoughts and be heard. The first question was specifically chosen to allow the participant to talk about a descriptive account or experience which promotes a comfortable atmosphere for further discussion (72). Prompts were included for my view only, as a way of keeping any questioning focused on the study objectives. The use of field notes taken during the interviews served as a secondary source of data collection, especially noting the nonverbal communication and contextual information evident during the interviews.

2.5.1 The interview schedule

The interview schedule included six subheadings with a total of 16 questions. These questions aimed at achieving insights to meet the study objectives. The first section was for “background” and contained one question. The second section was “baseline knowledge as a doctor about child deafness” which also had one question. “Parent experience” was the third section which included

seven questions. The fourth section, "dual reflection" included the subsections of the doctor influence on parenting, and the parent influence on medical practice. Each of these subsections had two questions. The penultimate section "experienced reflection of the field professionally" had two questions. Finally, the last question was a general invitation to add any information that the participant wanted to share. The full schedule which includes prompts, that were not necessarily used, is included in the appendix (Appendix E).

2.5.2 Equipment

Audio recording equipment included a Philips Voice Tracker Dictaphone and an iPhone 7 voice recording application for back up. A notebook was used for field notes.

2.6 Pilot Study

A pilot interview was conducted with a matched pilot participant who had not been included in the study. This enabled the interview protocol and questions to be evaluated as a tool that led to free-flowing open conversation from participants. This tested the overall process and rhythm of the interview, which included assessing the proposed timing of the interview, identifying any unclear questions and testing the recording technology (72).

Table 2.1 Results and Recommendations from the Pilot Study

Aspect Assessed	**Results**	**Recommendations**
1. Equipment • Philips Voice Tracer Dictaphone • iPhone 7		
a) Battery duration	Voice Tracer batteries lasted duration of interview. iPhone used significant battery power.	New batteries for Voice Tracer for each interview (with spares). Fully charged iPhone for each interview

Aspect Assessed	Results	Recommendations
b) Possible interruptions	Pausability of Voice Tracer checked iPhone recording interrupted by messages and calls	Become well acquainted with Voice Tracer iPhone on airplane mode for interviews
c) Quality of recording	Recording devices can be a meter away for clear voice recording.	Both Voice Tracer and iPhone produced clear voice recordings.
2) Flow of introduction	Introduction too long to be read verbatim	Introduction by virtue of an information letter to be sent ahead for thorough reading and then a practiced summary to be shared in person just before the interview.
3) Flow of interview schedule	Flowed well, often specific questions not needed as content tended to emerge spontaneously. No questions required rewording or further clarification.	Allow for spontaneous flow of content even if not in the order set out in the interview schedule, send core questions to participants beforehand to think through their experiences.
4) Additions or omissions	One extra question was needed regarding doctors' knowledge about deafness. Some of the prompts were unnecessary as the information was shared spontaneously.	The extra question was added and the unnecessary prompts removed.
5) Time allocation for interview	The pilot interview took 65 minutes.	Expect interviews to range between 60 and 90 minutes

2.7 Data Collection Procedure

After final edits to the interview protocol (Appendix E), the core questions (Appendix F) were sent by email to the participants so that they could consider what information they wanted to share to ensure that a limited time for recall did not bias the data. Appointments were made with

each participant at a time and venue that best suited them. Four of the five participants opted for interviews to be at their own home as this was a comfortable and familiar setting (72). Study information letters (Appendix B), were sent two weeks in advance so that the participants would be able to carefully read through all the details and understand what they were giving consent for, as well as how long to expect the interviews to take. Templates of both consent forms, consent for participation (Appendix C) and consent for being recorded (Appendix D) were also sent via email two weeks in advance to allow for them to be read carefully and question if necessary, thus practicing informed consent. It was in the information letters where I disclosed that I was also a parent of deaf children. I wanted this to make participants feel safe being interviewed by someone who has journeyed similarly, but for this disclosure to happen well before the interview itself, so that the interview was not about our comparative experiences, but rather solely focused on entering the lifeworld of each participant (72).

While the intention was to interview each participant in person and individually, Participant 2 was joined by another doctor parent, Participant 3, who also met my inclusion criteria and they wanted to be interviewed together. I critically appraised the data that I was recoding simultaneously in this interview, and found that there was no influence on each other's opinion. In fact, there were many occasions where they expressed having seen things differently on their individual journeys. Participants 1, 4 and 5 were interviewed individually. All participants were fluent speakers of English, and so all interviews were conducted in English. The following procedure was followed with all interviews:

- Before the interviews started, the main points from the study information letters and consent forms were summarized to confirm that each participant had made an informed choice and was comfortable to proceed.
- Time was also taken to establish a rapport with each participant (72).
- During the interviews themselves, an interview schedule served as a prompt for the interview, but participants were able to flexibly share as little or as much as they wanted to around each topic that was raised, with the primary objective of entering each participant's lifeworld (62,72).
- Interviews allowed me to engage in a dialogue with each participant, with the flexibility to modify any questions depending on responses (72).

- With consent, the interviews were recorded on two recording devices simultaneously.
- During the interviews, field notes were taken to capture any nonverbal behaviours in the efforts to maintain integrity of the data (62).
- Participants were told that they were able to withdraw from the research any time during or directly after the interview without any consequence to themselves.
- Once recording had ended, participants were then debriefed by myself to ensure that each felt safe emotionally and had access to emotional support. This was done informally and organically.
- A time of reflection directly after each interview was observed by myself whilst note taking, to capture any thoughts, impressions, or questions that field notes or interviews may have missed.

Within days of the interviews, they were each transcribed verbatim by myself, taking care to include all relevant gestures or nonverbal communications and behaviours. This was an extraordinarily time-consuming process, but I chose to do it manually and personally for two reasons. Firstly, I wanted to respect the confidentiality in being the only person that accessed such intimate and honest data. Secondly, I wanted to honour the privilege of sharing the lived experience, by giving the interviews my full, undivided attention, allowing me to get very close to the data myself. After spending many hours listening and re-listening to the interviews, when reading excerpts at a later stage of analysis, the voice, tone, and expression of each participant could be remembered as I read and reflected. The interviews were five and a half hours in total and amounted to 87 pages of verbatim transcription. Transcribed interviews were stored under password protection and recorded interviews were deleted off the iPhone whilst the Dictaphone was stored securely.

2.8 Data Analysis

2.8.1 Level one analysis

Analysis was commenced by reading and re-reading each transcription several times to ensure an immersion in the data. The first two read throughs happened whilst simultaneously listening to the recorded interviews. Being able to imagine the scene, the voice, and the nonverbal behaviour

of each participant thereafter when reading the transcription, added to facilitating a more complete understanding of the data and analysis (72).

At the stage of level one analysis, summaries of core themes which included direct quotations as well as expressions of my understanding of participant's perceptions and understanding were compiled. These represented a variety of information shared and amounted on average to three to four pages each. The relevant summary was then emailed to the individual participant as a means of observing member checking (78). Here, the accuracy of descriptions and understanding of experiences was checked by sending these summaries back to participants to correct or add to should they feel necessary. This was a step in assuring credibility and trustworthiness to maintain the integrity of the data. Descriptive validity was checked through having sections that reflected factual accuracy. Interpretative validity was checked through summaries which reflected the understanding of the meaning of what was shared (77). In these member checking summaries, all efforts were made to de-identify the participant. Participants were also asked to comment if they felt this was not done thoroughly enough. No discrepancies were noted.

2.8.2 Level two analysis

A second level thematic analysis was done in two stages. Firstly, manually through inserting the transcripts into a table of "developing emergent themes". The original transcript was inserted into the middle of three columns. In the right column, "exploratory comments" were made. This comprised of descriptive comments, conceptual comments, and linguistic comments (72). In the left column, "emergent themes" were noted. A sample of this process can be seen in the appendix (Appendix G). Stage two of level two analysis included the use of an electronic data analysis tool, NVivo. As a reliability measure, NVivo 12 for Mac was downloaded and used for electronic auto coding. Initially, all transcripts had to be formatted. At this stage the transcription which included both Participant 2 and 3 was separated to create a narrative text document for Participant 2 and then for Participant 3. An "edited synthesis" of each transcription was uploaded into NVivo 12 for Mac. An "edited synthesis" included my interview protocol whilst de-identifying all the data to maintain confidentiality (79). Thereafter, a careful process of coding each transcript into various "parent nodes" or organizing themes, and "child nodes" or emerging themes with various additional "nodes" or subthemes, allowed me to observe the overall themes that were emerging, as well as the weighting of each theme. Both manual and NVivo analysis

revealed the same themes as the process, while more efficiently organized with NVivo, is still a manual one.

NVivo was helpful with visualizing the weighting or hierarchy of the various themes which emerged, through level two analysis as well as observing which themes were coded consistently with all participants. Another result query that NVivo facilitates is a word frequency query. Word clouds are an example of such a query. The larger the word within the cloud, the more frequently it was referenced. These are useful as an initial or confirmatory step, enabling one to view at a glance the core discussion words. This is helpful to determine or confirm themes, as well as note major differences or similarities between participants. Words greater than four characters were selected. "Stop words" such as "because" were automatically excluded. Certain stop words such as "child" and "hearing" were omitted as these words were expected to come up often considering that the questions themselves might also lead to frequent responses which include "my child" or "hearing loss" (80). I felt these would bias the word frequency. Stemmed words were also included e.g. "deaf" and "deafness" were included as "deaf". Word clouds are generated individually per participant, as well as a combined representation including all participants. A word cloud showing the word frequency for the combined responses for all five participants can be seen in the appendix (Appendix H).

Word clouds are also useful in accessing the references at a glance around the most frequently occurring words for a bird's eye view of all engagements with that word. These are called word trees. This again is useful when making meaning of emergent themes. An example of a word tree - the word tree for 'family'– can be found in the appendix (Appendix I). I had selected it to include a range of nine words before and after the index word 'family', to allow for sufficient content and appropriate insight to context.

2.8.3 Level three analysis

The final steps of the analysis involved the interpretative aspect of IPA. Thus, enabling a means to fulfil the hermeneutic dialogue. An important aspect of meaning-making enabled me as researcher to contextualize the lived experiences of each participant. Within the themes extracted, a process of identifying the sense-making of each participant in their own experiences, followed by a further process of interpreting this, allowed for a fuller understanding of their

experiences. Similarities and differences between each participant were sought to deepen the representation of the participants' experiences.

2.9 Validity and Quality

Yardley's four criteria for assessing validity and quality in qualitative research have been considered and met throughout this study (72). The first principle, sensitivity to context, was addressed through close attention to the detail and the particular. The careful interview planning and subsequent care in interpretation, as well as including member checking, fulfills sensitivity to context. Secondly, commitment and rigour, was maintained throughout the data collection process as well as the careful pilot interview to ensure that my interview schedule was appropriate and sensitive. Allowing for flexibility throughout the interview process by no means jeopardizes the rigour of the approach (76). All efforts have been made to attend closely to what each participant had to say. The analysis was done both manually as well as with NVivo (computer assisted qualitative data analysis tool) in the pursuit of rigorous analysis, even though this sample size could have adequately been managed manually. The third principle is transparency and coherence. This has been observed through care in documenting the research process in detail. Finally, Yardley's last principle, impact and importance, is something I've aspired to, in choosing a research topic in a field that still has much room for growth, as well as opting for IPA, an appropriate means for eliciting and interpreting the relevant data.

This research also meets Maxwell's five types of validity for qualitative research (77). Descriptive validity is met in that participants' accounts are factually accurate. Much effort was made to capture every detail of the interviews including the tone, context, and nonverbal aspects. Interpretive validity is facilitated through my unique position as researcher enabling me to "catch" the terms, meaning and intentions of the events that the participants described. This study is theoretically valid in that it conforms to the existing knowledge of the phenomenon discussed. Whilst IPA does not necessarily strive to produce generalizable data, this study does produce results that can assist the understanding of others with similar experiences of parenting deaf children. Evaluative validity also pertains to this study as observations made towards the hearing health and medical systems in South Africa, are common to every participant and also coherent with what is already known about these systems.

The instrument used allowed for the objectives of this study to be met, speaking to the content validity of the data obtained.

2.10 Reliability

Being conscious and careful about validity and reliability from the get go, has been important to monitor for bias in every step of the process, from designing the interview schedule to final analysis. With regard to reliability, some important steps that have attempted to maximize this, included strategies in the interview process such as a careful development of rapport to ensure fluid and free expression of feelings and experiences of participants. Taking care to not have biased prompting, but rather committing to entering the lifeworld of each participant, has been a core constant focus. Member checking to ensure that there were no misunderstandings was an important step in reliability and trustworthiness. Being consistent throughout the coding process, and then also using NVivo to cross-check the manual coding, has also been a step to carefully maintain the integrity of the data which is a core piece of promoting reliability (77).

2.11 Summary of Chapter

This chapter lists my aim and objectives which strive to capture insights gained through the lived experiences of doctors who are also parents of deaf children. Qualitative research is an appropriate way of exploring the lived experience. The ontology and epistemology of the phenomenon are both important aspects of qualitative research. IPA is a methodology chosen to elicit and interpret the lived experience of participants. Thus, allowing for a process of sense-making of experiences as the research methodology enables engagement with each participant's lifeworld. A small sample size was chosen for this research and an in-depth semi-structured interview provided an effective data sourcing tool. A pilot project allowed for the testing of the tool and equipment. Thereafter, a careful process of data collection proceeded. Three levels of data analysis engaged the process of extracting organizing themes, emerging themes, and subthemes whilst interpreting the individual experience further. Care was taken to ensure that data gathered was both valid and reliable and done in an ethical manner.

CHAPTER THREE

3 RESULTS AND DISCUSSION

3.1 Introduction

In this chapter, the coded data will be presented systematically as per IPA methodology. Initially, a concise summary with visual representation of the broad distribution of the data in the different organizing themes, emerging themes and subthemes, will highlight the study findings. Thereafter, the results comprising of transcript extracts from participants under the various emerging themes and subthemes which were common to all five participants, will be presented. These sections will also include an interpretation of the data obtained to complete the first hermeneutic loop of IPA research (72). Thereafter, each of the themes which coded at all five participants will be discussed further to complete the second hermeneutic loop of the IPA process (72).

3.2 Summary of the Data

The themes that emerged through the coding of 358 references in total, included four organizing themes, twelve emerging themes, and a number of subthemes. While Participants 1 and 4 had the most coded references, and Participants 2 and 3 the least, the organizing themes with their emerging themes and subthemes which were coded at all five participants, will be the focus of the results and discussion. The distribution of coded references per participant can be seen in the appendix (Appendix J).

Of particular interest are the emerging themes and subthemes which coded at all five participants indicating experiences common to all five. The relative frequency proportion of the emerging themes and subthemes which coded at all five participants is illustrated by a treemap in the appendix (Appendix K). In total 17 themes (16 subthemes and one emerging theme that did not have a subtheme) coded at all five participants. These include: *grief*, *trauma*, *vulnerability of parents*, *confusion*, *anxiety*, *costs*, *future*, *education*, *intensity*, *hope*, *negative experiences with*

audiologists, *informed choice*, *general knowledge about deafness*, *newborn screening, occupational gains*, *lived experience,* and *need for certainty*.

The following table depicts these organizing themes, emerging themes, and subthemes, while linking these themes to the study objectives as outlined in Chapter Two (section 2.1). The emerging themes and subthemes that coded at all five participants are highlighted in grey. The specific number of coded references for each organizing theme, emerging theme, and subtheme can be found in the appendix (Appendix L). This has been included as evidence of trustworthiness and credibility of the thematic representation following a rigorous process of data analysis.

Table 3.1 Table of the thematic breakdown of the data as well as the study objectives to which these link.

(The emerging themes and subthemes highlighted in grey represent those coded at all five participants.)

Organizing theme (parent node)	**Emerging theme (child node)**	**Subtheme (node)**	**Linked study objective (see 2.1)**
The Parenting Journey			**1**
	Initial Stress		
		grief	
		guilt	
		trauma	
		vulnerability of parents	
		confusion	
		disappointment	
	Ongoing stress		
		anxiety	
		education	
		future	
		intensity	
		sacrifices	
		costs	

Organizing theme (parent node)	Emerging theme (child node)	Subtheme (node)	Linked study objective (see 2.1)
	Acceptance		
	Hope		
Experiences with Professionals			**2**
	Family- centeredness		
		general family-centeredness	
		informed choice	
		holistic care	
		insight into the real life of parenting a deaf child	
	Experiences with audiologists		
		negative experiences	
		positive experiences	
	Unclear pathway		
Plurality of Perspective			**3**
	Misperceptions and incomplete information about deafness		
		general knowledge about deafness	
		newborn screening	
		perceptions of deafness	
	Gains		
		occupational	
		lived experience	
		parenting	
		personal	
Identity			**3**
	Self		
		need for certainty	
	Family		
	Child		

3.3 Thematic Composition

The following treemaps depict the relative weighting within the four organizing themes, relating to the emerging themes and their various subthemes.

