"We Do Not Understand Each Other:" **The Experience of Caregivers of Deaf Children in a Rural South African Setting**

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By

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Abstract

The complexities of deafness, especially within a rural context characterised by poverty of resources and structural barriers to agency and self-efficacy, suggest that childhood deafness may impact significantly on the experience of caregivers of deaf children. Theoretical, practical, audiological, and contextual contributions to the understanding of deafness and Deafness revealed that these can impact on the caregivers' experience as do factors related to the specific support structures and requirements of caregivers of deaf children in a rural setting.

A qualitative approach was used in this study so as to interact respectfully within a human rights viewpoint. The experience of caregivers of deaf children in the Ehlanzeni District of Mpumalanga, South Africa, was explored by conducting 19 semi-structured ethnographic individual interviews and two group interviews with caregivers of deaf children. The participants were recruited through purposive, convenience sampling and snowball sampling strategies. Interviews were conducted in siSwati, South African Sign Language (SASL), and English. One principal and two assistant context mediators were recruited to conduct the interviews in siSwati and SASL. The siSwati and SASL interview transcriptions were translated into English and these, together with the transcriptions of the interviews conducted in English, underwent thematic analysis using the Framework method.

Five overarching domains appear to characterise the caregivers' experience: communication, finances, schooling, psycho-emotional support, and the caregiver role. Within these five domains, sub-themes were identified which delineated the specifics of each domain. This thesis confirms that the experience of deafness is mediated by its context. Within the five interconnected domains, caregivers within this study, especially women, appear to have low self-efficacy and agency within their constrained structural setting and seem to experience a devolution of agency and also an embodied third-party disability.

These findings have implications for practice, policy, education, and further research with regard to the need for contextually attuned interactions and mutually co-constructed opportunities for structural developments and agency enhancement.

Keywords: deafness, Deafness, deaf children, caregivers, South Africa, Mpumalanga, siSwati, South African Sign Language (SASL), audiology, qualitative research, context, self-efficacy, agency, structure, disability, devolution, embodiment, third-party disability, community of practice (COP).

Declaration

I declare that this dissertation is my own unaided work. It has never been submitted for any degree or examination at any other university. All sources which I have used, made reference to, or quoted have been indicated and acknowledged.

Victor Manuel de Andrade

March 2015

Signed:

This thesis is dedicated to the memory of

Pai, Avô, Avó Ludovina, Padrinho, and Greggy

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“People are human beings, produced by the society in which they live.

You encourage people by seeing good in them.”

Nelson Mandela

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List of Abbreviations

ABR – Auditory Brainstem Response

AIDS – Acquired Immunodeficiency Syndrome

ASSR – Auditory Steady State Response

CBR – Community-based Rehabilitation

CDG – Care Dependency Grant

COP/COPs – Community of Practice/Communities of Practice

CSD – Child Support Grant

dB – Decibel

DG – Disability Grant

EHDI – Early Hearing Detection and Intervention

GNI – Gross National Income per Capita

HI HOPES – Home Intervention Hearing and language Opportunities Parent Education Services

HIV – Human Immunodeficiency Virus

HPCSA – Health Professions Council of South Africa

Hz – Hertz

ICD – International Classification of Disability

ICF – International Classification of Function, Disability and Health

ISHP – Integrated School Health Programme

LLR – Late-latency Response

MLR – Mid-latency Response

OAE – Otoacoustic Emission

SAHRC – South African Human Rights Commission

SANPAD – South Africa Netherlands Research Programme on Alternatives in Development

SASL – South African Sign Language

UN – United Nations

UNICEF – United Nations International Children’s Emergency Fund

US$ - United States of American Dollar

WHO – World Health Organisation

Wits WAB – University of the Witwatersrand Hearing Aid Bank

YLD – Years Lost to Disability

ZAR – South African Rand

Chapter 1: Orientation to this Thesis

“What fills and satisfies the soul consists not in knowing much,

but in our understanding the realities profoundly and savouring them interiorly.”

St Ignatius of Loyola

(Healey, 2009, p. 46)

Figure 1.1. The view across one of the villages in rural Mpumalanga where this study was set.

It reflects the undulated landscape of the caregivers’ experience with regard to their children’s deafness and it was in this context that I sought to understand people’s realities profoundly and savour them interiorly.

1.1. A Matter of Perspective

At the time of writing up this PhD thesis, I have been practising audiology for approximately 16 years, during which time I have come to appreciate the multiplicity of different people's realities in the variety of settings in which I have worked and have developed a desire to understand more deeply these personal and experienced realities. One of those settings was in Mpumalanga, a province in South Africa, the name of which means 'where the sun rises' in siSwati, the language spoken in that region, and it was this place which illuminated my interest in understanding the experience of the caregivers of deaf children. It seemed to me as though, very often, the deaf children themselves are the focus of attention in terms of audiological, medical, educational, social development, and vocational research, policy and practice, but that their caregivers, who are not the direct recipients of the attention, also have certain experiences and that these may be invisible to those people providing audiological services and that the caregivers' experience also merits attention. This interest translated into the desire to explore formally, not only anecdotally, caregivers' experiences and to interrogate their daily interactions with deafness.

In research and in practice, audiologists may take the 'etic' position, that is, the position of an outsider in the different dimensions of deafness: work, study, analysis, interpretation, and advice-giving. Furthermore, we may engage in professional, ethical, academic, and, often, personal interactions with deafness. However, in working with deafness, audiologists do not always necessarily live this deafness as part of themselves or as part of their daily, personal and familial responsibilities in the same way that caregivers of deaf children may do. Therefore, as an audiologist with a particular interest in the social aspects of the often medicalised notions of deafness, I came to this project with a particular and specific interest and focus.

There is an acknowledgement that within the field of audiology, there is the need for a multifaceted approach to understanding audiological phenomena (Knudsen et al., 2012). The caregivers to whom I spoke while conducting this study shared their insights around that experience and I tried to put across the general themes which could be useful in understanding the lived experience of caregiving for deaf children so as to gain an insight into people's every day. Denzin and Lincoln (2011) refer to the researchers who have a qualitative orientation as the "quilt makers" of research as they try to create a "pieced-together set of representations that are fitted to the specifics of a complex situation" (Denzin & Lincoln, 2011, p. 4) in order "to provide a holistic understanding of research participants' views and actions in the context of their lives overall (Snape & Spencer, 2003, p. 7). Within the qualitative orientation to this study on deafness, it was implemented as a collaborative exploration of the caregivers' experience of childhood deafness without the reduction of the caregivers to purely vessels of answers (Holstein & Gubrium, 2004) or "mere objects" (Parker, 2004, p. 5) especially because it is acknowledged that contextual variables are insufficiently considered in research, especially with regard to caregivers (T. L. Jones & Prinz, 2005).

From my background in audiology I recognise that communication comprises a significant domain of the deafness experience, both for caregivers and for deaf children. However, by engaging in this qualitative and deep exploration of caregivers' experience, I also acknowledge that as audiologists and as people who interact with deafness and with deaf people, there is not necessarily always that deep understanding and appreciation of the caregivers' experience, hence the choice of title for this thesis which came from the interview with Participant 3: *"We do not understand each other.*" This statement originally referred to the difficulty a child's mother experienced in communicating with her deaf daughter but I thought it was an appropriate quotation to encapsulate the thesis as it reflects that these misunderstandings do not just refer to misunderstanding language. In the bigger picture of this study it also summarises the misunderstanding of the context and how that shapes experience. It can also refer to audiologists' and others' surface understanding and misunderstanding of caregivers' experience while also alluding to the need to understand and respect the rights of caregivers who, like the tree in the photograph on the cover page, find themselves isolated, exposed, and vulnerable.

1.2. Deafness: Physiological and Contextual Considerations

It is important to consider childhood deafness and the shared context of the participants in this study when exploring the caregivers' experience of deafness. With regard to childhood deafness, more than 6000 children a year are born with, or develop early onset deafness, in South Africa (Swanepoel, Störbeck, & Friedland, 2009). There appear to be more cases of childhood deafness in communities in which people have restricted socio-economic means and that children from poorer areas appear to receive later intervention for their deafness (Swanepoel et al., 2009) which appears to link with the argument that people's contexts become embodied within them (Krieger, 2008). Delays in the identification of deafness may result in communication delays in children who are deaf (Widen, Bull, & Folsom, 2003) because they may not learn spoken language as they cannot hear spoken language and may not learn signed language because they are not identified as being deaf and are not exposed to signed language. The early identification of childhood deafness and the subsequent intervention usually results in a reduced delay in communication and improved communication abilities (Kennedy et al., 2006) which provides an incentive for early intervention because hearing amplification options can provide the groundwork for learning spoken language and exposure to signed language can facilitate the development of language in that modality. However, despite this recognised benefit of early identification, the mean age of identification of infantile deafness in urban areas of South Africa is only approximately 23 months of age while the mean age for the acquisition of hearing aid amplification in these urban areas is approximately 28 months and it is postulated that it is even later in rural areas (van der Spuy & Pottas, 2008). In comparison, it is reported that, in the United States of America, identification of deafness tends to occur by 3 months of age while the provision of hearing aid amplification can be offered by 4 months of age while the mean age of identification of childhood deafness is 5.5 years age in Kenya (van der Spuy & Pottas, 2008).

Despite the shared experience of being caregivers to deaf children, it cannot be assumed that the caregivers' experience of that common feature is the same and therefore research ought "not assume that there is a single unitary reality" (Krauss, 2005, p. 760). People's experiences can be varied and could be a collection of different constructions and understandings (Snape & Spencer, 2003) of a phenomenon which suggests that the meaning of the phenomenon of deafness is socially and contextually constructed. While physiological deafness is not a social construction because it is quantifiable in terms of the physical measurement of the degree of deafness, the meaning around this physiological deafness may be contextually constructed and even contextually mediated. Krieger (2008) argues that the physical deafness may be an embodiment of the social conditions in which people live when she defines embodiment as "how we literally incorporate, biologically, the material and social world in which we live, from in utero to death" (Krieger, 2008, p. 225). Therefore, it seems as though deafness does not exist in a vacuum but within social and contextual settings and that these aspects of individuals' lives need to be considered. As Marx argued, "society does not consist of individuals; it expresses the sum of connections and relationships in which individuals find themselves" (Wacquant, 1992, p. 16).

1.3. Considering Context

Weber "emphasised that the researcher must understand the meaning of social actions within the context of the material conditions in which people live … (and) … the aim is to understand subjectively meaningful experiences" (cited in Snape & Spencer, 2003, p. 7). That which the researcher collects is analysed and understood in the context of the geographical location (Macintyre, Macdonald, & Ellaway, 2008) as well as the "history, biography, gender, social class, race and ethnicity" (Denzin & Lincoln, 2011, p. 5) of the participants. There is the recognition that "knowledge is established through the meanings attached to the phenomena studied…(and that)…knowledge is context and time dependent" (Krauss, 2005, p. 759) while recognising that "the analytical process takes into account the nature of the links and the inherently reflexive character of the knowledge" (Davies, 2001, p. 98). In this project I sought to construct an understanding as an audiologist of the caregivers' perspectives and their insights since "they tend themselves to develop accounts, conjectures, hypotheses or theories of variations" (Lofland, 1971, p. 63). Especially with regard to caregivers, there is the need to consider that "numerous contextual factors, such as the social, situational, and temporal circumstances under which events occur" are important (Coleman & Karraker, 1997, p. 50). More specifically, I approached the study thinking:

> that individuals seek understanding of the world in which they live and work. Individuals develop subjective meanings of their experiences – meanings directed toward certain objects or things. These meanings are varied and multiple, leading the researcher to look for the complexity of views rather than narrowing meanings into a few categories or ideas. The goal of the research is to rely as much as possible on the participants' views of the situation being studied…Often these subjective meanings are negotiated socially and historically (Creswell, 2009, p. 8).

1.4. The Particular Context as Impetus for the Study

The context in which research is conducted and in which people experience particular phenomena may shape the constructions around that phenomenon. In other words, where people live matters in their ability to access resources because resources and facilities tend to be fewer in poorer areas which may be compounded by “the interacting or multiplicative effects of personal resources” (Macintyre et al., 2008, p. 901). This appreciation of impact of context on practice I witnessed during the provision of audiological services to people in this geographical area and in the supervision of students from the Department of Speech Pathology and Audiology from the University of the Witwatersrand who attend their rural practice placement in the province. The university has various research interests undertaken by different departments and, more closely linked to my research, through the Health Communication Project I became involved in research on communication in health settings. Through this involvement in the Health Communication Project in Mpumalanga, I developed an interest in the particularities of that district in terms of audiological services, an interest which could be termed an intrinsic ethnographic enquiry (Ellis, 2013) because it is a geographical and professional area in which I have participated myself. This participation has played a large part in fuelling the interest for this thesis and for focussing it in the Ehlanzeni District of Mpumalanga Province.

The Ehlanzeni District of Mpumalanga is a combination of a predominantly rural setting with pockets of urbanisation and is described by the South African Human Rights Commission and the United Nations International Children’s Emergency Fund as being representative of “spatial concentrations of deprivation, often located in rural interiors” (SAHRC & UNICEF, 2014, p. 32). Although there are other parts of the country which are very rural and may share similar characteristics to the area of interest for this study, the southern part of the Ehlanzeni District appeared particularly interesting to me because in my work in this largely rural area, it appeared as though services for deaf children were not always readily and consistently available. People said that there was very little in terms of the support offered to caregivers of deaf children. In providing audiological services in the district, it became apparent that caregivers of children in that district were employing particular strategies in light of their particular contextual factors and that their experiences were not being documented. Instead, the focus in the audiological work appeared to be on the measurement and rehabilitation of the children's deafness and these services were not necessarily always family centred and seemed to remove the child from the context of the family and the physical setting. Also, recommendations for assessment and intervention for deafness may not always have been congruent with the caregivers' resources and access. Therefore, because of my interactions with people from the area, I became interested in finding out how caregivers navigate the route of being caregivers to their deaf children within this context. Caregivers seem to have to contend with, amongst others, caring for other children who are not deaf, unemployment, and the availability of audiologically related services, especially in a post-apartheid era. It also became apparent that there was the need to explore their experience with regard to their children because, according to the South African Human Rights' Commission (SAHRC), "in the two decades since South Africa's transition to democracy … it is disturbing that there is still such widespread evidence of considerable and deep-rooted poverty amongst children" (SAHRC & UNICEF, 2014, p. 4).