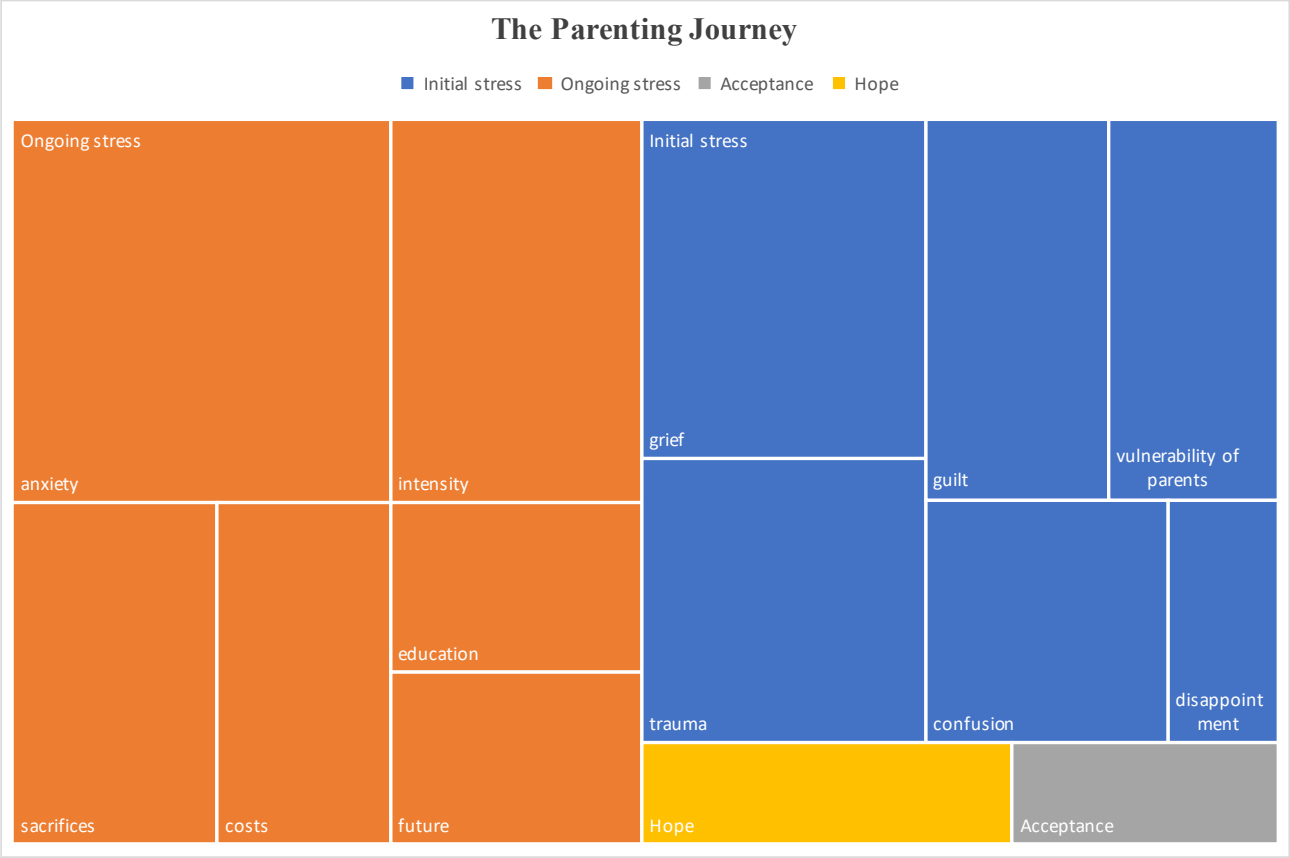

Figure 3.1 Treemap of the organizing theme, *the parenting journey,* showing the weighting of the coded emerging themes and subthemes.

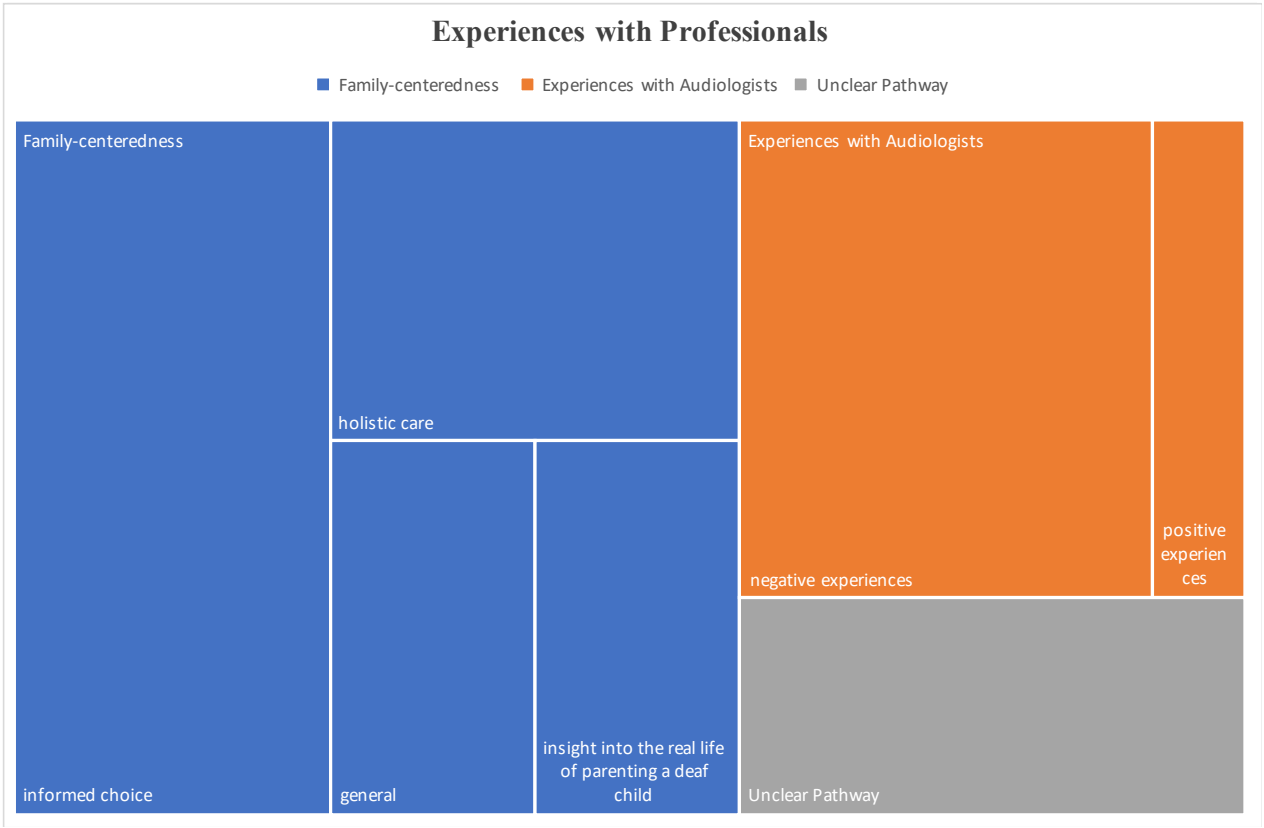

Figure 3.2 Treemap of the organizing theme, *experiences with professionals,* showing the weighting of the coded emerging themes and subthemes.

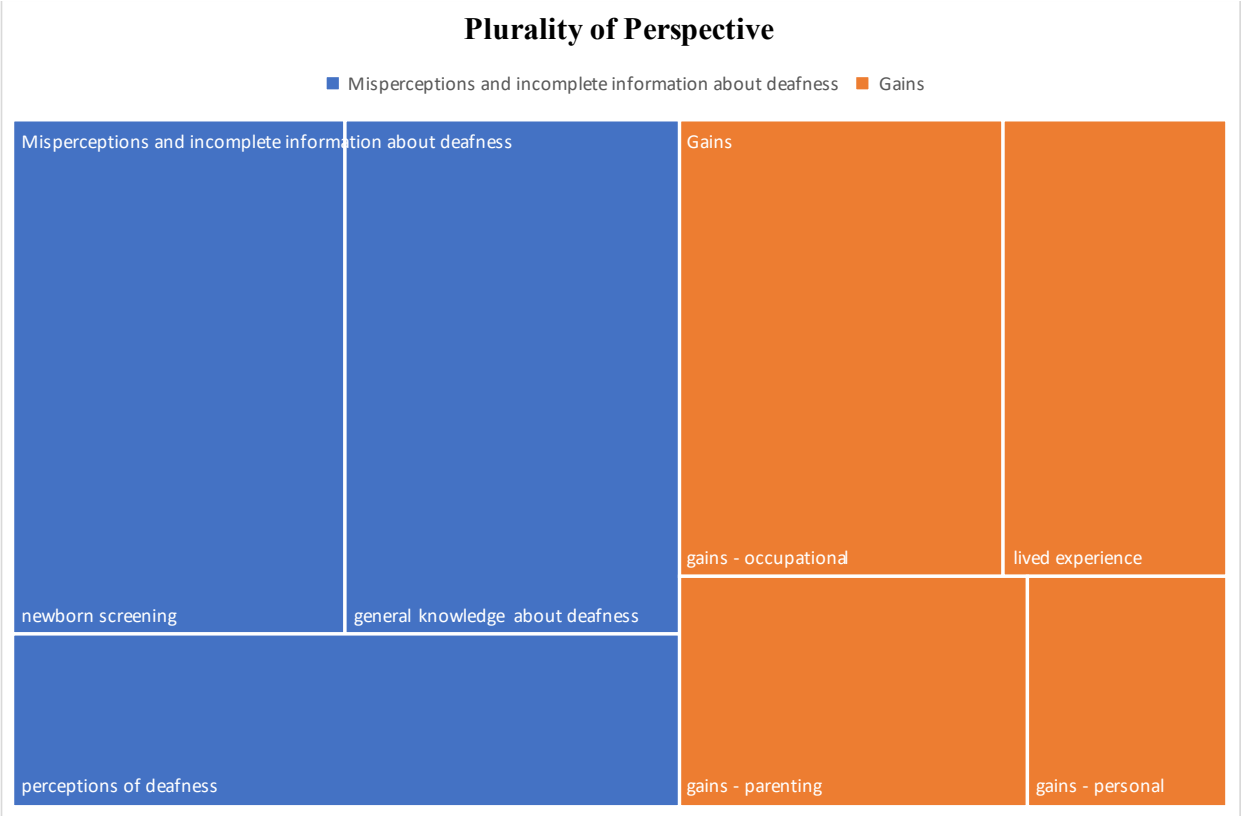

Figure 3.3 Treemap of the organizing theme, *plurality of perspective,* showing the weighting of the coded emerging themes and subthemes.

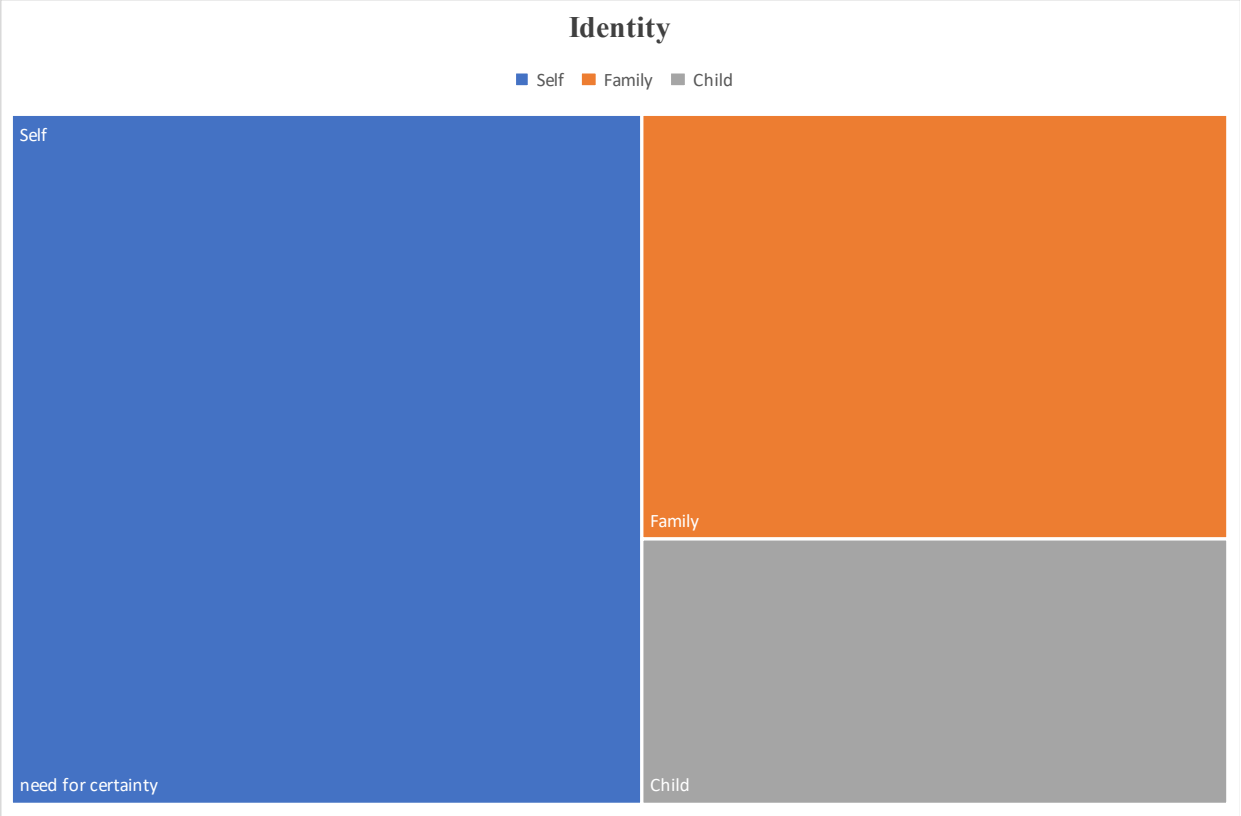

Figure 3.4 Treemap of the organizing theme, *identity,* showing the weighting of the coded emerging themes.

3.4 Participants as Individual Data Sets

Participants included both females and males, with deaf children between the ages of two and ten years. All had work experience in state healthcare and four had work experience in private healthcare. All were consumers of private healthcare. The target population of this study is small and very unique, thus participants would be relatively easily identifiable if specific demographic data were to be included in these results. Consequently, for the sake of confidentiality, specific participant demographic data will be omitted. All participants met inclusion criteria as detailed in Chapter Two (section 2.3.1).

It is important to get an indication of the spread of references coding across each participant. Not only would an extreme discrepancy potentially serve as a form of selection bias to the overall representation, but it is valuable to see how some of the emphasis varies between participants. This serves to further enhance the credibility and trustworthiness of the data. Individual NVivo

bar charts per participant, showing the number of coded references at each theme, or as NVivo terms “nodes”, can be found in the appendix (Appendix M 1-5).

3.5 Organizing Themes

3.5.1 The parenting journey

The largest organizing theme which captivated the interviews was *the parenting journey*. Throughout the interviews all participants made reference to aspects of their journey as parents - from discovering that their child was deaf, to their current time, as well as considering the future aspects of the journey. Within this organizing theme, their experiences have been grouped into emerging themes focused on the *stress*, *acceptance,* and *hope* experienced on the journey. These emerging themes and various subthemes which coded at all five participants, allow for insight into the parenting journey itself, as participants described their thoughts, feelings, and fears. These specifically fulfil the first objective of this study.

3.5.1.1 Initial stress

Stress has been divided into *initial stress* and *ongoing stress* although there are areas of overlap. *Initial stress* refers mostly to the time around identification of their child’s deafness and the first intensive phases of intervention. For some, this period was two to three years while their child was undergoing the process of receiving cochlear implants. This is often a prolonged process due to the extensive audiological work up, a typical trial of hearing aids, cochlear implant work up, surgery, “switch on”, and then rehabilitation. Thus, the initial stress can be drawn out for quite some time. It is important to note that all of the participants had opted for cochlear implants for their children. This was not an inclusion criterion for this study, but rather an incidental finding, which may have impacted the specific stressors encountered.

Stress is acknowledged in much of the literature as being moderately higher in parents with deaf children compared to that of hearing children (81–84) because the deafness belongs to the family as a whole rather than the deaf child alone (82,83,85). There is some controversy however, as there are studies which have concluded that parents of deaf children do not experience higher stress than normal (82,83). Explanations for these surprising findings include that parents in these studies had already been enrolled in very supportive intervention programmes. It is

generally understood that stress occurs when parents' perceptions of the tasks ahead overshadow their believed capacity (86). Parental stress is important as it can have implications for poor language outcomes and child behaviours (81) as well as contributing significantly towards an overall negative sense of well-being (87,88).

Under the emerging theme, *initial stress,* are the subthemes that include *grief*, *trauma*, a sense of the *vulnerability of parents,* and *confusion*.

A number of emotional experiences are common to parents of deaf children. These often include a sense of hopelessness, deep sadness, shame, and anger (83). Parents consider the impact on their emotional well-being as the biggest overall impact of deafness on their quality of life as parents and families (87,89).

Grief: Participant 1 expressed acknowledging a sense of loss when he shared, "You know, this is the hard part about having a disabled child. My child can no longer compete with [her] friends. It's hard you know. It's hard because as a parent, you want your child to be the best, and you want to know that they're going to do well, and [then] you realize that actually, at this point, you can't compete anymore because of the hearing loss." Participant 2 said, "Initially, after the ABR (whispers) because I knew [she] was deaf, I sobbed and said, 'Why me?' " Participant 3 expressed the grief aspect of denial, as he "…was in denial for some time about the…" (sentence not completed but the conversation was relating to the new diagnosis of profound bilateral hearing loss and the emotion of the moment made it difficult to know what vocabulary to use). Participant 4 when asked how she felt on finding out that her child was deaf said, "Depression was one thing, there was a kind of depression." Participant 5 elaborated on the perception of losses, "There's that little pang…for the loss for what [she] will miss out on and you know at the time you think, [she's] not going to live a normal life, and you think [she's] going to miss out on so much."

The participants expressed facets of the complex process of grief which included the difficulty to believe and process that this was happening to them. This was possibly because they are doctors and ironically deafness was so unfamiliar to them. Consequently, perceptions made subconsciously about deafness may have translated to a sense of loss for their children, but also a sense of loss for themselves and how they had imagined parenting prodigies. The recurrent

difficulty in fluently finding vocabulary when talking about the hearing loss, as well as the expression of emotion, may also suggest that the grief had not completely resolved.
Each of the participants made reference to their own grief but also concluded that being a medical doctor in itself may have helped them deal with the grief better. "You know a family who is not exposed to all those conditions, that [having a child identified as deaf] is typically THE (emphasized) end of their world." This was attributed to having learned to deal with difficult situations in medicine and having a cognitive approach to problem solving. In spite of this buffer, grief was experienced across the board. Participants also mentioned that in fact, while they were medically trained and have skill sets for problem solving, when it is their own child, they are the parent and they are experiencing events similarly to any parent. Participant 4 said, "On the one side I'm medical, okay. I don't see myself as a medical doctor with a deaf child, I see myself as a parent with a deaf child, and there's a big difference." Here it seems evident that the priority for this participant was that of identifying as a parent to their deaf child rather than their identity as a medical professional. This ties into the organizing theme of *identity* which will be discussed later.