Because I was quite familiar with the setting through my prolonged and repeated exposure in the area, I used to discuss these matters with the caregivers and used to look to tailor services in line with the caregivers' requirements. However, it became apparent that the experience was not the same for everyone since different people lived in different settings: some lived closer to the urban centres, some were employed, some were parents, and some were extended family or friends. Nonetheless, although I appreciated these contextual particularities, I did not fully comprehend the underlying meaning and experience, not to mention the care of the carer which drove the interest in this project. The focus appeared to be on the child in terms of assessment, hearing aid provision, educational placement, and aural rehabilitation. However, there appeared to be very little interest in the caregivers. This information seemed of utmost importance since their experience impacted directly on the deaf child. I assumed that the caregivers' experience was the one which determined what services the child received since the caregivers' economic, geographical, occupational, and literacy factors, amongst others, could influence the services their deaf children received.

I also wanted to explore formally the support for the caregivers from their perspective. I did not want to evaluate or audit the current programmes as legislated or advocated in the province. Instead, by speaking to the caregivers themselves, the expectation was that I would get the real lived experience of caregivers in providing for their deaf children within this context of various levels of access to resources and availability of resources and support. Therefore, this district of Mpumalanga was selected to explore the penetration of audiological and related support services in an area where people may have different levels of access to services for deaf children and for themselves, a new orientation which had not been undertaken in the field of deafness in South Africa, an interrogation and approach which I found difficult. As Wittgenstein said,

> Getting hold of the difficulty deep down is what is hard. Because it is grasped near the surface, it simply remains the difficulty it was. It has to be pulled out by the roots; and that involves our beginning to think in a new way. ... The new way of thinking is what is so hard to establish (Wittgenstein cited in Wacquant, 1992, p. 1).

The literature review referred to various 'domains' (Ahlert & Greeff, 2012; Coleman & Karraker, 1997; Jackson, Traub, & Turnbull, 2008; T. L. Jones & Prinz, 2005; Macintyre et al., 2008; SAHRC & UNICEF, 2014) which require further exploration in the endeavours to understand people’s interaction within contexts of constrained and limited resources as was the case in this study, especially as they relate to deafness. It has been found that “many deprived areas lack core services, including education, health, financial and support. … This lack increases the problems deprived neighbourhoods already face through restricting the opportunities available. ... This is now recognised as an important issue.’ (Macintyre et al., 2008, p. 902). There is a call to consider the “distinct domains including material resources, employment, education, health, social participation, and community membership” (SAHRC & UNICEF, 2014, p. 32). More specifically to South Africa, the call to explore “the domains of health, education, wealth and assets, family and social networks, and space” (SAHRC & UNICEF, 2014, p. 4). Cognizant of these different domains, this study was considerate of context with regard to the caregivers’ experience of their children’s deafness.

1.5. Immersion in Context

My sustained engagement and immersion in this context has been enhanced by linguistic factors where my conversational level isiZulu has been beneficial in my interactions in this region because siSwati is very similar to isiZulu, a topic which is further detailed later in the thesis, and so I am often able to interact with siSwati speaking people. Nonetheless, even though I may be able to engage in conversation with people in isiZulu, there was still the need to collaborate with a language and culture mediator to conduct the interviews to explore the deeper concepts involved in the caregivers’ experience. Some of the insights I have garnered from working and living in the community I have included in the analysis, together with the especially important insights and elucidations offered by the language and culture mediator who also conducted the interviews. Her insights and reflections added an extra dimension to the interpretation of the data since she lives in the community and offered a cultural and linguistic mediation to my interpretation of the data, thereby providing a bridge between the caregivers and the position of audiologist and researcher. Also, her role as a collaborator in the research is acknowledged from the outset and I recognise that she was more than just a translator and that she served a brokering and mediating role in terms of language and culture while providing insight into the context. As Temple and Young (2004, p. 171) argue, especially in their experience of working in the field of deafness, "the translator always makes her mark on the research, whether this is acknowledged or not, and in effect some kind of 'hybrid' role emerges in that, at the very least, the translator makes assumptions about meaning equivalence that make her an analyst and cultural broker as much as a translator."

This collaboration with the language and culture mediator was necessary and appropriate because I recognised the emic and etic factors inherent to this study. The emic position is one in which the observer shares an identity with the participants while the etic position is one in which the observer is outside of the participants' identity (Reagan, 2002). In other words, the emic position is one of the cultural insider while the etic position is one of the cultural outsider (Andrews et al., 2010). I acknowledge my etic position as a person of another race, language, culture, geographical area, occupation and background to the caregivers of deaf children in the Ehlanzeni District of Mpumalanga. Moreover, this etic position also applied to my not being a caregiver to a deaf child nor being deaf myself (Young & Hunt, 2011). Also, I recognise that my position as an audiologist adds another dimension to my etic position. Therefore, I engaged in reflexivity in this study, that is, the critical reflection of the self within the project (Lincoln, Lynham, & Guba, 2011) because it is accepted researchers produce an understanding of phenomena in "reference to their own understanding of concepts and debates filtered through their own experiences" (Temple & Young, 2004, p. 165). This reflexivity recognises that the researchers' personal backgrounds need to be acknowledged and recognised within the research process because "the disciplinary and broader sociocultural circumstances under which they work have a profound effect" (Davies, 2001, p. 5). Therefore, I had to reflect on my role and identity within the project, not in an egotistical way, or without becoming, as Davies puts it, self-absorbed (Davies, 2001), but rather in a way which recognises and acknowledges the influence of my background, history, and profession in relation to the project, because in qualitative studies, the researcher is involved in collecting data but also involved in the constructing of the meaning in the data (Lincoln et al., 2011).

Notwithstanding my etic position, I share an insight into people's experience around caregiving from my work as an audiologist, although that work cannot be equated to the participants' daily lived experience of being caregivers to deaf children. My collaboration with a language and culture mediator from the same setting as the participants was to encourage emic identification between her and the participants. Although she lives in the same context as the participants and thereby has an emic position with regard to culture, geographical area, language, and background, she does not share the experience of being a caregiver of a deaf child and, therefore, also occupies an etic position. Her simultaneous emic and etic positions together with my positions within the study were considered.

1.6. The Qualitative Turn

The human aspect, the human dimension of deafness needs to be explored too, not only the decibel levels, signal to noise ratios, percentages and logarithmic scales with which deafness may be studied. Therefore, there is a call for research to be more considerate of gender, language, race, ethnicity, belief systems, income, social class, and education (Esposito, 2001). Although it is acknowledged that some of the foundational work in audiology is based within the field of medicine (Knudsen et al., 2012), there is a recognition that this medical orientation tends to dominate and that the "the domain of orthodox biomedicine is asserted by medical practitioners in contrast to the world of everyday experience" (Atkinson & Gregory, 2008, p. 598). Therefore, within this study, there has been an engagement in a more personable and qualitative approach to the study of deafness, thereby shifting from the purely epidemiological and medical aspects of childhood deafness in the Ehlanzeni District of Mpumalanga to a more humanist one which is framed by the caregivers' context. The turn for qualitative research is necessary because I suggest that it offers a fuller and meaningful view of caregivers' experience.

I acknowledge that while conducting this study, there were times when medicalised and biomedical aspects had to be interrogated with the caregivers, for example, in relation to their children's acquisition of hearing aids or in relation to the caregivers' endeavours at the diagnosis of the deafness so as to give a broader and more contextually attuned account of the experience of being caregivers to deaf children in the Ehlanzeni District. Also, in order to maintain a more humanist orientation to this exploration of the caregivers' experience, through consultation with the language and culture mediator and because of my experience in the region, I tried to avoid assuming a magnanimous, superior, and paternalistic position in relation to the participants and instead tried to recognise the participants' strengths and contributions (Bloor, 2011). I felt it important to consider the personal, conceptual, and contextual aspects of deafness which contribute so much to the experience of deafness and the caregivers' lived experience around deafness because

> health care research was, and is still, dominated by medical research with an agenda of treatment and cure, using experimental clinical trials, rather than the more subjective, experiential agenda of qualitative inquiry. Medical researchers tend to focus on disease, rather than the person (Morse, 2011, p. 402).

Within qualitative research, it is accepted that the researcher's interpretation of the data is influenced by that researcher's personal, cultural and historical experiences (Creswell, 2009, p. 8) and so I attempted to use considerate terminology while exploring aspects of the caregivers' experience. Within this more qualitative orientation to exploring the caregivers' experience, the choice of terminology was consciously considered to explore aspects of 'deafness' rather than 'hearing impairment' and 'hearing loss' in order to shift the focus from a purely medical framework of study. Similarly, in this thesis I make reference to children having 'deafness' so as to include children who may have been born deaf and children who acquired deafness because the term 'hearing loss,' besides being medically loaded, could suggest that the thesis was referring to caregivers of children who had been able to hear and who then went deaf. Similarly, I considered the use of the words 'Deaf' and 'deaf' in describing the children of the caregivers in this study.

While conducting this study and engaging with participants and their deaf children, I recognised the way in which labels given to people "may convey information about them, and this raises questions about what information should and should not be included" (Hammersley, 2010, p. 557) and may influence the way in which people are understood. I, therefore, chose to use the lower case 'd' to refer to children who are deaf so that I could include people who are physiologically deaf and people who identify themselves as culturally Deaf since the deafness is the commonality between Deaf and deaf people. By choosing to refer to deafness I did not impose assumptions about people's Deafness identification. By using the word 'deaf,' I was able to explore aspects around caregivers' and other people's conceptualisation of deafness as disability which would not have been the case if I had only focussed on Deaf children. As I explain later in the thesis, I suggest that many contexts in South Africa do not offer deaf and Deaf people the opportunity to choose a Deaf identity because, for many people, their deafness can be disabling. These are contexts in which deaf people are not empowered or have minimal access to resources to foster a Deaf identity and they may face limited educational, vocational and economic opportunities (Ross, Störbeck, &

Wemmer, 2004). Related to the use of terminology, there has been a move to use person-first language in which the emphasis is on the person, not the disability (Folkins, 1992). Cognizant of this foregrounding of the children's personhood, in this thesis, I use the terms 'deaf children,' 'children who are deaf,' and 'children with deafness,' amongst others, interchangeably while remaining fully mindful that the children are not completely and wholly defined by their deafness but it is this feature of the children which I explored with the caregivers in this study. The children and their caregivers have other characteristics, traits, dimensions and personalities, all of which interplay with their deafness and I acknowledge their personhood and recognise them while exploring the caregivers' experience.

1.7. Chapter Outline of the Thesis

In order to understand the caregivers' experience, this thesis has been set out in various chapters to present the foundations to this study and the study itself with its results and discussion.

The foundational chapters offer the building blocks upon which this study was founded where this first chapter provides an overview of some of the concepts which formed the foundation of this study and which oriented the study. The second chapter explores the complexities of deafness and some of the arguments made with regard to the understanding and definition of deafness, including the disability versus difference considerations, especially within the South African context. In Chapter 3, influences with regard to the experience of deafness are presented so as to better illuminate the contextual considerations such as rurality, poverty, structure and how this context embodies itself in the experience of deafness. Chapter 4 provides insight into the caregivers in South Africa, especially those who are caregivers to children with deafness while accounting for the different present-day and historical influences on their role as caregivers as well as the different types and dimension of support which caregivers may need so as to address the challenges they experience and to empower them. Research in audiology is often described within quantitative research paradigms and can be geared towards understanding the specifics of hearing and deafness. Therefore, Chapter 5 proposes that qualitative research is also necessary with regard to understanding deafness and that the focus ought not remain only on the physiological and medical aspects of deafness and on people who are deaf but ought to include significant others, such as caregivers of deaf children as well as an exploration of context sensitive, experiential research.

The methodology chapter, Chapter 6, provides an overview of the factors which had to be considered while conducting this study relating to the logistical and practical aspects, but also, very importantly, the contextual and ethical considerations so that the study was respectful of people and the participants who agreed to be interviewed. The thematic analysis using the Framework is discussed and how the qualitative approach was appropriate for studying caregivers' experience while also providing information to offer the reader insight into the trustworthiness of the data and the interpretation of these data.

In the results chapter, Chapter 7, the participants' voice is preserved by providing examples of their verbatim reflections and the first of the two results chapters represents the three domains that relate to the contextual variables which seem paramount in the understanding of the caregiver experience while the second results chapter looks at the support and experience of that caregiver role as influenced by the variables identified in the earlier chapters of the thesis.

The discussion is presented in Chapter 8 and provides an elucidation and expansion of the results, especially in light of the context and how the context has mediated caregivers' experience in the Ehlanzeni District with regard to the different domains of their experience.

Chapter 9 offers a conclusion and looks at some of the implications that have been highlighted by this thesis so as to consider a more broadly encompassing interaction with deafness by audiologists, other hearing care personnel, and the particular formal and informal structures which were identified in this thesis.

1.8. Chapter Summary

This project is oriented towards exploring the dimension of deafness as it relates to the caregivers of deaf children's experience. It has looked at this aspect of childhood deafness from a qualitative perspective and one that recognises that the experience of deafness and around deafness can inhabit different dimensions and can be looked at from different angles which means that the experience of and around deafness ought not be studied one-dimensionally but ought to consider different domains of people's contexts and experience in order to more fully appreciate the human and the person who is the focus of attention while including the researcher's role in the reflection of that experience. The six foundational chapters before the results and discussion build the thesis and set are the grounding onto which the results of this study are founded. Therefore, in using Denzin and Lincoln's (2011) quilt maker analogy, throughout these chapters, I thread the foundational ideas of this thesis and acknowledge that similar concepts may recur in different chapters which is deliberate and appropriate. This threading demonstrates that their experience cannot be compartmentalised into discrete units and that these concepts interplay and are interconnected within the domains of the caregivers' experience.

Chapter 2: Deafness: Dimensions and Complexities

> "And when he sees me in all and he sees all in me,
>
> then I never leave him and he never leaves me."
>
> (*The Bhagavad Gita*, p. 34)

Figure 2.1. This view over one of the villages where the study was set represents the multiple dimensions and complexities of deafness in light of the communicative aspects represented by the telephone wire.

It also depicts plants which have developed particular characteristics to adapt to the specific environment, an adaptation similar to that which people who are deaf often have to do too within their context of limited resources. The complexity is further represented in the broader landscape captured in the background.