Research shows that finding out that your child is deaf, is experienced similarly to having a death in the family (90). Kubler-Ross's stage theory of grief considers a linear progression through the stages of denial, anger, bargaining, depression, and then finally acceptance. This is falling out of favour since grief is often more complicated with regards to time course, fluctuations and the coexistence of said stages (91). Due to the ongoing nature of this journey, unlike death, the grief in parenting a deaf child is relatively chronic (90). While elements of grief stages could be seen in the participants in this study such as denial, anger, depression, and acceptance, the exactly prescribed linear stage template was not clearly identifiable. Medical professionals have minimal training in grief per se, let alone how to manage families who may experience chronic grief. Being aware of this significant aspect of the parenting journey is an important element in managing the family holistically while nurturing the well-being of parents. This holistic approach that also considers the life course and overall functioning of those with a disability, is an element recognized as important by the WHO's ICF (12).

Trauma: Participant 1 made several references to trauma, "It was such a traumatic pathway that you walk. I don't think even the professionals who are doing the cochlear implants realize how traumatic it is." Participant 2 described a traumatic experience when her child was admitted for

their cochlear implants, "[She] came out of theatre with a tissued drip, a massive leg, and stridor…and [she] desaturated most of the night with me lying next to [her] prodding [her] whilst the nursing staff just stayed at the nursing station." Participant 3 described a traumatic experience relating to the radiological work up for cochlear implants, "They literally wheeled [her], intubated, bagging [her], through the hospital, and we pushed the anaesthetic machine whilst the guy bagged [her]. Ja that was quite stressful." Participant 4 described an almost dissociative experience when considering what she would need to deal with, explaining, "…and you understand that this is going to change everything." Participant 5 expressed the responsibility in having to check on medical professionals and making decisions as being traumatic, "…those things are traumatic, like when you are having to explain to people who should know and people are not helpful, or they don't care about your situation…having to make tough decisions."

One common experience of trauma was related to finding out that they had a deaf child, describing the day of identification as "traumatic". This is not unique to these participants. Parents of deaf children are often shocked, devastated, and quite distressed when they find out their child is deaf, especially because they know nothing about deafness (14,15,83). Another aspect of trauma relates directly to experiences with professionals. This will be discussed later under the theme *experiences with professionals*. Trauma was also related to some of the difficult experiences during diagnosis, work up for cochlear implant surgery and the surgery itself. The trauma described often related to a complex struggle between knowing too much as medical doctors, such as what could go wrong in surgery, to knowing nothing about deafness as parents. Thus, a suspension between being ignorant as a parent but also as a doctor, while feeling like their medical identity should mean that they ought to know more, resulted in a multifaceted experience of inadequacy.

It was also described that times of doubt throughout the journey, when participants did not know who or what to trust, were specifically traumatic. Research into patient-physician trust emphasizes that trust encompasses a respect for autonomy and clear communication as well as mutual understanding. Trust between health provider and consumer is acknowledged as being essential to having a sense of being cared for, reducing anxiety and contributing to an overall sense of well-being (92). Again this also links to *experiences with professionals* which will be discussed later.

Vulnerability of parents: Participants did not express vulnerability per se, but rather described situations which reflected how they were dependent on other medical people out of sheer desperation. Most times, the participants themselves were not necessarily aware of their own vulnerability. Participant 1 described how, "You are completely reliant on who you would expect to be the professionals around you like your local audiologist or GP or your ENT surgeon, and some of them are CLUELESS (emphasized)." Participant 2's vulnerability was expressed in the feeling of being persecuted by fellow colleagues, "I became the subject of people's dinner parties." Participant 3's desperation for answers and solutions can be said to have made him vulnerable to accepting any advice, "I very much left it up to them…'You're the expert, you tell us what to do.' " This participant seemed to have followed an expert model of trusting the training of colleagues who he considered to be experts in the field. In contrast, Participants 1 and 4 admitted having spent "days" on the internet researching peadiatric hearing loss and cochlear implants. The literature supports the behaviour of Participants 1 and 4, suggesting that increasingly more parents are seeking information over the internet as they are able to go through information at their own pace and in the comfort of their own homes (93,94). Participant 4 expanded further on the need to make decisions very quickly and said, "You kind of don't know where you stand, there're big decisions that need to be made relatively quickly." Participant 5 expressed, "You're on the back foot, because even though you have a medical degree, you don't know anything."

All participants expressed stress and being overwhelmed particularly regarding the urgency in needing to make important decisions that have life-long implications. Parents may be vulnerable when they feel overwhelmed by their complex emotions whilst faced with difficult, and often conflicting information. During this time they typically have no foundation of knowledge in the field of paediatric hearing loss and find themselves desperate for intervention, while at the mercy of those they perceive as knowledgeable and trustworthy. Participant 1 expressed this well when saying, "I think the point is, that uhm, you know you are COMPLETELY (emphasized), as a non-medical professional, at the mercy of whoever happens to be standing near you."

A typical parent's initial desperation to "solve the problem" of their child's deafness may in these cases be further exacerbated by being trained in medical model thinking. The knowledge deficit in having no background information about deafness, while being subject to conflicting information regarding choice options, is an overwhelming situation for parents. This is further

compacted by the pressure of making decisions quickly due to a critical period for language development (which medical doctors might have a deeper appreciation of). The consequence to this would be feeling at the disposal of someone else "who knows better" to make the decisions about their deaf child's future. The participants, although medical doctors, were not more empowered to make decisions as one may have assumed, as they had no baseline knowledge about deafness. The primary difference between doctors and any other family, may have been having already known colleagues in the field of hearing loss who they could consult timeously, such as ENT surgeons.

Linked to vulnerability, is the sense of *confusion*, which was also experienced by all five participants. Feeling confused in itself can be overwhelming.

Confusion: Several different factors led participants to feel a sense of confusion, whether it be about actual information regarding choices, relating to progress and not knowing what next to do or simply not being able to understand one's own child. Participant 1 said, "The conflicting information…there are so many different opinions around the world, so many different companies telling you, 'don't do this or do that,' and you cannot make sense of it." Participant 2 described confusion in not knowing how to gauge progress after the child's cochlear implant as the child did not seem to be responding to sound, "I was so worried, because [she] was getting nothing." Participant 3 expressed the confusion in choices and decisions as, "You kind of don't know where you stand." Participant 4 explained that there was much confusion around the time of diagnosis as the family's concerns about the child's language development were repeatedly explained as being due to fluid in the middle ear. She expressed her desperation and confusion to their ENT asking, " You know, is there any way we could know exactly what's actually going on?" Participant 5 found daily life communicating with her child to be confusing, "…that communication barrier, I think that was the hardest thing for me." Not having enough information, or having conflicting information or lacking the necessary skills about something as serious as your own child's disability during a time of perceived urgency, seemed to have been experienced by all participants. For a group of individuals who in their own professional capacity are expected by themselves and others to "have the answers" to such dilemmas, these unmet expectations may be why the expression of aspects of confusion seemed particularly relevant when discussing their experiences. Confusion is also documented in the literature, especially concerning information about surgery and rehabilitation pertaining to cochlear implantation (83).

Confusion also has areas of overlap with the sense of not having a clear pathway mapped out for parents. Generally, clear next steps and holistic provision of services is not easily navigable nor accessible for parents (35). An important consideration would be to extrapolate the potential difficulty and confusion in not having a clear roadmap for the average family, if medical doctors with experience in both state and private health systems, found this a challenge.

The sense of being overwhelmed and confused, experienced by parents due to conflicting information, is not unique to this study. Polar ends of a spectrum that include cochlear implants, and then a total rejection of the "medicalization of deafness" in a Deaf cultural perspective, compete for parental conviction (14). It is important to consider that if medical doctors, some with more than 20 years of experience in medicine, all felt confused with some aspect of the journey, how much more confusing can the navigation task ahead be, for families with no education or exposure to disability? As Participant 1 expressed, "I think you know, if you don't have a medical background…you'd be completely lost about how to approach hearing loss."

Confusion also speaks to the subtheme, *informed choice* which explores the quality of unbiased information that guides decisions. This will be discussed in the *experiences with professionals* organizing theme.

3.5.1.2 *Ongoing stress*

The second emerging theme of the *parenting journey* - that with the most coded references - is *ongoing stress*. This included the subthemes *anxiety*, *education*, the *future*, the *intensity* of the journey, and *costs*. The literature refers to parental stress being most evident in the early years but also acknowledges chronic stressors and parental concerns around the future (82,83,86). Ongoing stress is well documented and often refers to stress about communication, education, and finances (83).

Anxiety: *Anxiety* was coded as general anxiety, although aside from general anxiety, all participants expressed anxiety around *education* as well as their child's *future*. Participant 1 expressed, "It's a very anxious time…I worry about the teenage years, I worry about the psychology about being different, I worry about progression…I worry about the future." Anxiety about the *future* was a common thread coded for by all participants. Participants had thoughts

about the future which included whether their children would have friends, whether their children would get married, whether they would find appropriate schools for them and whether they would cope at school. Participant 2 tearfully considered, "Am I going to be at [her] wedding? Who is [she] going to marry? [She's] going to be deaf! I don't want people to be cruel to [her], that's my biggest fear for the future (cries)… I don't know how long I'll be around to make sure that everything is okay." The consideration of a syndromic placement of their child's deaf diagnosis was a significant source of anxiety for participants. "What else could be wrong?" was an underlying question expressed in different ways, "It's scary you know when you think of [the] things it could possibly be and some are progressive and others aren't, so we don't know," explained Participant 1.

Sources of anxiety included needing to make big decisions under pressure. Participant 5 said, "Everybody was saying, you know the neural pathways will stop forming after three and all of that…it was so much pressure and it was so scary all that time, uhm just the pressure to get her implanted as soon as possible…and make magic happen." Participant 4 said something similar, "There're big decisions that need to be made relatively quickly, especially when it comes to cochlear implants." Doctors are used to making decisions under pressure. It is not a skill set they are specifically trained in but rather one that develops, and in spite of this, much anxiety exists around decision making.

Parents were anxious during the time of work up for cochlear implants, firstly hoping that their child would be a candidate and then the surgery itself was also a source of anxiety. Participant 3 said, " You know, a lot of stress, when [child's name] had the CT and MRI…that was stressful." Similar experiences of anxiety around core cochlear implant related events is well documented in the literature (86,95). Participants were anxious even after their child received cochlear implants as they now wanted their child to be listening and learning at every opportunity as Participant 4 expressed that there was "constant worry about [their child's] progress". This included whether there would be enough steady progress and whether they were doing enough as parents to facilitate progress. With the high expectations following cochlear implantation, the anxiety towards progress was further intensified. Participants, as medical doctors, tend to be "outcomes based" as expressed by Participant 1 who went on to describe their continuous thoughts about their child's daily progress outcomes "…the constant nature of it, you know thinking, have they heard today? Did they do well today? How is their speech doing today?" It is acknowledged in

the literature that parental expectations around the outcomes of cochlear implantation are high (96,97). Expectations further fuel anxiety as parents wait in anticipation for the outcomes they desired. For participants with a medical model background, the need "to fix" problems, may have made their high expectations even more concrete.

Regarding *education*, for Participant 2, the anxiety in having her child accepted into a school was significant, "You'll be surprised about how many people just didn't reply to my emails when I disclosed that I had a child with a hearing loss." Participant 3, described significant general anxiety and also anxiety around finding an appropriate school, "You know, a lot of stress… So I phoned all the different schools, [and asked] 'How big is your classroom?' " Participant 4, "There's stress, family stress and relationships and so forth, you know it's not a an easy thing…[she] went to a few preschools, [there were] lots of problems because they didn't want to take a non-hearing child, uhm. You know so it took a lot of convincing to get [her] in." Participant 5, "We've even thought about leaving the country and trying to find a country that has better [education] facilities." Then when describing the relief after the efforts and anxieties in finding a school, "We got her accepted at [school's name] which was great." These medical doctors as participants would have previously not likely worried about school acceptance nor school failure and the impact these would have on their own futures. For participants who had taken their own education seriously and taken care to build their own careers, reflecting on the insecurity of their child's education and future may have been something they had not anticipated being anxious about as parents. This, now being a new reality in question on behalf of their offspring with a heavy sense of responsibility for these outcomes, would be sufficient fuel to the fire of complex anxiety. *Education* is a common source of anxiety for many parents of deaf children (83,97).

Anxiety around work accommodations to allow parents time off to attend therapy sessions was expressed by participants. One participant expressed disappointment that a medical entity offering services to children, would be so resistant in offering time off for a staff member to access the necessary services that her special needs child required. She explained that after disclosing to the hospital where she worked that her child was deaf, she received minimal empathy and accommodation saying, " …you'd expect a hospital to be more understanding. I mean, I got the, 'Well, you can't expect to get any time off!' "

The literature mostly refers to parental "stress" and does not often tease out the individual elements such as anxiety. The sense of worrying and feeling concerned, even described as "seeds of fear" (98) about different elements on the parenting journey, is however included in parental stress discussions, which by definition is anxiety. All reasons for experiencing anxiety in this study were linked to the unknown and the inability to control the unknown. Having a medical background led some to consider possibilities that the lay person might not consider, contributing further to the dual experience as both parent and doctor. It is also fair to remember as mentioned above already, that when it is your own child, it's harder to be objective. For a parent, navigating the path ahead, was considered initially by participants as "a big problem". Generally, participants acknowledged that had they not been medical professionals, their anxiety would have been greater, "I think someone who isn't medical will be tremendously more anxious." This statement is what the global evidence suggests. Parents with higher levels of education tend to experience lower levels of stress and anxiety (83). There may be a number of reasons for this including the relative ease of access to support services and resources.

Intensity of the journey: This *intensity* refers to the constant nature of the intervention and rehabilitation efforts for parents. Participant 1 explained, " …the constant nature of it, you know EVERY (emphasized) day, maintaining the hardware every day." Participant 2, "I was driving to [audiologist's name] twice a week, having new moulds made, and they didn't fit, they just could not get it to fit, and we kept trying, we would persist, and we would put the hearing aids on and they would screech nonstop. I'm really careful about making sure that [her] batteries are changed, and everything's connected and that [her] lights are still on, that [she's] always got access to sound." Everyday activities also took on a level of intensity as Participant 2 explained that, "Since [child's name] had cochlear implants, [she's] never had a bath without hearing…in fact I don't talk whilst we're changing [her] kit so [she] doesn't miss out on whatever I've said." Participant 3, "The whole speech therapy experience, you know that happened two or three times a week at that stage, you know it was quite intensive." For the some of the participants in this study, travel efforts were extreme in some cases with families flying to other provinces for intervention at regular intervals, as Participant 4 said that she had to "…fly to [province], that was a mission, because every three, four weeks we had to drive up or fly up and realizing very quickly that this wasn't going to be a very long term solution." The intensity of the journey included aspects of constant advocacy as Participant 5 expressed, "Everything was on me, to make those decisions so that was very tough…there is a level of having to fight for things if you

want them. The opportunities don't just come knocking."

The reality of the daily journey of raising a deaf child was very much described as an often all consuming, never ending, constantly changing journey. In the literature, this intensity is also noted and referred to as "daily demands" (86) which includes the demanding nature of rehabilitation (83). Such efforts involve constant home intervention, constant thoughts and checking of equipment and regular visits to the audiologist and speech therapist. These efforts are intensive.

The theme of *intensity* also reflected on the participants' perseverance, expressed by Participant 1 with regards to the rehabilitation process after cochlear implantation, "People have no idea how long it takes to teach them one word. Ok, so (laughs), it takes LONG (emphasized) literally hundreds and thousands of repetitions of the same word over and over again." Participants acknowledged their constant role in facilitating progress for their child. The impact of such intensity is significant sacrifice and constant hypervigilance. As doctors, sacrifice and vigilance would not be unfamiliar experiences, yet for these points to be emphasized by participants, the nature of the sacrifices and hypervigilance should be understood as a far higher intensity typically known to medical doctors. The sheer dedication evident in all these families might be the benefit of having relatively driven doctor-parents, and may also have an underlying drive of guilt in not feeling adequately equipped or informed about deafness in spite of being medical doctors. The ordinary becomes extraordinary when parenting a deaf child, highlighting the relentless intensity of the journey and the dire need for holistic support.

While *sacrifices* was extracted as a separate subtheme under *ongoing stress*, and although it was only specifically coded for at three participants, *sacrifices* also link to the *intensity* of the journey. Participant 2 said, "I changed jobs because of [her] diagnosis…I took the job that I didn't want…so it was a bit of a demotion, from head of [department] to being one of many specialists in a hospital." Participant 4 explained, "I knew that my goals were never going to be what I thought work wise, it literally changed in 24 hours. Your goal changes, not trying to be the biggest professor in medicine, you're trying to get a non-hearing child hearing. The challenge for the latter is MUCH (emphasized) more difficult, that's for sure." Participant 5 shared, "It was life changing, everything, you know you have to throw out a lot of dreams." For people who had likely already made sacrifices to study medicine with goals and dreams for their own careers, the

entity of sacrifices added to the sense of personal loss in having a deaf child, as well as the intensity of the journey, linking back again to their *grief* journey.

The reality of the need for parents to make various sacrifices is also directly linked to a critical predictive factor for the outcomes of deaf children. Research tells us that a deaf child does best when his or her parents are actively involved (89,98). The entity of active involvement has not yet been fully explored or quantified. It would be reasonable to consider that in order to be actively involved, significant time would need to be made to create the capacity for this level of involvement. This would require other things to be set aside. For the participants who spoke of significant sacrifices, the task ahead of raising a deaf child was considered to be substantial. This new journey would require the attention, time and resources which may have otherwise been invested into the dreams that were laid down. These participants were sacrificing much to enable the possibility for active involvement in their deaf children's lives.

Costs: The extreme *costs* of parenting a deaf child was emphasized with particular reference to cochlear implants. Costs were also expressed concerning genetic testing overseas, travel for therapy and intervention services, work up for cochlear implantation such as CT and MRI scans, and the rehabilitation thereafter. Participant 1 expressed, "When I'd first learned about the costs, I could not believe how expensive these things were. The costs are prohibitive." He went on to continue, "I would say that it was definitely an eye opener to see what had to be done every year, new coils, new batteries…and the insurance on them and stuff like that." Participant 2, when recalling the medical aid shortfall she had to pay said, "…more than a hundred thousand, I remember because I transferred the money." Participant 3, "The cochlear equipment is RIDICULOUSLY (emphasized) expensive. The batteries! So, I've just gone through SARS now. This year wasn't too bad, just for spares, and a few other things was just over 25000." Interesting to consider that relatively to the high costs, an additional cost for maintenance of R25000 in one year was not seen as "too bad". Participant 4, "What I wasn't aware of was the insurance on these things, they are very expensive…the speech therapy, you know medical aid gives you a certain amount per year and you finish that in a month." She also went on to explain the cost of the time spent in therapies, "…it's time out of the practice, you know people forget the negative loss, see the other side of it, if you don't work you don't get income." Of particular mention was how unexpected maintenance related costs, which as Participant 3 mentioned, "is something that (was) not really fully disclosed". These included the maintenance of equipment and insurance.

This incomplete information about ongoing costs is also linked to the subtheme, *informed choice*, which will be discussed later. Participant 3 expressed that "[he] will dig into [his] bond" if he had to. A rhetoric was posed by Participant 5, "How are people supposed to come up with that kind of money, when you are on a deadline, you have to get this child aided before [she] turns three and then how are you supposed to come up with hundreds of thousands of rands?"

Costs were particularly relevant because of the immediate need for the interventions, and the consequent pressure to come up with the required funds as a matter of urgency. All participants acknowledged that their positions were privileged as middle class South Africans, allowing them to have relative access to funding and medical aids, yet the reality and weight of the costs of access to sound were significantly emphasized.

It is interesting to note that while a lot can be found in the literature about the perceived stress experienced by parents of deaf children, the stress of the financial burden, while mentioned, is not in the forefront of the emphasis. This is probably because the research is typically done in resourced countries where much of the costs, if not all, are carried by the national health systems in those countries. This is a stark contrast for South Africans. A recent study exploring the perceived challenges faced by families with implanted children in South Africa, has costs as one of the very first challenges mentioned (97). Costs in general link ahead to the entity of *informed choice*. If costs are prohibitive, then choice options are not equally accessible, often resulting in professionals gatekeeping information about choices that they have decided the family could not afford (43).

These subthemes describe a journey with a constant unremitting nature. Unlike a medical career, where one leaves the patients at the hospital and survives grueling hours of often emotionally taxing work, yet is still able to escape for a 'post call', the parenting 'job' never relents.

3.5.1.3 *Hope*

The emerging theme, *hope,* particularly relates to the experience of parents meeting other parents and families. Participant 1 advised that medical professionals encourage families to learn from each other's lived experiences and said, " …they weren't medical but they were never the less families with kids of different ages. And that gave us a good community to kind of ground

ourselves in. You know, we weren't alone in the whole thing, there were others like us and others who had gone before us. And it was a little bit more helpful to be able to see what can be done. It gave us kind of goal posts to see, weigh in points along the way." Participant 2 in relation to meeting other families said, "So that I think was quite helpful in terms of easing and seeing what CIs can do and things like that." Participant 3, "[The family's name] were awesome about having us reassured about the journey that was going to happen, and giving us an idea of how things could turn out… I think that gave me a little bit of hope." Participant 4 described meeting other families as "…that was worth gold," and said, "… that's the first time I kind of saw hope." Participant 5, "I think after seeing other parents and other children, uhm, and also getting to know your child through a different light as well, you realize that 'normal' by definition, is not accurate."

The participants all saw the hope that the sense of sameness brings. Information that may have been shared with them or learned by them through self-research, was suddenly made tangible as they saw various outcomes in reality and engaged in shared experiences with other families. The sense of not being alone was experienced as a source of hope. At times this discovery of the concept of experiential expertise, may have even been surprising for medical professionals, who typically view expertise as a consequence of academic learning and clinical experience.

The research shows that parents value support from other parents with deaf children as a significant source of support (26,44,45,89,99). Parents want to connect with fellow parents. Those who develop relationships and who interact with other parents of deaf children, find this to relieve stress and facilitate a sense of belonging (26,86,89). Often parent peer support is ranked in the top three sources of support as Jackson's study (2011) with 456 participants saw parent peer support ranked second after professionals' support (89) concluding that, "Professionals and providers need to realize that parent support from someone who has been there is invaluable."

A scoping review exploring the evidence around parent peer support from 39 peer reviewed articles between 2000 and 2014 saw that parent peer support contributed to overall parent well-being, empowerment and knowledge, in a number of different ways (26). Parents learn many things from fellow parents, including how to advocate for their child, how to navigate their system, where to find resources, as well as being coached through and having important skills modeled. These include making decisions, problem solving, and self-awareness. There is

significant knowledge exchange between parents since parents with a lived experience are often more knowledgeable than many professionals (26).

The growing evidence and appreciation for parent peer support has seen it be included in global best practice recommendations as an essential entity. The JCIH position statement (2007) includes fellow parents as important stakeholders in Family Centered Early Intervention and states, "Opportunities for interaction with other parents of children with hearing loss: Intervention professionals should seek to involve parents at every level of the EHDI process and develop true and meaningful partnerships with parents." It goes on to appreciate parent peer support to the extent of acknowledging that parent leaders should be remunerated for their expertise (28). This is further supported by the Family Centered Early Intervention Consensus Statement (2013) which recommends that parents should be referred to parent peer support systems, "Service Providers: Ensure that all families have access to parent-to-parent support from other families of children who are D/HH. Recognize the key role of parent-to-parent support in promoting social and emotional well-being for families" (42). Ironically though, the HPCSA has not stated parent peer support as a necessary stakeholder in Family Centered Early Intervention but rather de-emphasize this as a possible source of support, "Depending on the needs of the child and family, the early intervention team could also include (but not limited to) individuals with hearing loss, family-to-family support, physiotherapists, occupational therapists, psychologists, and educators with expertise in deaf/blind, developmental delay, and/or emotional/behavioural issues" (31). The participants in this study valued parent peer support no less than the international evidence that has guided best practice with it being described "as gold" by one participant and all indicated that it was a key source of "hope" and even a positive turning point on their journeys.

Knowledge about the emotional well-being and stress experienced by parents is important because of the significant impact this has on the deaf child (81,87). It must be considered that these experiences may also be influenced by the social construct of deafness, which for medical professionals, is further influenced by medical model training. Deafness is seen negatively (15), as a defect and impairment which limits opportunity (14). This is the groundwater in which a perception of deafness for new parents of deaf children grows. It is further influenced by the fact that these parents are managed by medical professionals with the same negative lenses to the difference of deafness. If parents are to navigate this journey purposely for their deaf children to

reach their full potential, an emphasis needs to be on hope, to see a transition from despair into the space of "more" being possible.

3.5.2 Experiences with professionals

Under the organizing theme, *experiences with professionals,* were two emerging themes that coded at all participants. These were *family-centeredness* and *experiences with audiologists.* The subtheme, *informed choice*, was the predominant theme coded under *family-centeredness. Negative experiences with audiologists,* was the predominant subtheme coded under *experiences with audiologists*. Both emerging themes provide insights into the medical interactions, support, and services experienced by participants, fulfilling the second objective of this study.

3.5.2.1 *Family-centeredness*

Participants all related experiences on their own journeys pertaining to family-centeredness, identifying the subthemes of *informed choice*, *holistic care,* and *insight into the real life of parenting a deaf child*. *Informed choice,* a dominant subtheme*,* will be the focus of this discussion.

Informed choice: When asked whether participants were given a spectrum of options after the diagnosis, Participant 1 said, "No…and there was definitely a process of discovery where you feel COMPLETELY (emphasized) isolated and alone in this whole process." Participant 2 said, "No. 'If you want your child to speak, she's getting CIs' ". Participant 3 simply answered, "No." Participant 4 explained having both communication modalities mentioned and went on to explain, "Did they explain both of them for an hour long [each]? No. Okay, so you're going to have to choose…either you go for signing and you stick with it, or you go for cochlear implants and then you stick with that, because we were told that you can't interchange them. Because the cochlear implants wouldn't work if they signed." Participant 5 shared, "They assumed we'd go the oral route. We weren't given choice, we weren't given options…our audiologist didn't even discuss an implant because it was not something she could offer in her own scope of practice, so it wasn't even discussed." Participants all experienced the reality of being managed by a biased professional early on their journeys. The various service providers offered censored information based on what they believed to be best, without practicing true informed choice. Professionals

may have assumed doctors would already know a lot of information. Generally, the advice given was offered because one choice was perceived as the right choice for the family by the professional.

The shift away from a medical model approach to the management of disability holistically is endorsed by the WHO through promoting a biopsychosocial approach to disability (41,100). A move towards patient centricity in the medical field has emphasized the need to engage holistically with patients. Patients are regarded as important participants in their own care, as healthcare workers strive to achieve a deeper understanding of patient needs for the ultimate focus of optimal patient outcomes (101). Participant 2 expressed how professionals focus on the diagnosis rather than having a holistic approach to the family, "I don't think anybody ever asks the parents how they are. Uhm, I'm not sure how many people greet the parents and the patients on the ward rounds, you know just acknowledging them as people and not just the diagnosis in the bed." For deaf children specifically, considering the family is critical, as we increasingly appreciate that their deafness does not belong to the child alone, but rather the whole family (82,83). Thus, in order to holistically manage the index patient – the deaf child - a patient-centered approach would fall short of holistic care as it omits the critically specific social component of the family. For paediatric entities, one has to consider the child's whole family (42,102). Family-centeredness is believed to be the approach that best meets the holistic needs of children with disabilities (47).

The literature describes family-centeredness as an approach that promotes family-professional partnerships. There are seven core principles that constitute family-professional partnerships. These include trust, respect, communication, commitment, equality, professional competence, and advocacy (102). Family-centered care emphasizes dignity, mutual respect, honesty, and open communication that allows for flexibility in decision making (42,102,103). Informed choice, an important component of decision making in family-centered care, includes the sharing of information to facilitate gaining knowledge and understanding (95,104). Information is shared with care, in a way that is not descriptive but rather evaluative (104). Typically however, professionals do not share equal information about all choice options with families (43).

Participants in this study described receiving unbalanced information, where possibly a variety of choice options were mentioned, but a "preferred" option received the spotlight. The

participants were not referred further for equal information regarding the other choice options. Participants were also given erroneous information which they believed to be true at the time. An example that is well known to the field, is the misperception that exposure to sign language will stop a deaf child from learning to speak (105). With regards to communication modality choice and outcomes for deaf children, research has "not found significant differences in developmental outcomes by mode of communication" (28).

Most South African families with deaf children would access state healthcare (21) with far less access to the full range of choices available to private healthcare patients, such as cochlear implantation (97). Here choice is greatly limited for children with a severe to profound hearing loss, as cochlear implants would be viewed as a "privileged intervention" (97). While cochlear implants would be an appropriate choice option for these children (106), as mentioned in the discussion about *costs*, informed choice cannot even be considered when there is no choice to begin with.

The way information is framed is also an important component of informed choice (104) and can significantly affect the way people perceive information and make decisions (57). Professionals typically present their advice and opinions through a medical model lens of deafness (67,95). This has a strong influence on parents in terms of how they view their deaf child and decisions going forwards (95,98). Overall, comprehensive discussions considering the various outcome possibilities were not had with these participants. One participant explained the incomplete information received about the outcomes of cochlear implants. He was told, "they promised hearing." The expectation of this family of their child's outcome with cochlear implants was consequently hearing, speech, and mainstream schooling, without being informed of the spectrum of possible outcomes. Outcomes with cochlear implants are variable as they depend on a number of complex factors and are not simply a cure for hearing loss (83,98). Not explaining these details to families such as the participants in this study, is by definition a breach in informed choice and a contradiction to family-centeredness.

3.5.2.2 *Experiences with audiologists*

Experiences with audiologists are significant to families navigating the journey of paediatric hearing loss. Families have ranked their professionals as a leading source of support (89). There

is a window of opportunity, during the first few encounters with families, that professionals have the privilege to greatly influence the way the parent views their journey going forwards. The psychology concerning heuristics and decision making acknowledges the influence that first impressions have on the future perceptions of something. This is known as the "halo effect" (58). The way healthcare providers engage with families matters, especially the first impressions they receive regarding their own competence and confidence for the journey ahead. For the participants in this study, there were significant negative experiences with early encounters with professionals, namely audiologists.

Negative experiences with audiologists: Participant 1 had a negative experience with the first audiologist he approached, "…our own audiologist down the road here did the hearing test and she said, 'Look, ah, you know I'm not quite sure what's going on, we're not getting a result here,' and gave us no information about anything to do with hearing loss at all. She couldn't get us out of there quick enough. That was a VERY (emphasized) traumatic experience for us that day at the initial [visit] and we changed audiologists." Participant 2 described her experience with the referred audiological team as traumatic and explained, "The thing that troubled me was really the way they treated people, and I really thought, if that's how they treat other people who perhaps don't have any insight into hearing loss…" Participant 3 reflected on the politics experienced between professionals, "I suppose a little bit surprising is that there is still a territory battle, I suppose between the audiologists." Participant 4 described having been "threatened" by an audiologist after seeking the opinion of another and said, "And the problem that we saw is that if you struggle with a certain person, you are totally screwed, okay, so you [then] have to travel, which we did." Participant 5, disclosing the process of looking for information about cochlear implants said, "We had to go and look that up ourselves and find an audiologist who could do it and have like a secret conversation with her because our audiologist almost gave us the impression that she was against implants."

If one examines their accounts, the glaring omission relates back to the practice of family-centered care. These negative encounters were described as "traumatic" by some, and recalled with much emotion. Verbs used to express the way participants felt treated, included "chastised", "messed around" and "threatened". A stark contrast to the family-centered ethos of treating families with respect, professional competence, and dignity. These negative experiences would likely have also been a point of self-reflection for the participants' own clinical practice. The

experience of a sense of vulnerability may have also been realized through these experiences since help, expertise, and compassion would have been expected. Professionals in the field may have assumed that medical doctors might know more than they already did about hearing loss, not primarily treating them as parents but possibly as doctor-patients.

Participants expressed the sense of perceived politics between audiologists which they as parents, felt they needed to navigate carefully. The "territory battle" described by one and another feeling they needed to "secretly" ask another audiologist for information that their initial audiologist was not offering, are examples of this. Considering the stress outlined previously which parents are already facing, the complex internal politics in the field of paediatric audiology adds unnecessarily to this stress. The professional space should be one that holds a family at times of perceived crisis. Professionals need to be working with other professionals in intervention teams collaboratively, with the well-being of deaf children and their families at the core of their focus, as an element of family-centered care (102). The Global Coalition of Parents of Children who are Deaf and Hard of Hearing, sums up the essence and purpose of collaborative family-centeredness, "A respectful and collaborative approach from all stakeholders in the system and an understanding of the important role that each one plays contribute to the well-being of the family and their confidence in their ability to raise a child who is deaf or hard of hearing" (102).

While not coded for at all participants, I think it is relevant to present the findings about subsequent *positive experiences with audiologists* as a true representation of the participants' experiences with professionals on the whole. The sincere gratitude towards the positive difference that this made was expressed using words such as "amazing", "reassures", and "professional". Stress was either worsened or relieved significantly depending on the participant's interaction with the audiologist.

Participant 1 expressed sincere relief and appreciation at being managed professionally by an audiologist, "I'll never forget, [audiologist's name] sat us down in the waiting room there, uhm and [she] said that [she] doesn't know what the outcome will be with [child's name] but whatever the outcome there is so much hope for the child." Participant 2 described an audiologist as, "…[she] was just amazing, [she] reassures you," and went further on to describing the perceived professionalism in the interaction and also mentioned the appreciation in being asked

how she as a parent was doing by one of the professionals in their management team at each consultation. Participant 3 further elaborated at the importance of professionalism and the confidence he felt when an audiologist had "equipment that worked" well and showed confidence in their own ability to manage paediatric hearing loss. These participants felt reassured when service providers were kind, patient, and empathetic. Competence was important to them and eased some of the anxiety being experienced. When service providers managed participants as whole family units while caring about the well-being of the parents, trust was established. Yet again, this eased anxiety.

3.5.3 Plurality of perspective

Plurality of perspective had two emerging themes, *Misperceptions and incomplete information about deafness,* and *Gains. Misperceptions and incomplete information about deafness* had further subthemes, namely doctors' *general knowledge about deafness* and knowledge and perceptions specifically about *newborn screening*. The concept of perceived *gains*, and specifically *occupational gains* reflecting the value of a *lived experience,* also emerged. The duality of perspectives shared under these subthemes by definition, fulfilled the third and final objective of this study, which specifically sought a plurality of perspective, which participants might have as parents, medical doctors or both.

As medical doctors with a lived experience of being South African parents of deaf children, participants were now in an authoritative position to appraise the baseline knowledge of South African doctors about hearing loss. They were also able to insightfully consider how their own lived experience as parents, has influenced their medical practice. Lastly, it is interesting to contemplate how being a medical doctor may have impacted their journey as a parent.