2.1. The Complexity of Deafness

In exploring and describing the experience of caregivers of deaf children in the Ehlanzeni District of Mpumalanga, it is necessary to provide a contextualisation of the intricacies of deafness because deafness occupies different discourses in relation to identity, language, and disability, amongst others. Discussions around deafness are complex because the description of people’s hearing levels is insufficient to describe the deafness because there are other interrelated variables. The reduction of deafness to a focus on the audiogram alone is problematic because that focus remains on the medical, biomedical, quantifiable aspects related to hearing levels and the measurement of hearing or the measurement of the absence of hearing rather than on the people who are deaf and, therefore, reinforce a deficit model by making reference to people in relation to a measurement of the deviation of hearing thresholds from the pre-established norm rather than to them as people. In audiological terms, there is the use of the audiogram, to measure how far or near to zero decibels people can hear. Within the biomedical perspective, this measurement and quantification of the deviation from the norm is used for the diagnoses of deafness and for the possible action which is deemed fit and appropriate for the people who are found to have deafness. Cognisance is taken that this medical model may place great emphasis on the quantifiable deafness and the person is seen as the deaf object, rather than looking at the person who has deafness. This objectification of the study of deafness is reportedly longstanding (Young & Hunt, 2011) and suggests that the subject and object positions differ within the medical and the non-medical points of view. Nonetheless, because, in matters related to deafness, so much hinges around the measureable and biological deafness these matters need to be set out in order to better understand the personal dimensions related to the physical deafness and in order to define deafness.

2.2. Touching on Aspects of Audiological Deafness

The focus of this study was the experience of caregivers of deaf children in the Ehlanzeni District with regard to various domains as they relate to permanent and severe deafness. Therefore, it is important to first, briefly, delineate the way deafness is described audiologically so as to then consider the other dimensions of deafness and to make these other dimensions more salient within the more dominant medical discourse. A very cursory overview of audiological concepts pertaining to deafness, primarily summarised and referenced from the established texts in audiology by Clark (2008), Martin and Clark (2009), and Stach (2010), will be touched upon and outlined in the following section so as to provide a background to the descriptors of deafness because a detailed description of physiological deafness and its audiological measurement is beyond the scope of this thesis since this thesis deals with the experiential dimensions of being caregivers to deaf children within their contexts rather than the description, or aetiology, or epidemiology of the children’s deafness.

Physiological deafness, from an audiological perspective, refers to an elevated threshold of hearing for sounds, including speech and is defined, in biomedically loaded terminology, as a “hearing sensitivity loss … characterised by a reduction in the sensitivity of the auditory mechanism so that sounds need to be of higher intensity than normal before they are perceived by the listener” (Stach, 2010, p. 101). Because of physiological deafness, sounds that would ordinarily be accessible to people, are not accessible to people who are deaf and this inaccessibility may result in communication difficulties where deaf people may experience difficulty hearing spoken language while people who speak to people who are deaf may have difficulty conveying their spoken message to them. Moreover, people who are deaf may not hear environmental sounds and warning sounds in their environments. In light of the variation in the degrees of physiological deafness, for the purposes of this study, I explored the experience of caregivers to children who were formally diagnosed as having permanent deafness to a degree that hearing aid amplification was considered, prescribed, or worn and for whom, with or without such amplification, speech at a conversational level and loud sounds cannot be heard.

Deafness can take various forms. The following description is a brief overview of the basic descriptions of deafness. People can present with permanent or transient deafness. Transient deafness is usually associated with temporary changes in the auditory system which may alter people's thresholds of hearing and may resolve itself on its own or may do so after some form of medical treatment. Often, these transient types of deafness tend to be conductive in nature because the deafness results from an obstruction in the conduction of sound through the outer and middle ears on the way to the inner ear. Other deafness may be permanent, and permanent deafness tends to be due to atypical functioning of the sensory and neural organs of hearing, in other words, sensorineural deafness. Children with permanent deafness do not usually get medical treatment but may, instead, if that option is available, get prescribed hearing amplification devices such as hearing aids or cochlear implants. Some caregivers choose for their deaf children not to wear hearing aids while some children's degree of deafness precludes the use of hearing aids. Most cases of permanent deafness tend to be sensorineural deafness although some conductive deafness may be permanent too. In relation to children's deafness, children can either be born with deafness, that is congenital deafness, or may acquire the deafness after birth, that is acquired deafness. Acquired deafness can be transient or permanent where the transient types of deafness tend to be conductive in nature while the permanent types of acquired deafness tend to be sensorineural. Deafness may also be unilateral, that is present in one ear only, or may be bilateral where both ears have deafness. Bilateral deafness may be symmetrical, in other words, the hearing thresholds as plotted on the audiogram are at similar levels in both ears whereas, in asymmetrical deafness, the thresholds are different in each ear.

In audiological terms, deafness tends to be measured in decibels (dB) which is then categorised into degrees of deafness in order to standardise the description of the deafness. More specifically, hearing levels that fall within the -10dB and 10dB level are considered to be within normal limits; those that fall within 11dB and 25dB level are considered to indicate a slight deafness; thresholds of hearing which fall between 26dB and 40dB are deemed to suggest a mild deafness; while thresholds between 41dB and 55dB suggest a moderate deafness and those ranging from 56dB to 70dB suggest a moderately severe deafness; thresholds between 71dB and 90dB suggest a severe deafness; and thresholds exceeding 90dB and extending to 120dB are classified as indicative of profound deafness (Stach, 2010). These thresholds, when plotted on the audiogram, can follow different configurations which can be associated with particular otological diagnoses and predicted auditory abilities.

Audiological assessment is the method by which people's hearing levels are measured. Psycho-acoustic measurements are recorded for people's hearing of different sounds which can include pure tones and speech and which are recorded on an audiogram, a graphical representation on an x-axis and y-axis of the hearing levels, in decibels, in response to pure tone signals presented at different frequencies, in Hertz (Hz), ranging from 250Hz to, usually, 8000Hz, although higher frequencies may also be assessed. The threshold of hearing at different frequencies is plotted on the audiogram and is interpreted in terms of the laterality, symmetry, degree, configuration, and type of deafness. These descriptors are used to classify the deafness and this information is used to decide on the course of action around the diagnosis of the deafness. Other measures of auditory function include, amongst a myriad of others, the use of tympanometry to assess the middle ear status; otoacoustic emission (OAE) measures to check cochlear stereocilia function; electrophysiological measures such as the auditory brainstem response (ABR) to assess the integrity of the auditory pathway to the level of the brainstem; the auditory steady state response (ASSR) to estimate the threshold of hearing based on central measures in response to sound, and other electrophysiological measures such as the mid-latency response (MLR) and late-latency response (LLR) which assess the auditory integrity of the central system. Audiologists have a collection of different instruments and measures of hearing which are beyond the scope of this discussion, suffice to say that the assessment of hearing has changed dramatically and that hearing can be assessed without people's active participation in the assessments. The electrophysiological measures of hearing are often conducted while people are asleep and, especially in children, may even be medically sedated in order to avoid muscular movements from obscuring the very sensitive measurements.