3.5.3.1 *Misperceptions and incomplete information about deafness*

Doctors' *general knowledge about deafness*: When Participant 1 was asked about whether his undergraduate medical degree was informative about deafness, his answer was, "Absolutely not! (giggle) Absolutely not!" He also went on to describing the knowledge perception of professionals in the field of deafness and said, "This is their area of expertise and they're clueless." He continued to further elaborate on some of the medical model reasoning behind

misperceptions or incomplete knowledge and said, "You know you come out of medical training and a specialty just knowing one thing, and that's how to fix things." Participant 2 said, "[University name] doesn't teach about hearing loss at all." She went further to explain how she had learned that the Child Health Diploma a few years before had almost all of their candidates fail the question on paediatric hearing loss, "One out of fifty got the question correct. ONE (emphasized) out of fifty, uhm, forty nine out of fifty failed the question." Participant 3 explained, his undergraduate knowledge about deafness "… is [limited to] Rubella." Participant 4 expanded on why doctors' might have the misperception that hearing loss is not serious, "That's the scary part about this whole thing, you're going to dismiss things very easily…it's not that bad, it's not a heart attack, it's not a stroke, you know, so you don't actually see the warning signs at any part of this journey, you know." Participant 5, when explaining their medical colleagues' responses when learning of their child's deafness said "…they were very empathetic, but nobody really wanted to talk about it or go into details (giggle) because they were in exactly the same shoes in knowing nothing about deafness."

Participants expressed that medical doctors had little to no appreciation of the neurodevelopmental emergency that language deprivation posed to a child's developing brain. Colleagues in the field, such as ENT surgeons were quick to explain the child's hearing difficulties as "fluid in the ears" which would resolve, further delaying diagnosis and intervention. "There were quite a few of these tests, you know they were about six weeks apart and every time…fluid, fluid, fluid." For this child, six months of her early brain development was spent chasing fluid, rather than following best practice principles of screening and diagnosis, which should not take more than three months (28). A delay between presenting with concerns and diagnosis is quite typical. In South Africa, this has been shown to be two months for the private sector and seven months for the public sector (25). Every day of language development time lost is critically significant (29,34,107), making a few months of unnecessary delay due to knowledge gaps, an unacceptable statistic. For medical doctors, all of whom would have had undergraduate paediatric training, and some of whom would also have had postgraduate paediatric training, such knowledge gaps must speak to deficits in medical school curricula.

Participants at large admitted that their deaf child was "…the first deaf person [they'd] met." The literature also suggests that professionals in the field have often not engaged with deaf or hard of hearing people outside of their professional capacity, nor have families often engaged with deaf

people prior to having their own deaf child (102). Involving d/Deaf and hard of hearing people in early intervention teams is recommended by both the JCIH and the FCEI Consensus Statement (28,42,102). Since families and professionals alike, have misperceptions and knowledge gaps about deafness on a whole, d/Deaf and hard of hearing adults can serve as mentors, role models and consultants to both families with deaf children and professionals working in the field of hearing loss (102).

Participants admitted to having entered the parenting journey with *perceptions of deafness* that were very medical model founded, saying, "we were very medical." It is worth considering how their foundational medical perspective affected their experiences and even choices as parents. Research suggests that medical students (not those directly working with disability) typically view disability more negatively compared to the average population (5). It needs to be considered whether this is the case due to the way that disability has historically been framed in undergraduate training.

The vocabulary used to refer to the deaf child by participants in this study was an interesting observation. Words used instead of the word "deaf" included "non-hearing" and "abnormal" and at times even silent pauses, whilst it was understood that the word "deaf" was the word that was intended. Through the course of the interviews, this tended to change to using the word "deaf". Having a knowledge foundation in the medical model of disability had possibly set doctors up to view disability in a specific way. The consequence, a real challenge in shifting their views of disability and deafness once their own child was diagnosed as such, as this phenomenon changed from being one of professional interest to personal reality.

All participants had chosen cochlear implants for their children who all had severe to profound hearing loss. Cochlear implants are considered as the most appropriate medical intervention for severe to profound hearing loss. Participants were all asked whether they thought their medical background influenced their choices as parents. No one admitted to decisions being influenced due to being medical doctors before being parents. This homogenous factor can be appreciated as an appropriate intervention for the levels of hearing loss that their children all had. The benefits of cochlear implants for speech and language development are well documented, although the outcomes are variable and not guaranteed (97). More children are receiving cochlear implants globally with an estimated 80 000 children having been implanted (96,97). According to the

recent 2019 JCIH update, cochlear implants have been stated as a mainstay of treatment for severe to profound sensorineural hearing loss, should speech be a desired outcome (106). While cochlear implants have largely been viewed as a medicalization of deafness and rejected by the Deaf community, this is slowly being replaced by an acceptance of cochlear implants being one of a continuum of choices (108). With access to private healthcare, it would be expected that the participants in this study all chose cochlear implants for their deaf children, since all of their children met candidacy criteria for cochlear implants.

Participants were surprised by their own lack of knowledge about deafness. As doctors they embarked on the journey as parents, needing to acquire as much knowledge as possible, as a matter of urgency. This self-reflection about their own training and knowledge gaps led them to appreciate the general lack of knowledge about deafness in the medical field at large. As parents experiencing the biopsychosocial aspects of raising a deaf child, the participants were made aware of the multifaceted nature of child deafness which they admitted, even experts in the field of deafness had little understanding of. It was their first-hand lived experiences of deafness that allowed a new appreciation of the limited understanding of medical professionals about paediatric deafness.

Newborn screening, particularly referring to knowledge around Universal Newborn Hearing Screening being best practice: The general understanding around *newborn screening* meant that doctors themselves did not know to get their own baby's hearing tested. This was the case for participants, and they expressed how their paediatrician did not know to have the baby's hearing tested at birth either. Participant 1 admitted, "I would have left it, I must be honest. I wouldn't have done it, I thought it's not important. In fact, the paediatrician that we saw for the six week checkup, we asked him, 'Do you think we should do hearing loss test?' And he said [just by looking at her], 'No, don't worry, the child is hearing fine.' " Participant 2 admitted not realizing that all babies should have newborn screening and explained how antenatal ultrasound was the gauge she was using to check the health of her baby, "I was really grateful at my 20 week scan, you know, ten fingers, ten toes, four chamber heart, the things we look for (laughs) the things we can see, you know the brain looked normal, intestines are in the right place, so you know grossly looked ok." When asked specifically whether she knew that all babies ideally should have their hearing tested, she shook her head. Participant 3 also did not know that all babies should have their hearing tested routinely, explaining that in his experience, "[They've] had intermitted OAE

screening, so [they] have a company and audiologist that comes, maybe twice a week and screens the babies…it's opportunistic, not every baby gets screened." Participant 4 described her understanding of the relevance of newborn screening further, "[She] was born normal, ok, so we knew nothing…didn't have any idea that there was something like that, so [she] was about six, seven months old, you know when I started having this question… I missed it. It's extremely easy to miss." Participant 5 simply said, "…it didn't bother [me], I did not THINK (emphasized) about hearing at all." A sense of guilt and almost humble embarrassment was expressed by participants in not knowing that Universal Newborn Hearing Screening for all babies was international best practice and the personal consequences of their knowledge gaps to their own children.

Universal Newborn Hearing Screening was one of the greatest points of learning for participants regarding paediatric hearing loss. All expressed that their parent experience had made them advocates for newborn screening within their medical occupation and influence. Participant 1 expressed that parents would all "be pro-screening" due to his acquired appreciation of the consequences of late identification and language development – medical knowledge newly gained through a parent experience. In developing countries where newborn screening is not government policy, knowledge about its importance and global best practice is incomplete. Due to this, medical professionals themselves are often responsible for the delays in detection and intervention that is typically seen (54). This is not the same in developed countries where newborn screening is the norm (109).

When possible desired outcomes were discussed by participants, the overall sense was to see their deaf child happy, loved, and contented. Towards the end of one interview, Participant 3 philosophized the importance of happiness and the accessibility of this, "You know, in the end, if you are deaf, it doesn't mean you're not happy. And just because you've got a disability, it doesn't mean you can't be happy. Being doctors doesn't make us happy, you know. Our children must just be happy, whatever they are and whatever they're doing. That's where our focus should be." This is a very interesting process of meaning-making coming from a medical doctor who has journeyed a full circle of questioning the meaning of success, well-being, and wholeness. Yet again, this actually speaks to the family unit. An unhappy family unit is unlikely to grow a happy child – another reason as to why a family-centered approach to care is vital.

3.5.3.2 *Gains*

All participants said that the journey of parenting a deaf child had significantly resulted in positive *gains.* Participant 1 shared, "In some way the journey is hard, but the people you meet are wonderful. The places you visit are wonderful. Life takes on a different flavour but [is] just as good. You're not going to miss out on anything, it just may be slightly different…it's changed my practice as I have a lot more insight." The notion of gains included *parenting gains* as Participant 2 said, "I don't think I would have been as involved in my children's life and plotting their journey. I don't think I would have been as involved if they were normal hearing." This admission that they would not have been as present as parents or as purposeful had they not walked their journey as parents of deaf children thus far, served as a time of cathartic reflection. Participants contemplated the gains to themselves *personally* and the world at large, because their deaf children have a unique contribution to make. Participant 4 said, "I think [she] impacts the world [in a] much bigger [way] than I do."

Certainly the greatest area for perceived gains, was that of *occupational* gains – gains to their professional identity of being a medical doctor. This was greatly linked to the perceived benefit in having a *lived experience* as a receiver of care. Participant 1 said, "I think that has singularly changed my attitude as a doctor… the ability to understand people who have had hardships. I'm glad that has happened, I must be honest. I don't think I would have been the same, if it hadn't happened. I'd say, it's very important for all medical professionals to be exposed to the outcomes of deafness, and to gain an understanding of what's involved with parenting a deaf child." Participant 2 explained, "I think I've changed practice, just based on having [child's name]. I was forced to change practice, and in my own little way, I'm trying to make sure that the people who are supposed to be child health champions are actually vigilant about hearing loss." Participant 3 explained how the lived experience in simple parenting has changed his practice, "…just having children has changed the way I practice, no doubt, not necessarily the fact that I've got a child with a disability, but just generally having children." He also went on to describe how he now advocates that every baby has their hearing screened. Participant 4, "I'm a lot more compassionate now, even just the way I treated patients, from that day onwards…I never treated a patient bad[ly]…but you know I would listen just two minutes longer [to] what they're trying to say. It certainly changed my view of working with patients and so forth, so I'd try the extra bit harder to get the diagnosis." Participant 5 referring to patients he may see with a disability

explained, “I think I just am a lot more empathetic to those people and I want to make a difference and create more awareness with that person and include family. I feel like I need to make sure I make a difference and share what I have with them in dealing with life changes, things that will last a very long time. In that sense, you know I have changed my approach. I feel like there’s so much missing. A huge amount missing. From my experience, the first person that I met who was deaf was my [child] and how is that, why is that? So we definitely are lacking in that sense, and yet it’s all around us.”

The literature also reports doctors who experienced disability or illness directly, acknowledging their personal gain in making them better professionals due to having had a lived experience (61,63,64). All participants acknowledged being more empathetic since journeying as a parent of a deaf child, and all participants described entities of being more family-centered. Psychology recognizes how threatening circumstances can result in cognitive adaptations. From adversity, depending somewhat on the disposition of the person, a process of benefit finding is often seen (110). Benefit finding contributes overall to the well-being of the parent and the child. It is arguable as to whether benefit finding is a means to coping with the trauma or a true indication of cognitive transformation. Either way, benefit finding is considered a means of mitigating the difficult thoughts, experiences and emotions that occur with different forms of losses (111). This time of transformation can also be considered a marker of acceptance of the journey.

In spite of shock, grief, unpleasant experiences, and significant stress, the general impression was that of an overall sense of gain. Gains in which the participants experienced their professional engagements with people following lived experiences with their own children. Participants all engaged in a process of meaning-making through considering the hopeful purpose of what was at least initially, a difficult experience. There was consideration that other medical professionals would also acquire professional empathy through new perspectives gained through exposure to lived experience. Research in developing empathy in medical professionals sees a positive impact made when students are exposed more to “experts by experience” (61,112).

On identifying their unique position of their dual perspective to paediatric hearing loss, participants considered what changes they might initiate, were they ever to be in an authoritative position in undergraduate training. All participants said that students should meet deaf people

and families with deaf children and suggested additions in the line of family-centeredness. One participant said, "I would focus a lot on family-centeredness, on dealing with the social needs of families and rehabilitating families to fit back into society, so holistic management. We never really got it, you know even when we studied, we studied this subject and that subject and they never met each other, that's how you get taught, and you don't even have one exam that pulls the knowledge of everything, you know so that kind of thing."

The World Health Report (2008) acknowledged that clinicians rarely consider the holistic needs of patients (113). The report also explained that addressing the holistic needs and context of patients, not only reduced anxiety of patients, but also an increased job satisfaction for clinicians. Considering the fuller picture to patient needs and context is considered a "luxury good" offered to the minority of those seeking care. This quote from the report encompasses what the participants in this study expressed when considering what they would change about healthcare in undergraduate training, "In practice, clinicians rarely address their patient's concerns, beliefs, and understanding of illness, and seldom share problem management options with them. They limit themselves to simple technical prescriptions, ignoring the complex human dimensions that are critical to the appropriateness and effectiveness of the care they provide" (113). Through their own experiences, the participants in this study came to appreciate the value of exposure to the lived experience, in impacting a holistic perspective and approach to patient care.

3.5.4 Identity

3.5.4.1 *Identity* and *need for certainty*

Throughout the interviews, a common thread evident and thus chosen as an organizing theme, was that of *identity* with emerging themes of identity related to the *self*, their *family* unit, and their deaf *child*. *Identity,* and more specifically an underlying *need for certainty* in the *identity of self,* was the final subtheme to emerge.

Woven through all the themes and especially in light of a dual perspective in *plurality of perspectives*, is the perception of a shifting identity. Were participants' children deaf, disabled or "fixed" now that they had cochlear implants? Were they "normal" or "abnormal"? After all, "What is normal?" This was questioned as some participants specifically referred to their deaf

child, at least initially in the interview as “abnormal” whilst others specifically stated that they did not view their deaf child or family as “abnormal”. What initially seemed foreign to them as both parents and doctors, with time and experience, started becoming a “new normal”. Over this time course, were participants primarily parents or doctors and when did these identities overlap? Participants acknowledged primarily being identified as the parent, or at least wanting to be identified as the parent. This was not always possible as their identity as doctor may have influenced the ways they were treated by other professionals in the field, the choices presented to them as well as their insight into the medical and surgical procedures that their children underwent. How did their identity as parents or doctors change, as one affected the other over time and experience?

Deep to the data was an underlying *need for certainty*. This is unsurprising as Anthony Robbins theory of human needs states, “All human motivation is directed by the drive to meet six basic human needs.” Certainty is one of these six human needs (114). None of the participants spelt this out literally, but all made comments lending to the desire for, or the move towards, a certain perceived outcome. Participant 1 explaining his desire, “There’s no rational authoritative voice that speaks out of the computer saying, ‘listen, given all the pros and cons across the world, this is what I feel, given my experience, as a physician with 30 years of experience in implantation, this is what I really think you should do.’ ” Participant 2 said confidently, “We decided right from the start, that was the way we were going to go.” Participant 3 admitted, “I think the whole initial process was focused on that [she’s] going to hear.” Participant 4 found herself frequently questioning, “[Am I] actually winning or [am I] actually losing? [Do] I need to put in more work, or [are] we getting there or not?” Participant 5 understood that certainty was something that he as a doctor engaged with frequently saying, “We’re giving you medicine as a doctor, it’s going to fix you and you should get fixed by the next time I see you.” The need to make a right choice, have predictive outcomes and receive absolute answers was expressed by all participants. Medical professionals are trained to look for evidence and answers to achieve good outcomes. This would have further driven a deep desire to steer their experiences as parents towards outcomes where “everything would be okay”. The underlying need for certainty may have been more amplified for doctors working in a field that demands certainty much of the time.

A complicated course of identity switching between being the child’s parent and being a medical doctor in the space of an unfamiliar medical field, likely contributed to some of the emotions

expressed by participants including an overwhelming sense of uncertainty. Identity, a complex theme, relates mostly to the third objective of this study, as the identity switching aspect can be also considered as perspective shifting experience.

3.6 Summary of Chapter

Medical doctors, when parents of deaf children, experience the journey of parenting a deaf child similarly to any family. Some experiences may have been intensified due to medical model influence, while others mitigated by advanced knowledge of the medical field. Experiences with professionals highlighted similar experiences of the process and the services to that of other families as expressed in the literature. A dual perspective, as parent and medical doctor, revealed an honest appraisal of knowledge and perceptions about deafness. Reciprocally, all participants expressed the positive influence that the lived experience of parenting a deaf child has had on their medical practice as professionals. Consequently, further recommendation was made on how exposure to the lived experience would be beneficial for all medical professionals. Through expressing insights gained as parents, participants were able to consider changes that would benefit the South African medical field at large. The data obtained under these four organizing themes, whilst focusing on the emerging themes and subthemes which coded at all five participants, comprehensively met the three study objectives.

CHAPTER FOUR

4 CONCLUSION

4.1 Study Context

It is estimated that 34 million children are living with a disabling hearing loss, and the majority of these children are from developing countries (17). Thus, paediatric deafness should be a significant part of the global focus of paediatric neurodevelopment. The field of paediatric deafness is a complex one. As an allied medical field, it shares the same medical model history and influences as medicine in general. Due to this influence, both medicine and paediatric audiology in practice, can fall short of fully practicing holistic patient care. This was evident through the experiences of the participants in this study. Change however, is possible (59). With the exposure to the lived experiences of those navigating hearing loss, traditional views and perspectives can be shifted. “Invisible gorillas” need to be exposed, as stakeholders are shown alternative ways of thinking about disability. In doing this, the holistic needs of the index patient can be understood, and in the case of paediatric deafness, family-centeredness can be truly realized.

This research aimed to gather and present the lived experiences of a small cohort of participants who have a complex epistemology of paediatric hearing loss. As fellow medical doctors, I hope to have other medical colleagues identify a sense of sameness with the participants. In doing this, considering the experiences and opinions of participants as more than anecdotal contributions, but rather as insights from “experts by experience” (112). This could facilitate an invaluable process of knowledge transfer. An effective way of exploring such experiences, is qualitative research. Through the methodology of IPA, a researcher is given the privileged position of joining each participant in their lifeworld, to share in their first-hand experiences and perspectives (62,72,75). IPA also allows the researcher to have their own voice, as themes are explored and interpreted further.

4.2 Study Summary

The aim of this qualitative study was to explore the experiences of medical doctors in South Africa as parents of deaf children, examining how the field of paediatric hearing loss can be better understood by medical professionals' insights gained as parents. Through in-depth semi-structured interviews, the experiences of these unique participants were shared and interpreted.

The experiences of participants were coded under four broad organizing themes, 12 emerging themes and several subthemes:

Organizing theme 1: *The parenting journey* including the emerging themes: *Initial stress*, *Ongoing stress*, *Acceptance,* and *Hope.*

Organizing theme 2: *Experiences with professionals* including the emerging themes: *Family-centeredness*, *Experiences with audiologists,* and *Unclear pathway*.

Organizing theme 3: *Plurality of perspectives* including the emerging themes: *Misperceptions and incomplete information about deafness* and *Gains*.

Organizing theme 4: *Identity* including the emerging themes: *Self*, *Family,* and *Child.*

The emerging themes and subthemes which coded at all five participants were largely the focus of the results, interpretation and discussion. These themes have holistically achieved my proposed study objectives. *The parenting journey* revealed the complexity and reality of raising a deaf child in South Africa. An "insider perspective" of some of the difficult emotions experienced has shed light on this phenomenon for parents, which is far more complex than simplistic details of amplification and rehabilitation. A fresh appreciation for the importance of a holistic family-centered approach to care emerged. This included a need for the practice of informed choice - an entity not experienced by any of the participants. There was particular reference of the support from other families, an aspect not currently recognized as an essential best practice inclusion in Family Centered Early Intervention in South Africa. This support is seen as facilitating knowledge sharing, well-being, and parent empowerment (26) – all factors essential to the successful outcomes of deaf children.

Through reflecting on *experiences with professionals*, one again appreciates how family-centered care, while recommended by best practice principles, is generally not the cornerstone of current

practice. Professionals are acknowledged as being fundamental sources of support, and consequently greatly influence the parenting journey further. Unfortunately for the participants in this study, most early experiences with audiologists were not positive, adding significantly to the early stress experienced on the journey. Subsequent positive experiences with audiologists were a welcomed relief of reassurance for the perceived stress and fear about the navigation ahead. Thus revealing the critically valuable role of the audiologist, as well as their influential position, on the overall experience of the journey and well-being of the family.

A unique *plurality of perspective* of participants allowed for some honest appraisal of the medical field in light of paediatric deafness. Medical professionals were perceived as still being primarily medical model focused. Consensus was that medical doctors have minimal knowledge about deafness, including the importance of newborn hearing screening and the neurodevelopmental emergency of language deprivation. These knowledge gaps are important aspects of general practice relevant to every doctor at some point in their medical career. This can be largely attributed to minimal undergraduate exposure to disability on a whole, but specifically paediatric deafness.

Minimal inclusion of the lived experience of entities such as disability, was also considered a significant omission in undergraduate training. Knowledge gaps often occur due to limited experience and exposure. Participants all acknowledged the immeasurable gains of parenting a deaf child. Gains to their personal lives but in particular, gains to their professional lives, as having had a lived experience with something as complex as paediatric deafness, ultimately resulted in a perception of changing practice towards a more family-centered approach. Consequently, study recommendations include addressing the knowledge gaps in undergraduate paediatric training and incorporating the lived experience as an essential part of undergraduate exposure.

Lastly an entity of a shifting identity throughout this study was observed, as parents who started out as medical doctors, find themselves between what they have learned as clinicians and what they have experienced as parents. This entity ultimately allowing for the fulfillment of understanding the parenting journey whilst deeply appreciating the supporting systems, their short-comings, strengths and overall opportunities to improve the experiences of other families.

4.3 Study Limitations

The study included five participants who all had work experience in state healthcare. Of the five, four had work experience in private healthcare. As consumers, however, all were consumers of private healthcare. Thus the consumer experience itself can only be a reflection of private healthcare services. The small sample size, whilst appropriate to the chosen methodology, may be a limitation to the variety of experiences captured in the data. There may have been some information and experiences that the participants did not share for various reasons. These may include complex factors such as not being fully aware of how being a medical model "student" framed their view on deafness and their decisions as they approached their new identity of being a parent to a deaf child.

Lastly, while every effort has been made to have the authentic experiences of the participants expressed, this subject is of deep personal interest to me, and my subjectivity may be seen as a limitation. The "sameness" in which the participants identified their own complex identities of doctor-parent with mine, I believe facilitated the honest sharing of their experiences and perspectives with someone they believed, would sincerely understand.

4.4 Study Implications

This study has confirmed that the field of paediatric deafness is complex. The parenting journey itself is also complex. We know that parental well-being affects the outcomes of deaf children, so intervention systems need to be caring for the family unit at large. Knowledge and understanding of the complexities mentioned previously, would empower medical professionals working with families and deaf children, to practice within a family-centered framework. The reflections that participants had on the medical interactions, services and support have motivated these recommendations. These recommendations focus on empowering medical professionals further in better managing families with deaf children.

4.4.1 Holistic support for families

Families need healthcare professionals to understand the parenting journey. The holistic care of deaf children within their family context, is essential for the optimal outcomes for the specific

deaf child, and this needs to be the focus of the clinical team. Informed choice needs to be the benchmark for information sharing as families consider the decisions they face regarding their own deaf child. Families need to be managed within global best practices of Family-Centered Early Intervention (28,42). For fields involving paediatric care, a patient-centered approach is inadequate. Rather, family-centeredness needs to be an approach to care which infiltrates all areas of paediatrics. Formal coaching in counselling needs to be included as an essential part of training for professionals working in the field of paediatric deafness. Psychologists and counsellors should be actively part of the intervention teams working with families, since the evidence shows that the journey encompasses a large spectrum of complex emotional experiences.

Referring families to parent peer support programmes is a necessary part of FCEI. Local parent leaders should also be included in the appraisal of professional services, allowing for experiential expertise to influence practical service provision.

4.4.2 Best practice policy and principles

Excellent global best practice documents exist to guide health providers and policy makers with family-centered care for deaf and hard of hearing infants and children. A greater awareness of best practice documents is needed. Undergraduate students should be tasked with assignments that require them to become well versed with global best practices and principles. National policy should align fully to such global documents without changing the emphasis of any principles. Lecturers, tutors and mentors to undergraduate health students should be obliged to be up-to-date with best practice principles so that the content of their teaching reflects such.

The HPCSA's Early Hearing Detection and Intervention guidelines (2018) need to be uptated to be fully aligned with international documents from which these guidelines are derived. Current omissions that need rectification include prioritising parent peer support and D/HH role models as critical steakholders in Family Centered Early Intervention, rather than optional entities.

4.4.3 Undergraduate medical training

Universities as well as the Colleges of Medicine of South Africa need to promote the biopsychosocial model over the medical model for all medical doctors. This should be facilitated beyond simple lectures and readings, to include materials and presentations with people who are experts by experience regarding different clinical entities. Their contributions should be acknowledged as essential experiential expertise.

Disability should be included in undergraduate training. Elements of paediatric neurodevelopment, such as paediatric language development (which would then include hearing loss) need to be included in undergraduate paediatric training. This would ensure that essential child developmental theory is covered and understood by all practitioners. Every doctor, during the course of their internship, community service, and independent practice, is guaranteed to be managing children and families. Doctors receive minimal training in counselling patients and families. This is a core element of holistic care that needs to be included in undergraduate training and assessment.

4.5 Recommendations for Future Research

This research has produced a vast amount of data presenting a number of opportunities for further exploration. These recommendations serve to mention some specific areas which would be beneficial to explore further.

The value of the lived experience and inclusion thereof into undergraduate professional training is worth exploring. Curricula adaptions to include experiential expertise may serve as a useful tool to address biased perspectives that result from exclusive medical model training. Further research into how these lived experiences can be included, as well as beliefs and perceptions about disability before and after the new curricula interventions, would be useful to gauge the efficacy of any interventions.

Further research into the pathways for parents and families of deaf children could yield tools and interventions, making navigating the journey of raising a deaf child far less confusing for South African families. Of note would be to consider the differences that state care and private care

contribute to these pathways, especially in light of the proposed NHI transition. Families who have accessed private care would need to know what would still be accessible in light of changes. Often the medical care of deaf children is seen in isolation to the educational opportunities, when in fact, for families this is a continuum of care. Research considering the pathways, would best include a continuum of care considering all aspect of the child and family's well-being, which includes education.

Family-centeredness, promoting a collaboration of stakeholders, including fellow parents and d/Deaf role models, needs to be the gold standard that South African healthcare aspires to. Research considering models of care for multisectoral collaboration as well as implementation of such models in resource limited settings, would allow for best practice care to be accessible to the majority of families with deaf children.

4.6 Conclusion

Through this research I have been able to share insights into the experiences of families with deaf children. Through the lived experiences of South African doctors as parents of deaf children, there have also been some interesting reflections on the professional services, support and interactions which families with deaf children experience. The different perspectives as doctor, and then parent and ultimately both, shed further light onto the field of paediatric deafness. My research has also allowed me to have a renewed appreciation for the lived experience, and the benefit that similar exposure can have for other medical professionals working with families. Finally, as individuals indoctrinated to see disability and deafness as a medical tragedy, the lived experience and personal challenges ultimately resulted in an experience of gratitude. Gratitude for the new things gained. Gratitude for purposeful parenting and gratitude for another chance at treating patients and families holistically, with dignity and respect.

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APPENDICES

Appendix A

Ethics certificate

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
CLEARANCE CERTIFICATE NO. M180720

NAME: (Principal Investigator)	Dr B Birdsey
DEPARTMENT:	School of Clinical Medicine Department of Paediatrics and Child Health Medical School University
PROJECT TITLE:	The lived experiences with paediatric hearing loss: medical doctors as parents of deaf children
DATE CONSIDERED:	27/07/2018
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Dr L Joseph & Professor L Jacklin
APPROVED BY:	Dr CB Penny, Chairperson, HREC (Medical)
DATE OF APPROVAL:	25/09/2018

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Research Office Secretary on 3rd floor, Phillip V Tobias Building, Parktown, University of the Witwatersrand, Johannesburg.
I/We fully understand the conditions under which I am/we are authorised to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated from the research protocol as approved, I/we undertake to resubmit to the Committee. **I agree to submit a yearly progress report.** When a funder requires annual re-certification, the application date will be one year after the date of the meeting when the study was initially reviewed. In this case, the study was initially reviewed in **July** and will therefore reports and re-certification will be due early in the month of **July** each year. Unreported changes to the application may invalidate the clearance given by the HREC (Medical).

Principal Investigator Signature _____ Date _____

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

Appendix B

Study information document

STUDY INFORMATION DOCUMENT

The lived experience with paediatric hearing loss: medical doctors as parents of deaf children.

Thank you for taking the time to read this. I am Bianca Birdsey and I'm currently doing a Masters and Diploma in Paediatric Neurodevelopment. Part of my studies is a research report. I intend to explore a topic that is of personal interest to me, as I am also a mother of three deaf children.

Together with my supervisors, Dr Neethie Joseph from UKZN and Prof Lorna Jacklin from Wits, I would like to explore your experiences as both a medical doctor as well as a parent of a child with a hearing impairment.

We are inviting you to participate in this interesting research study.

Your participation would entail:

1. Being sent a set of questions to think about.
2. I would meet with you in a place most comfortable and convenient for you (your home would be a good option) for a verbal interview involving the same questions as in (1). This would take approximately 1 hour of your time.
3. The interview would be recorded and thereafter transcribed.
4. Confidentiality forms explain the details around confidentiality further.
5. After the interview, an "off air" debrief that would not be part of the research will be offered, as sharing such personal information can be difficult.
6. After the research report, I will see that results of my study are shared with you.

Risks of being involved in the study:

Whilst the utmost care would be taken to omit identifiable details from the interview, due to the nature of the project, I cannot guarantee anonymity.

Benefits of being in the study:

There are no direct benefits to you. This would be an opportunity to share what you have learned from your personal experiences as a parent and medical doctor to shed light on anything that you would like others, especially the medical profession, to know about being a parent of a child with a hearing impairment.

My aim is to conduct an Interpretative Phenomenological Analysis with the data. This methodology involves in-depth interviews to allow me to explore your experiences as both parent and doctor, with a particular focus on what your own experiences have meant for you.

Participation is voluntary, refusal to participate will involve no consequence to you. You are also entitled to withdraw during the interview, with no incurred costs. Directly after the interview, you are also able to withdraw the information that you have shared.

Confidentiality:
Information shared will be treated in the strictest confidence and will only be available to myself as the Principal Investigator (PI) and my supervisors, Dr Joseph and Prof Jacklin.

All data collected in the course of the study will be securely retained for two (2) years, if a scientific publication arises from the study and six (6) years, if there is no publication. Thereafter it will be destroyed accordingly.

After my research report, we hope to use the data in a sensitive manner to write a journal article for publication. Again, whilst anonymity cannot be guaranteed due to the nature of the research, the greatest care will be taken to omit details that might be identifying. These efforts will include: Not using your name or child's name or real initials, not using reference to any proper nouns such as your child's school or therapist, not disclosing your field of practice, province in which you live or number of hearing impaired or hearing children that you may have. If you mention these whilst being recorded, this information will be omitted in reports and articles.

These are our details. Please don't hesitate to contact us if needed:

Dr Bianca Birdsey
MBChB, UCT
biancabirdsey@gmail.com
0833686080

Dr Neethie (L) Joseph
B. Speech and Hearing Therapy, M. Communication Pathology, PhD
josephl@ukzn.ac.za
031 2607625

Prof Lorna Jacklin
FCP Med MSc
jacklin@netactive.co.za
011 4815192

If you encounter any problems, you are welcome to contact the Human Ethics Research Committee at Wits:
This study has been approved by the Human Research Ethics Committee (Medical) of the University of the Witwatersrand, Johannesburg ("Committee"). The Ethics number is M180720. A principal function of this Committee is to safeguard the rights and dignity of all human subjects who agree to participate in a research project and the integrity of the research.

If you have any concern over the way the study is being conducted, please contact the Chairperson of this Committee who is Professor Clement Penny, who may be contacted on telephone number 011 717 2301, or by e-mail on Clement.Penny@wits.ac.za. The telephone numbers for the Committee secretariat are 011 717 2700/1234 and the e-mail addresses are Zanele.Ndlovu@wits.ac.za and Rhulani.Mukansi@wits.ac.za

Thank you for reading this Study Information Sheet.
August 2018

Appendix C

Participant consent sheet

WITS UNIVERSITY

PARTICIPANT CONSENT SHEET

The lived experience with paediatric hearing loss: Medical doctors as parents of deaf children.

1. I have been given a Participant Information Sheet which explains the nature and processes involved in this study, which is attached hereto;
2. I was given time to read it, or had it read to me, in the language I best understand;
3. I was given time to ask any questions I wanted to and found any answers given to me to be reasonable and satisfactory;
4. I believe I fully understand why the study is being conducted and what the intended outcomes will be;
5. I understand that there will be no immediate benefit to me, should I agree to participate, nor will I receive any payment; conversely, participation will not cost me anything but my time
6. I understand that, even if I initially consent to take part in the study, I may subsequently withdraw during or after the interview, and would not be required to give any reasons; if that happened, any data collected about me for the purposes of the study would immediately be destroyed, unless I give consent for it to be retained
7. I have been given a range of contact details, listed below. If I require further information or become concerned about any aspect of this study I am free to speak to any of these contacts.

Contact details:

Dr Bianca Birdsey, Principal Investigator, telephone no. 083 3686080, or by e-mail at biancabirdsey@gmail.com
Dr Lavanithum (Neethie) Joseph, Supervisor, on telephone no. 031 2607625, or by e-mail at josephl@ukzn.ac.za
Prof Lorna Jacklin, Supervisor, on telephone no. 011 4815192, or by email at jacklin@netactive.co.za

Professor CB Penny, Chairperson of the Human Research Ethics Committee (Medical) at the University of Witwatersrand, on telephone no. 011 717 2301, or by e-mail at Clement.Penny@wits.ac.za.
Ms. Z Ndlovu or Mr Rhulani Mkansi, Committee Secretariat, telephone nos.: 011 717 2700 or 1234, or by e-mail at: Zanele.Ndlovu@wits.ac.za or Rhulani.Mkansi@wits.ac.za

Name of Participant: _____
Date: _____
Place: _____
Signature or mark _____

Witnessed by:

Name of Witness: _____
Signature: _____
Date: _____

Appendix D

Consent form for audio recording of study participants



CONSENT FORM FOR AUDIO RECORDING OF STUDY PARTICIPATION

The lived experience with paediatric hearing loss: Medical doctors as parents of deaf children.

I hereby consent to audio recording of the interview.
I understand that:

- The recording will be stored in a secure location with restricted access to the researcher and the research supervisors.
- The recording will be transcribed and any information that could identify me will be removed,
- The recordings will be erased within either (a) two (2) years of the publication of the research findings, or (b) six (6) years, if no publications arise from this research
- Anyone wishing to access this information in the future will first have to obtain the approval of the Human Research Ethics Committee (Medical) of the University of the Witwatersrand, Johannesburg
- Direct quotes from my interview, without any information that could identify me, may be cited in the research report or other write-ups of research.

Name of Participant: _____
Date: _____
Place: _____

Signature or mark _____

Witnessed by:

Name of Witness: _____

Signature: _____
Date: _____

Appendix E

Interview protocol and question schedule

Introduction: *care taken to create a rapport with the participants through a warm, safe and inviting tone and open body language*

I am doing my MSc in Child Health. A research report is a requirement for this course. I have chosen a qualitative research study about a topic that has personal interest to me. I, like you, am a medical doctor and about 5 years ago, found out that my three children are deaf. I'm interested in learning from others in a similar position of being both medical doctor and parent to a deaf child. Here the terms hearing loss/deafness/ hearing impairment will all be used interchangeably.