Although these descriptors of the degree of deafness established through different assessment methods are used to extrapolate people's ability to hear, they do not always adequately reflect people's ability to hear because some people hear functionally better than their audiograms would suggest while others hear functionally worse than their audiograms would suggest (Brett, 2003). People who have the same laterality, symmetry, degree, configuration, and type of deafness, may not have the same experience of deafness which is a reminder that the focus of audiological interactions ought to be people rather than focussing only on the audiological results. The audiological results do not define people; they are reflections of the physiological response to sounds and the assessments. They "only provide a very limited description of the consequences of hearing loss and … the effects vary from individual to individual and can vary widely over time in a given individual" (Danermark et al., 2010, p. 257).

There is a need to interpret deafness differently between children and adults. What is considered a level of deafness with disabling effects is different for adults and for children because, for children, who communicate via spoken language, to develop that spoken language, they need to hear all the aspects of speech and language which they may miss even when there is only a slight deafness. Although slight and mild deafness have significant effects on acquiring spoken language, for this thesis, the focus is on children who have more marked deafness since their deafness requires considerable alterations in communication with hearing people. For example, children with a severe deafness cannot hear spoken language without hearing amplification, and even when wearing hearing amplification, because of the degree of deafness, they may not be able to understand spoken communication as they may have difficulties discriminating between the different speech sounds and may miss some of the less acoustically intense sounds in speech.

Hearing amplification devices, such as hearing aids or cochlear implants, may be suggested for people who present with deafness in an attempt to amplify sounds so that they are made audible to the people who are deaf and wear such hearing amplification devices. Hearing aids tend to be removable devices worn on and in the ear and provide sufficient amplification so that the people wearing them may hear sounds which they may otherwise not have heard because of their deafness. Hearing aids amplify sound and this amplified sound is directed into the outer ear so that it can be received at a higher intensity by the cochlea which then perceives the amplified sound in the stereocilia of the cochlea whereupon these stereocilia send a neural response up to the brain along the cochlear nerve. Cochlear implants, on the other hand are implantable devices which transmit sound via a microphone on a removable sound processor of the cochlear implant worn on the skull to an electrical coil which has been surgically implanted into the skull, specifically in the cochlear in the temporal bone of the skull. Hearing aids cannot be seen as a panacea for physiological deafness and, despite the medical audiology advances, these advances in science and technology may not guarantee that people who receive these advanced devices necessarily all benefit in the same way from them. There are limitations to the amplification provided by the hearing aids. Some of the limitations are associated with personal characteristics such as the perceived benefit of the amplification devices, audiological characteristics such as the degree of the deafness, physiological characteristics of the auditory system such as the residual hearing in the cochlea or the structural integrity of the auditory system while other limitations are centred around the limitations of the aid itself, which is a technical device looking to provide amplification to a biological, and more importantly, a human system and so there may be a mismatch between the technical and the human interfaces of hearing, and of deafness.

For deaf children for whom hearing aid amplification options are explored, the costs associated with regard to the hearing amplification devices need to be considered too because the high costs associated with hearing amplification devices may preclude some children from being able to access them. It is estimated that hearing aids can cost over US$200.00 or approximately ZAR2000.00 each in developing countries (Brouillette, 2008) while cochlear implants can cost approximately US$30 000.00 or close to ZAR400 000.00 while also considering the additional cost of radiological investigations, consultations with ear, nose and throat surgeons, surgery and hospitalisation (Kerr, Tuomi, & Müller, 2012) in a country where 20% of the population lives on less than ZAR500 per month (Statistics South Africa, 2015). There are reports of attempts at introducing more affordable hearing aids and McPherson (2011) provides a detailed description of different technological options which are being explored to provide access to affordable hearing aid devices within developing contexts. Because cochlear implants are relatively more expensive than hearing aids, fewer people may have access to them and government services may only be able to subsidise a few of implants compared to hearing aids.

There are also running costs related to the amplification devices in the form of batteries to power the devices (McPherson, 2011) which can cost close to US$40 or ZAR400.00 per year for hearing aid batteries (Brouillette, 2008) or around US$200.00 or about ZAR2000.00 for cochlear implant batteries (Kerr et al., 2012), notwithstanding the repair, maintenance and replacement costs of the devices, new earmould costs, and the costs of the consultations with the deafness personnel. The South African Department of Health, in terms of Article 90 (I)(L) of the National Health Act, 2003 (Act 61 of 2003), covers the cost of the hearing amplification devices at state hospitals for people who cannot afford them, provided they can present a form of identification such as a South African identity document or birth certificate (The National Department of Health, n.d). Therefore, there appears to be some financial assistance from the state for people who may struggle to pay for audiological services. However, in a context of limited resources, when caregivers already face economic and financial challenges, they seem to encounter even more challenges because the hearing amplification devices are not items which incur once-off costs; the costs are recurring and there are related costs, such as the travelling costs and caregivers' time off work if they are employed.

2.3. Communication Considerations for Deaf Children

Because people who are deaf have elevated audiological thresholds and they cannot hear sounds at similar levels to people who do not have deafness, there are particular considerations with regard to communication which arise from their deafness which ought to be considered. Children who are deaf may experience challenges in communicating with other people because of their elevated hearing thresholds or because of a different mode of communication in the form of sign language which could have a disabling effect on the participation in communication which, it is argued, may have effects on children's independence, self-esteem, and social relationships (Simeonsson, 2003, p. s7). Decisions about the deaf children's modes of communication may result from their caregivers' choice of a particular mode of communication for their children when the deafness is diagnosed.

However, it may result from the caregivers being informed about the most accessible mode of communication available to them and their children and they, therefore, do not have the choice of communication mode for their children. Additionally, the use of sign language by caregivers is gendered and the caregivers' comfort and acceptance of sign language may influence their use of it. It has been shown that fathers are less likely to learn sign language than mothers which suggests that female caregivers have extra responsibilities and caregiver burden (Meadow-Orlans & Sass-Lehrer, 1995). Hereafter follows a brief description of the main communication modes used in the teaching of language to deaf children, especially within the South African context where "language choices have far less to do historically with meaningful choice than they have to do with the politics of economics and access" (Reagan, Penn, & Ogilvy, 2006, p. 201).

2.3.1. Spoken language.

Spoken language options include the auditory-verbal approach and the auditory-oral approach. Within the auditory-verbal approach, prominence is given to learning language only through hearing spoken language and no reliance is placed on visual cues, only on amplification provided by hearing aids or cochlear implants and there is total immersion within hearing and mainstream contexts (Gravel & O'Gara, 2003) while the auditory-oral approach is the same as the auditory-verbal approach except that this approach allows for the use of visual cues such as lip-reading for the child to learn spoken language (Gravel & O'Gara, 2003).

2.3.2. Spoken language and visual cues.

Cued speech is a method of learning spoken language by cueing the listener to the spoken sounds by using "eight different handshapes and four different hand locations around the speaker's face" (Gravel & O'Gara, 2003, p. 245) which are supplemented by lipreading and listening (Gravel & O'Gara, 2003).

2.3.3. Spoken language and signs.

Total communication is reportedly a combination of spoken and signed communication options where the child learns language and communicates through manual, oral, and auditory means. Amplification and hearing is still included in the communication, but the auditory component is supplemented by the use of manual communication (Gravel & O'Gara, 2003). Sim-com or simultaneous communication is a combination of speech, a sign system, and finger spelling and, unlike total communication, does not require use of audition (Gravel & O'Gara, 2003).