I have a series of questions which I'd like to ask you. Feel free to answer them as fully as you please. There are *no* wrong answers. I'm interested in *your* experience, thoughts and reflections. Take as much time to answer these questions as you need to. I will be taking notes and recording this interview with your permission. As a part of my research, our conversation will be typed up verbatim and analyzed by myself with the supervision of two experienced researchers. The purpose of this being to learn from your experiences and insights as both parent and doctor, extracting your wisdom to ultimately share with the wider medical profession to see families with deaf children being managed better.

We will do our best to maintain confidentiality such as, not using your real name or initials, not using your children's real names or referring accurately to their true sex, not revealing the area in South Africa where you live, nor your field of specialization, nor the number of children, hearing/hearing impaired that you might have. Whilst these details might be recorded as you speak to me, they will not be used in any report backs. The only people who would have access to these actual conversations would be me and my two supervisors. All conversations, both taped and typed out and field notes will be destroyed within 6 years if no publications are made, and 2 years if published, and per the Wits University protocol.

At any point during or directly after this interview, if you do not wish to continue, you are welcome to stop, with no consequence to you.

As you would have read on the consent form, there is no direct benefit to you. If any, the benefit may be viewed as an opportunity to share your gained knowledge for the overall betterment of the management of families who have hearing impaired children.

As mentioned on invitation, this interview will likely take about an hour of your time. Should you be comfortable with it taking longer and wish to take more time, that is completely fine. I'm really grateful for your participation.

Are you comfortable with us conducting this in English?
If it is stated that at times they would like to answer in their first language, I would then disclose that I would need to have someone translate those parts into English for me which would then add an additional person who would have access to the relevant parts of the conversation (and that person would sign a declaration of confidentiality).

Semi-Structured Interview Questions (16 questions in total)
Tape recorded with consent. Care to be taken to note any non-verbal behavior in field notes.

- Background

1. Could you give me a brief history of your journey as a parent of a child with a hearing impairment?
    Prompt
    (age of identification, age now first choices, where are you at now?)

- Baseline knowledge as a doctor about child deafness.

2. Do you think that you being a medical doctor prepared you in anyway differently, than you may have been prepared had you not had your medical background?
    Prompts
    Did your undergraduate paediatric training give you the information that you needed to know about paediatric hearing loss?
    Did you know much about paediatric hearing loss (*importance of new born screening, signs, management, implications)* when you graduated from medical school?
    Did you know to have your child's hearing tested as a newborn?

- Parent experience

3. Do you have any reflections of the time around diagnosis and initial management that you would like to share?
    Prompts
    Were there any particular challenges?
    What were some of the most difficult things, if any, considered during this time?
    Do you feel that you were given sufficient information regarding a variety of intervention options?
4. How do you think being a doctor may have impacted how you felt during the time of identification?
5. How did your medical colleagues respond when they found out that you have a child/children with hearing loss?
6. From a medical perspective, did anything surprise you about the field of paediatric hearing loss?
    Prompt
    Were you aware of the politics in the field? How have you navigated this?
7. If you had a magic wand and could change anything about your journey, what would that be?
8. What has been the best part of your journey?
9. Do you think much about the future?
    Prompt
    What sorts of things fill your thoughts about the future?

- Dual reflection

a) Did being a doctor affect the deaf journey?

10. Has being a doctor influenced some of the decisions you've made on this journey for your child?
    Prompt
    Do you think that any decisions may have been different had you not had a medical background?
    Who were some of the people you regard as primary advisors on this journey?
11. Had you previously been aware of the two predominant views to disability i.e. the medical model / social model.
    Prompt
    Where do you think you fitted before your child was identified? Do you think your position has changed since?

b) Has being a parent affected you as a doctor?

12. Has your journey as a parent changed your perception of deafness and disability as a medical professional?
    Prompts
    Do you think there are any benefits to being deaf/having a deaf child?
    What's the hardest part about having a deaf child?
13. Has your journey as a parent has in any way affected your practice as a medical professional?
    Prompts
    Do you think you are/were a family centered physician?
    Do you think you were/are able to manage the patient holistically and see past disability?

- Experienced reflection of the field professionally

14. Do you think that paediatric hearing loss is being managed optimally in South Africa?
    Prompt
    What services need attention and how?
15. What recommendations would you make to colleagues in the medical field when working with families with a deaf child?

16. Is there anything else you'd like to share/add?

Appendix F

Question schedule sent to participants

Thank you so much for your time. I wanted to send you this question schedule so that you have an idea of the topics that we will chat about. It also gives you time to think about your answers, as the aim is to gather your wisdom from your lived experience.

Just to note that the terms hearing loss/hearing impairment/deafness are used here interchangeably, and during the interview, we will use whatever terms that you most feel comfortable with.

1. Could you give me a brief history of your journey as a parent of a child with a hearing impairment?

2. Do you think that being a medical doctor prepared you in anyway differently, than you may have been prepared had you not had your medical background?

3. Do you have any reflections of the time around diagnosis and initial management that you would like to share?

4. How do you think being a doctor may have impacted how you felt during the time of identification?

5. How did your medical colleagues respond when they found out that you have a child/children with hearing loss?

6. From a medical perspective, did anything surprise you about the field of paediatric hearing loss?

7. If you had a magic wand and could change anything about your journey, what would that be?

8. What has been the best part of your journey?

9. Do you think much about the future?

10. Has being a doctor influenced some of the decisions you've made on this journey for your child?

11. Had you previously been aware of the two predominant views of disability i.e. the medical model / social model?

12. Has your journey as a parent changed your perception of deafness and disability as a medical professional?

13. Has your journey as a parent in any way affected your practice as a medical professional?

14. Do you think that paediatric hearing loss is being managed optimally in South Africa?

15. What recommendations would you make to colleagues in the medical field when working with families with a deaf child?

16. Is there anything else you'd like to share/add?

Appendix G

Example of stage 1, level 2 analysis

Participant X – Level 2 Analysis - Stage 1		
Emergent Themes	**Original Transcript**	**Exploratory comments**
Insight from meeting other children. Pathway	and showed us one of the kids and so forth. And then suddenly, I was like okay, this is possible. I think we go through all those emotions much faster than a typical family. We knew where to go to, this is the next step we need to find out this, this and this, so that helped. Researcher: How did you know where to go to? Participant X:	Again witnessing the lived experience gave hope. Pathway clearer on meeting other children and families
No real road map/Pathway Education	When [professional's name] talked about education, [they] kind of said the only school at that stage, [was]…but [child's name] was too young to go in at that stage, so that's why [child] was in other preschools before that, uhm because we could only get [child] in at certain age. The therapy was kind of set up, so you know, it's because it was part of the cochlear team, so that was like, you know, nice at one stage, you knew when to go to.	Favour in having a contact – fast tracked the initial process. No real roadmap but typical pathway – usual therapists and one school recommended.
Informed choice	We didn't know what the options were though, there were different practices we could use, it was very (pause) in brackets there were very few specialists that were treating this especially in [province name]. I think it's different now obviously, a lot more choice and chances. And the problem is that	A pseudo belief that options and roadmaps done well. Politics – feeling of minimal choices
Experiences with Professionals	we saw is that if you struggle with a certain person, you are totally screwed, okay, so you either have to travel, which we did, we went to [place name] which we did at some point, just to get an idea, how do they do it. The other things was that my [other child] was at that stage fluent [language name].	Had to travel as audiologist treated them badly and there weren't other options in [place name].

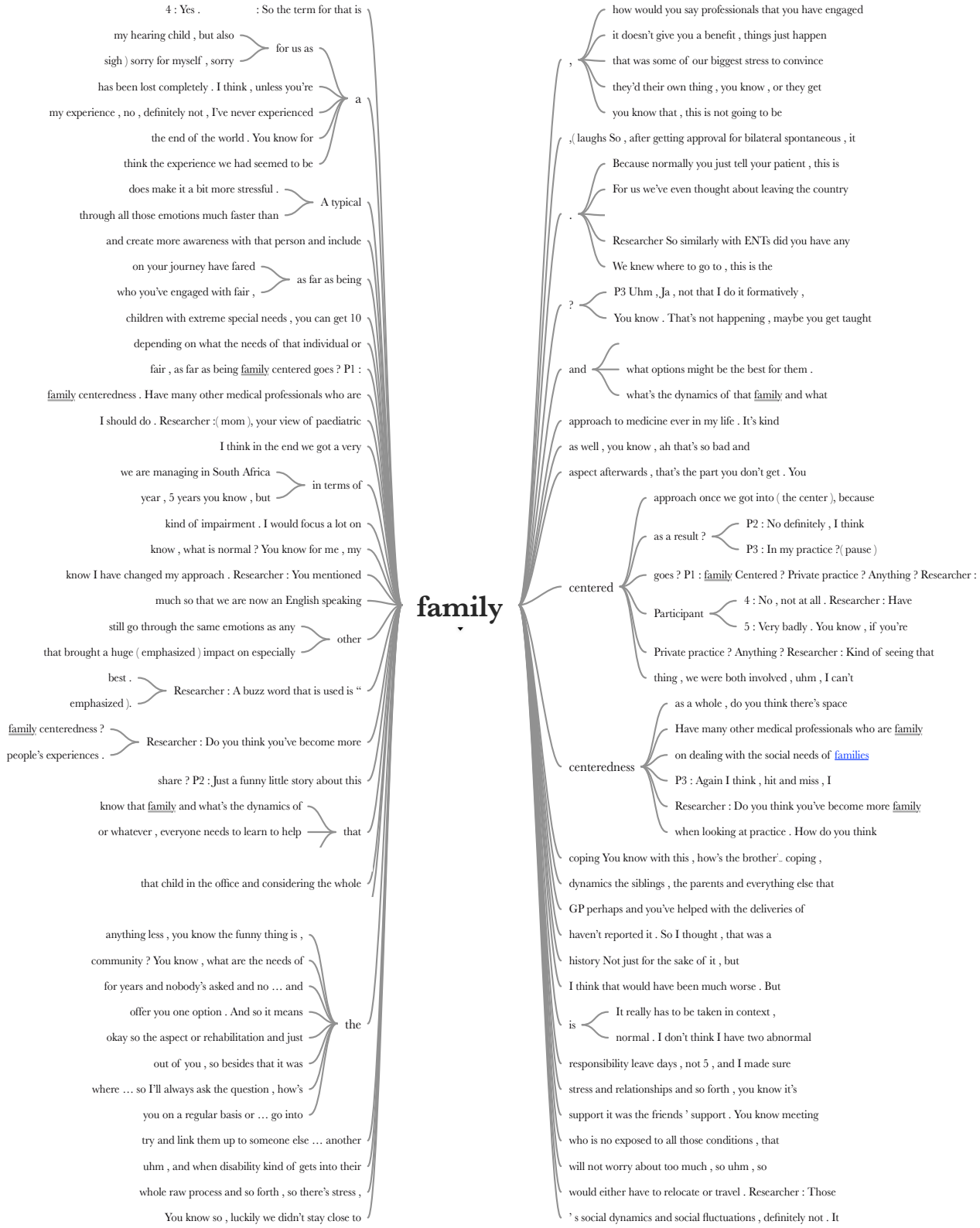
Appendix H

Example of a NVivo generated Word Cloud - Word Cloud showing the combined word frequency for all participants.



Appendix I

Example of a NVivo generated Word Tree - Word Tree for “family”



Appendix J

The number of coded references per participant and the relative percentage of the total coded data.

Participant	Number of references coded	Percentage of the total coded data
Participant 1	89	24.86
Participant 2	63	17.59
Participant 3	53	14.80
Participant 4	83	23.18
Participant 5	70	19.55
Total	358	100

Appendix K

Treemap of the 17 themes (16 subthemes and one emerging theme) which coded at all five participants.



Appendix L

The number of coded references at each organizing theme, emerging theme and subtheme.

(Grey indicates those emerging themes and subthemes coded at all five participants.)

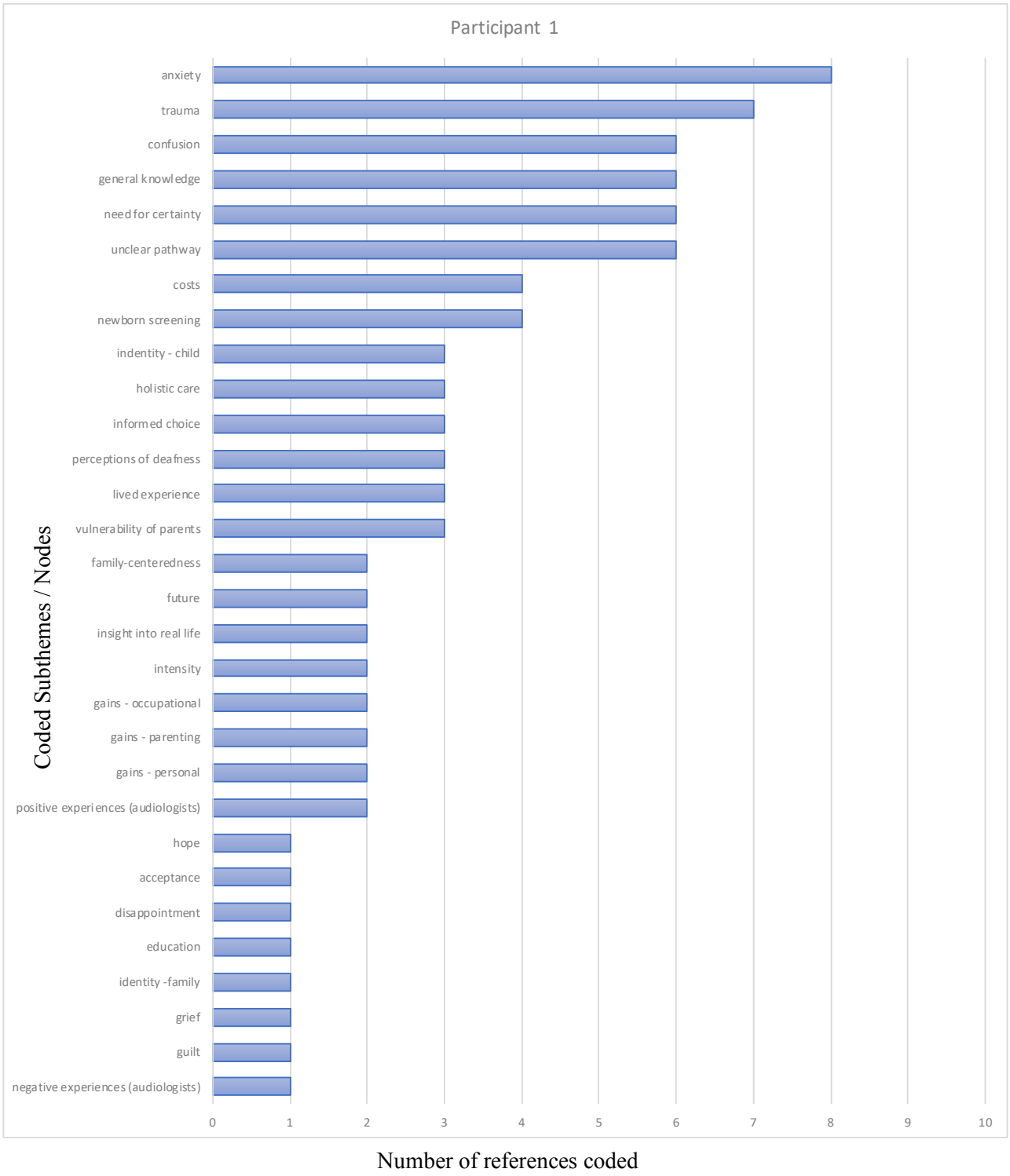
Organizing theme (parent node)	**Emerging theme (child node)**	**Subtheme (node)**	**Number of coded references**
The Parenting Journey			**171**
	Initial Stress		74
		grief	18
		guilt	13
		trauma	15
		vulnerability of parents	12
		confusion	11
		disappointment	5
	Ongoing stress		85
		anxiety	27
		education	8
		future	8
		intensity	18
		sacrifices	13
		costs	11
	Acceptance		5
	Hope		7
Experiences with Professionals			**80**
	Family- centeredness		48
		general family-centeredness	9
		informed choice	20
		holistic care	12
		insight into the real life of parenting a deaf child	7

Organizing theme (parent node)	Emerging theme (child node)	Subtheme (node)	Number of coded references
	Experiences with audiologists		22
		negative experiences	18
		positive experiences	4
	Unclear pathway		10
Plurality of Perspective			**73**
	Misperceptions and incomplete information about deafness		40
		general knowledge about deafness	15
		newborn screening	15
		perceptions of deafness	10
	Gains		33
		occupational	13
		lived experience	9
		parenting	7
		personal	4
Identity			**34**
	Self		9
		need for certainty	14
	Family		6
	Child		5

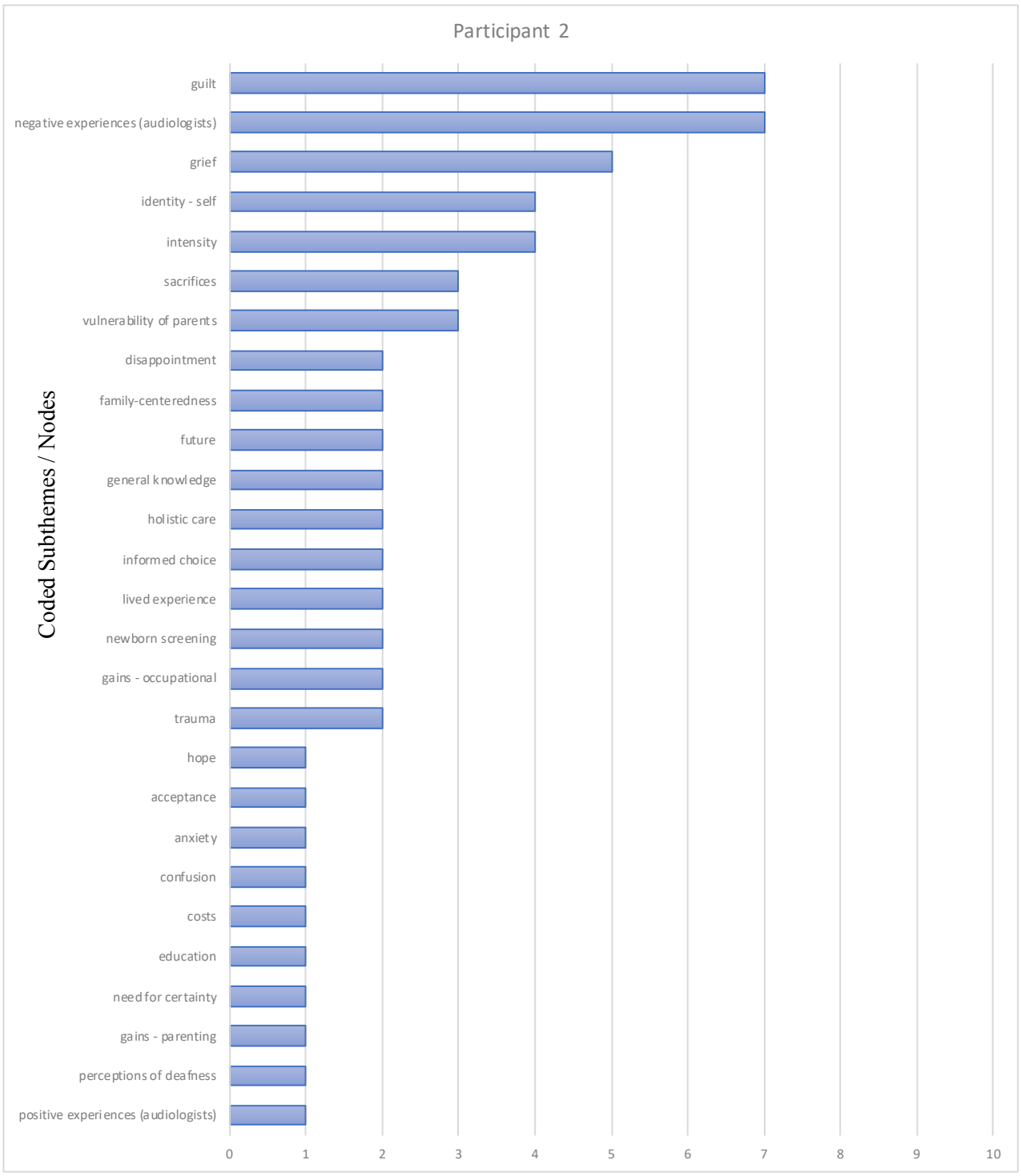
Appendix M (1-5)

Individual participant charts showing the number of coded references at each "node" coded in NVivo.

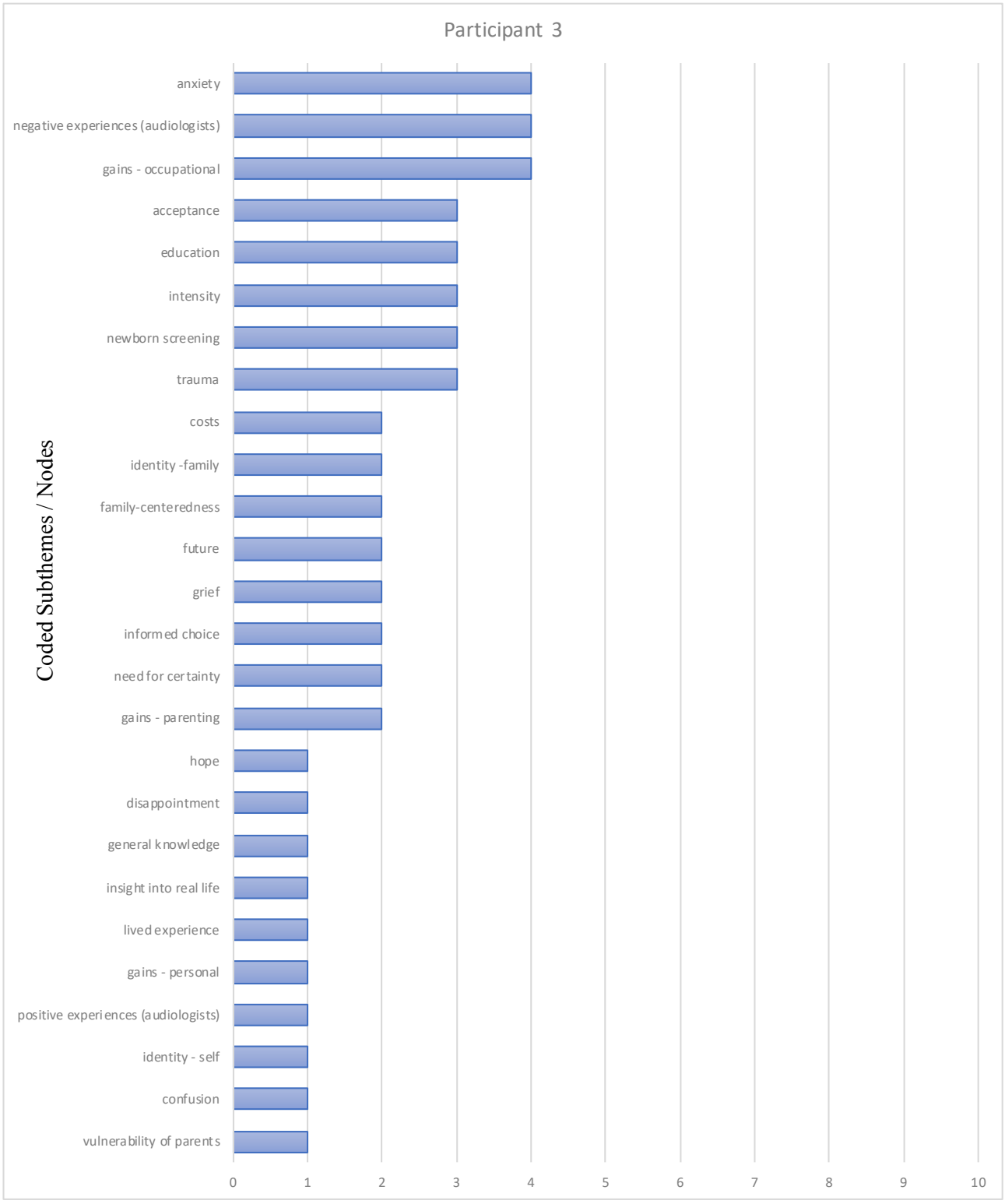
1. Participant 1



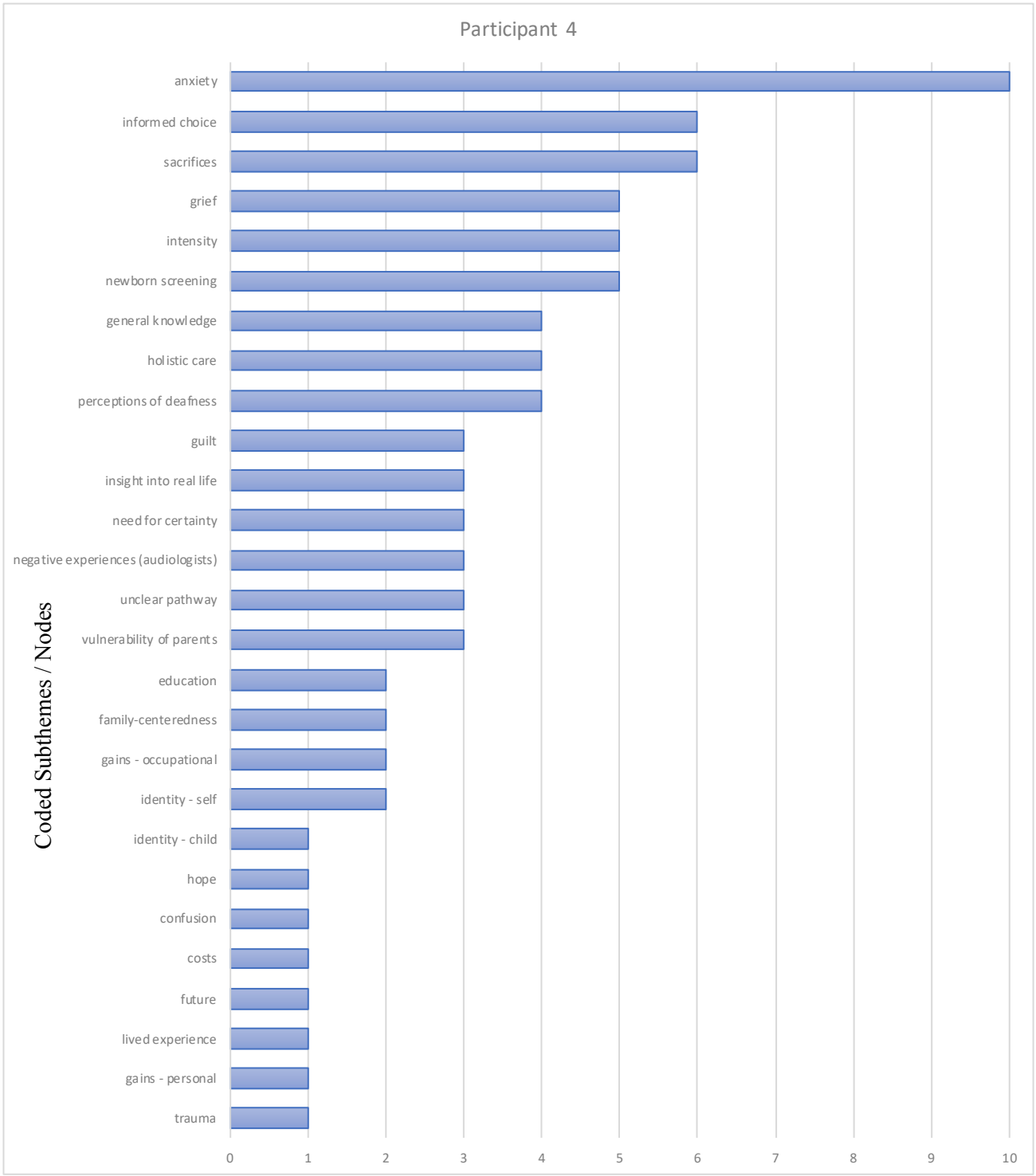
2. Participant 2



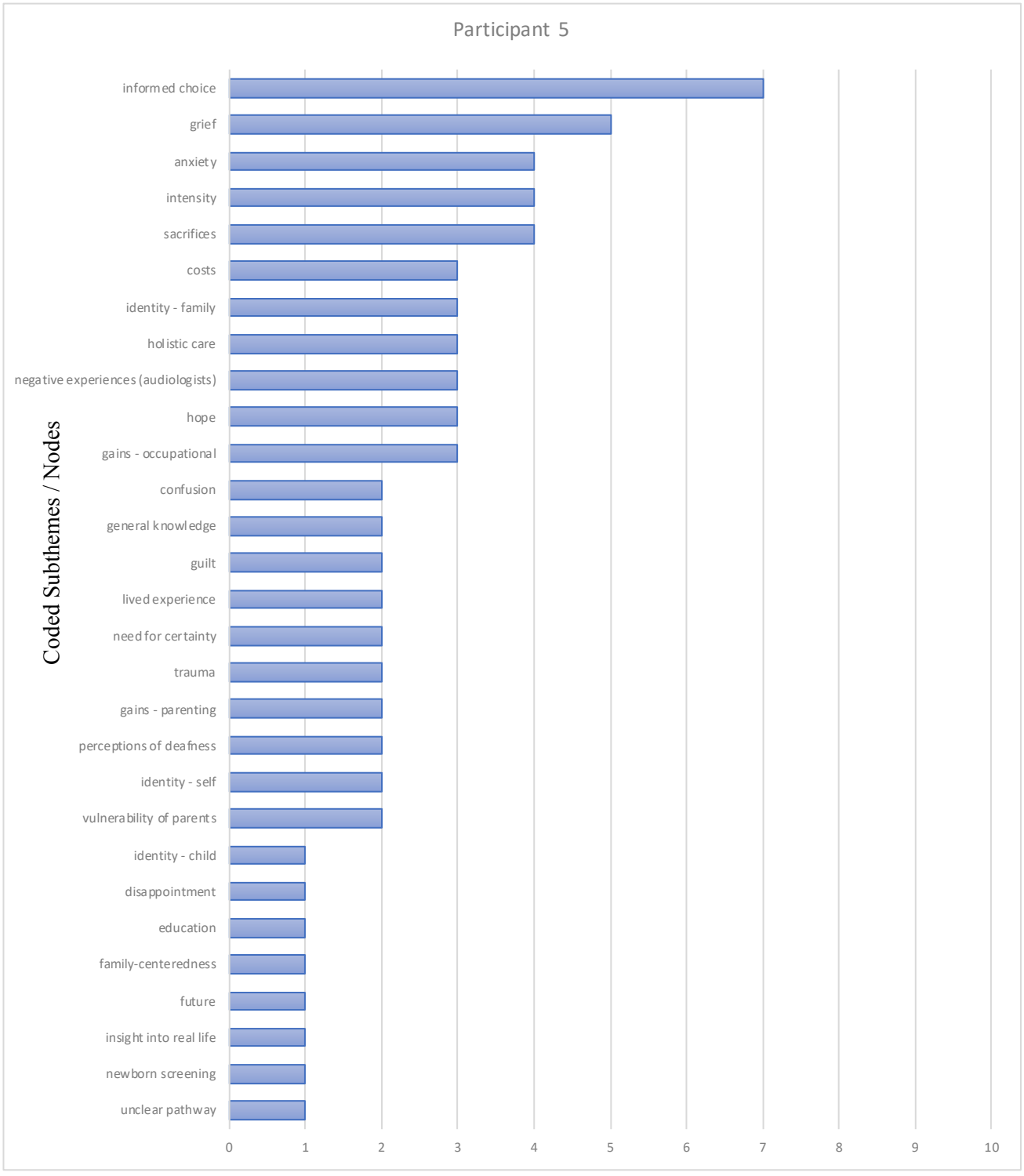
3. Participant 3



4. Participant 4



5. Participant 5



Appendix N

1. Turn-it-in report

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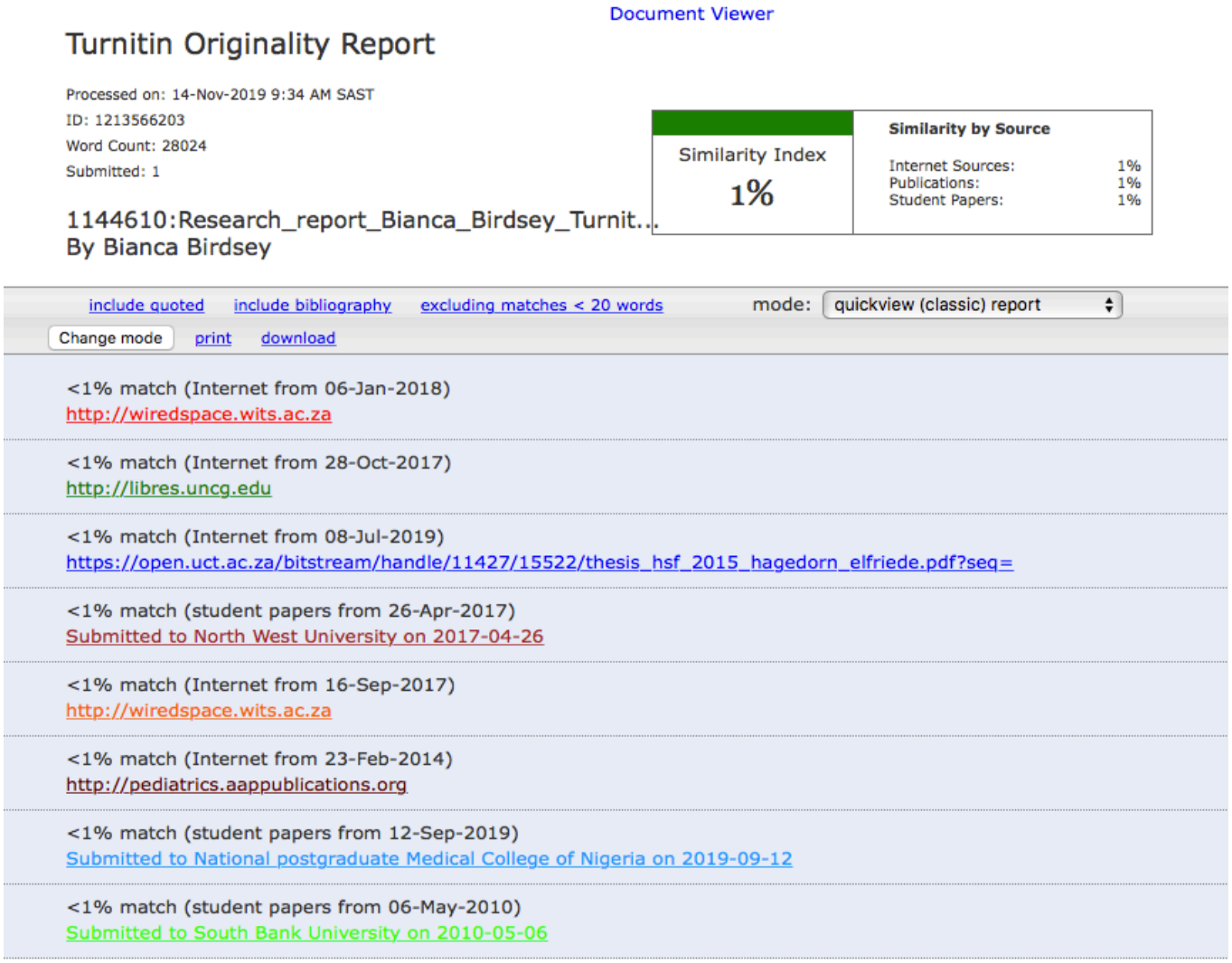
7	Submitted to South Bank University Student Paper	<1%

L Joseph
Research Supervisor

2. Turn-it-in report



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