2.3.4. Sign language.

Sign language is considered a complete visual language which uses a completely different structure to spoken language. This visual component includes signs, body language, facial expression, and movement. There is no reliance on hearing and amplification in the form of hearing aids or cochlear implants for communication but only for alerting, warning, and awareness of environmental sounds (Gravel & O'Gara, 2003, p. 246). Sign languages vary from region to region (Penn, 1993; Temple & Young, 2004) and, therefore, it is necessary to dedicate a section to discuss the particular character of South African Sign Language (SASL) hereafter.

2.3.5. South African Sign Language (SASL).

Specifically for Deaf people, use of Sign Language is a hallmark of their identification with Deaf culture and ethnicity while people who are deaf may use hearing amplification devices and spoken language or spoken and signed language. Therefore, especially with regard to Sign Language, there is the recognition of the interplay of different contextual factors in its use because “language is not a neutral topic. As a repository of cultural knowledge and symbol of social identity, it has been and continues to be a charged and embattled area linked closely to social, political and educational issues” (Penn, 1993, p. 11).

It is proposed that “Sign language is the natural language of the Deaf community” (Penn, 1993, p. 11) and the current status and use of SASL in South Africa is influenced by its history. It has struggled to assert its position because it has been confused with gesture or pantomime, it was thought to be less grammatical than spoken language, it was considered iconic and universal across spoken languages, and it was assumed that the grammar of SASL is derived from spoken language (Penn, 1993; Reagan, 2007). Within South Africa’s history of racial segregation during apartheid, the teaching of SASL was also racialized where white children were taught using an oral approach while black children were taught manual communication known as the Paget-Gorman system (Penn, 1993), a system of 37 hand signs and 21 hand postures based on English (Störbeck & Martin, 2010). The racial divisions in this use of SASL, it is argued, were economically and politically based because “oral education involves relatively expensive hearing aids and intensive, on-going speech and language therapy to be effective. Such resources, while available for white children, were not generally made available to others” (Reagan et al., 2006, p. 191) and because the education for deaf black children was only geared towards technical aspects (Penn, 1993). Teachers themselves may have had limited abilities to use SASL which resulted in the deaf children only being taught up to the level at which their teachers could communicate with them (Parkin, 2010, p. 491). The government’s enforcement of an oral approach for white deaf children “sometimes has had a disastrous effect on overall scholastic and vocational goals”

(Penn, 1993) because they could not learn in and from spoken language. For black deaf children, because of the government's enforcement of signed language use, there were few vocational opportunities when they left school and "many of the Deaf people who were seen did not have meaningful or good jobs, and they did 'arts and crafts,' which frequently did not provide enough income to improve their standard of living" (Rasebopye, 2010, p. 508). Therefore, it seems that the language options for deaf people in South Africa have not been optimal and children were learning variations of signed languages from friends (Penn, 1993) only when they started attending school, "mostly as a playground variant through contact with (slightly older) peers" (Van Herreweghe & Vermeerbergen, 2010, p. 126).

For a long time SASL was considered inferior and "as a result of communication barriers, uneven power relations, and the suppression of signing, both the notion and the act of signing became highly stigmatized for many Deaf South Africans" (Van Herreweghe & Vermeerbergen, 2010, p. 138). Only in the late nineteen eighties were steps taken to study the shared sign languages across South Africa which led to the establishment of SASL with its own Dictionary of Southern African Signs (Penn, 1993; Reagan et al., 2006) and it is now the primary language of many Deaf people in South Africa (Reagan et al., 2006) and there have been calls to recognise SASL as an official language (Magongwa, 2010). Although it is not an official language in South Africa, in the constitution's recognition of the country's eleven official languages, namely, Sepedi, Sesotho, Setswana, siSwati, Tshivenda, Xitsonga, Afrikaans, English, isiNdebele, isiXhosa and isiZulu, it also makes provision for the Pan South African Language Board to promote and develop SASL (Constitution of the Republic of South Africa, 1996) and it has recently been recognised as an additional language for teaching at schools (Department of Basic Education, 2013a). This multilingualism has created a complex and typically South African situation where, in the context of 11 official languages, deaf people who speechread are expected to do so in various spoken languages and code mixing may occur (Van Herreweghe & Vermeerbergen, 2010).

Even in contemporary South Africa, despite the advancement of SASL, there appear to be differences between policy and practice with, despite its status in the constitution, only 84 SASL interpreters officially registered in South Africa, 9 of whom were in Mpumalanga (DeafSA, 2011). Another example of the inconsistency in interpreting is the debacle around Tamsanqa Jantjie, the person who served as the interpreter at the late President Nelson Mandela's memorial. It transpired that he was a fake interpreter at the event which was broadcast across the world and where he incorrectly interpreted spoken language into fictitious sign language. He is reported to have acknowledged, after the fact, that his poor interpreting is reflective of the problems in the interpreting system in South Africa when he said, "Even if they call me a fake, I am the great fake because I expose what is going on in the government and the system" (SAPA, 2013b, n.p.). This poor provision of interpreting services raised serious questions about the limited interpreting services and the poor regulation of these services which could result in people getting incorrect information from interpreters who are not up to the necessary standards. It is reported that the Pan South Africa Language Board lodged a complaint about this interpreting service and used the opportunity to press the South African government to ensure that laws were enacted "to ensure language facilitation services were regulated, and that whoever rendered the service was competent" (SAPA, 2013a, n.p.). This incident reflects the inconsistency and the irregularity of the interpreting services in South Africa and the incongruence between people's needs and the service provided as well as the weak infrastructure to support for deafness and to promote a Deaf identity.

2.4. What's In a Name? Being deaf and Being Deaf

When writing about deafness, people may be referred to as Deaf with an upper case 'D' or 'deaf' with an lower case 'd' and these terms ought not to be interchangeable as they refer to different concepts. The use of the lower case 'deaf' refers to people who may have audiological deafness as described by their audiometric results (Penn, 1993; Ross et al., 2004) and their measurable deafness. They tend to use hearing aids to support their use of spoken language (Young & Hunt, 2011). It is postulated that most deaf people are not members of the Deaf community because they tend to use spoken language rather than Sign Language and are acculturated to a hearing society (Reagan et al., 2006). The upper case 'Deaf' refers to the cultural and social categorisation of people who identify with Deaf culture. The use of the upper case 'D' suggests that Deaf people do not consider themselves as disabled; instead they consider themselves as part of a minority grouping (Woodill, 1994) whose members share similar beliefs (M. A. Jones, 2002) and a "naturally occurring human identity … manifest through … norms of behaviours, cultural perspective, conventions and shared histories" (Young & Hunt, 2011, p. 2). The identity of being Deaf and the experience of being deaf and Deaf seems to transcend other identities, such as ethnicity, because "common experiences seem to have shaped their Deaf identity, in the sense that alienation from hearing people has led to solidarity among Deaf people (even from different ethnicities)" (Van Herreweghe & Vermeerbergen, 2010, p. 141). Therefore, because Deafness is a cultural identity rather than an audiological one, the cultural identification as Deaf is not restricted to people who are deaf and includes people who belong to the cultural grouping, regardless of their hearing levels and may include hearing spouses, family members and children of people who are Deaf because "hearing status is not the fundamental defining feature of what it is to be Deaf" (Young & Hunt, 2011, p. 1) and may include hearing family and friends of people who are Deaf. Deaf people tend to see their social and cultural identification with other Deaf people as the overriding consideration in their identity as Deaf and do not tend to see their deafness as a disability, but rather as a cultural difference. Therefore, there seems to be some tension between the medicalised outlook on deafness which also interacts with the notion of disability arising from the deafness and the cultural interpretation of Deafness.

2.5. The Medical Voice Has Been the Loudest

The language used when discussing deafness directs the way in which people may think about deafness and it is this medicalised voice which has been the loudest in the discussions around deafness. If deafness is discussed predominantly within purely medical terms, then it remains a medicalised phenomenon "through ideas, language, institutional behaviour, rituals, social relations and practices" (Munford, 1994, p. 270) in which "hearing society 'does' things to Deaf society … (and) … it is hearing culture that negotiates and filters the meaning of Deaf people's lives" (Temple & Young, 2004, p. 169). Because the diagnosis of deafness tends to occur within medical settings, it may perpetuate that medical paradigm (Woodill, 1994) and suggests that the person who is deaf is at risk of "being seen as the object of medical treatment (and) evokes the image of many ascribed traits, such as weakness, helplessness, dependency, regressiveness, abnormality of appearance and depreciation of every mode of physical and mental functioning" (Zola cited in Woodill, 1994, p. 214) and that "the individual who is deaf must learn to function as a member of a family and a community, in which deafness is a pathology in order to belong" (M. A. Jones, 2002, p. 52). Also, the medicalised discourse is criticised because it is said to "manufacture needs that have little relationship to the real needs of their clients … (and) … that professionals have built up a service industry that meets the professional need for career advancement rather than meeting the needs of their clients" (Munford, 1994, p. 275).

The power that the medical discourse exerts over other discourses in the field of deafness is reinforced by the structures which have assumed dominance. An example of this structural dominance is the World Health Organisation (WHO) which steers discussions around deafness in a medical direction and it is this organisation which appears to hold the hegemony in classifying and reporting on deafness in the world. The WHO, under the mandate of the United Nations (UN), seems to hold a position of power over deafness in its classification of different types and aetiologies of deafness as diseases and disorders of the ear in its International Classification of Disability (ICD) codes (WHO, 2010). In its reporting on the statistics around deafness, the human dimension may not be wholly reflected in those numbers and there is the need to infer a socio-economic link of the statistics and childhood deafness. For example, the WHO reports that there are an estimated 32 million children in the world who present with significant deafness (WHO, 2013a) and, relatedly, the prevalence of childhood deafness is the highest in South Asia, Asia Pacific and Sub-Saharan Africa (WHO, 2012, p. 2) where Sub-Saharan Africa is reported to have 6.8 million children whose deafness is considered disabling compared to the 0.8 million children in the high income countries group (WHO, 2012, p. 8). It also reports that the number of children who are deaf is greatest in the countries with the lowest gross national income per capita (GNI) (WHO, 2012, p. 13) and reports on the inverse relationship between caregivers’ literacy and children’s deafness in that the number of children who are deaf is greater in countries where caregivers have lower levels of literacy (WHO, 2013b, p. 7). It is reported that the most common aetiologies of childhood deafness appear to be predominantly sensorineural and permanent in nature and include: maternal infections such as rubella, other infections such as meningitis, measles and mumps, severe jaundice following birth, birth anoxia, chronic ear infections, use of ototoxic medicines, low birth weight, and noise (WHO, 2013b, p. 7). Worldwide, it is reported that “current production of hearing aids meets less than 10% of global need. In developing countries, fewer than one out of 40 people who need a hearing aid have one. The lack of availability of services for fitting and maintaining hearing aids, and the lack of batteries are also barriers in many low-income settings" (WHO, 2013a) for deaf people who may want hearing aids or who may want to communicate via spoken language.

Even the Health Professions' Council of South Africa (HPCSA) makes reference to the costs of deafness and deaf people's contribution to the economy rather than foregrounding their humanity when referring to the need "to ensure optimum, cost effective solutions that enable persons to communicate effectively, allowing them to develop to their maximum potential, and thereby to secure their full participation in, and contribution to, society and the country's economy" (Professional Board for Speech Language and Hearing Professions, 2007, p. 2). A further example of the depersonalisation of deafness within the medical dominance is the attempt at quantifying the effect of deafness in terms of years lost to disability (YLD) attributed to deafness between developed and developing countries. The YLD can be described as "years of 'healthy' life lost by virtue of being in states of poor health or disability" (WHO, 2008, p. 3). It is reported that there are 232 million YLDs to deafness in developing countries while there are 4.2 million YLDs in developed countries (WHO, 2008). More specifically, Africa has the highest number of YLDs and the greatest burden of disease when compared to other regions e.g. Europe, Americas, and South East Asia. Generally, there appears to be an age effect with regard to the burden of disease and it is reported that children up to the age of four contribute 31% to the burden of disease in low and middle income countries (WHO, 2008) whereas it is reported that the same age group only contributes 5% towards the burden of disease in high income countries (WHO, 2008).

However, this description appears very negatively loaded, thereby reducing people to economic indicators. It also reinforces the purely economic and structural considerations when referring to deafness over the human and experiential considerations. This quantification seems to imply “that the healthier the person, the more valuable their life is to themself (sic) and to society” (Arneson & Nord, 1999, p. 1425). Although it is understandable that statistics and economic considerations need to be taken into account for the planning around deafness, education for deaf children, and support services, amongst others, this focus is reductionist because it is directed at loss rather than the whole human experience of deafness. Moreover, “a valuation of human beings according to their functional capacity is in sharp contrast to the humanistic values laid down in the Declaration of Human Rights” (Arneson & Nord, 1999, p. 1425). The reader of these figures is expected to extrapolate the susceptibility of this age group to disability and the effect that childhood disability has on the community at large because an adult who is to care for a disabled child may not easily be engaged in paid employment which may perpetuate the cycle of poverty.

2.6. Understanding Deafness within a Developing Context

It seems as though an understanding and interpretation of deafness needs to be done within an interrogation and consideration of the context in which the deafness is experienced. It seems as though the removal of an interrogation of the influence of context from the experience renders the exploration of the experience devoid of meaning. The aforementioned statistics and units of measurement, although medically loaded, point to the links between contextual variables and deafness and how, in a cascading effect, the caregivers’ context filters and features in their children’s deafness. This recognition of the contextual variables has spurred the call for a humanitarian approach to the provision of audiology services in developing settings which are characterised by “a greater rural population, are less ethnically homogenous, are more linguistically diverse and have greater inequality” where the “costs generally associated with diagnostic and rehabilitative audiological services may be a barrier to all but the most privileged individuals in developing countries” (McPherson, 2008, p. 5).

Without suppressing or ignoring the medical voice in the discussions around deafness, there is the need to consider other voices in the understanding of the complex phenomenon of deafness and for those voices to be heard from all players because, "despite these challenges, the children with hearing loss who happen to reside in Africa deserve the chance to develop according to their potential as much as their peers living in more affluent regions" (Swanepoel & Störbeck, 2008, p. S2), especially because it has been reported that people who are deaf in developing contexts are more vulnerable to poverty (McPherson, 2011). It, therefore, appears necessary to account for factors such as, amongst others, people's access to education, their general health status, rurality, and political situation of the context in which deafness is experienced (McPherson, 2008).

2.7. Complexities Surrounding Deafness and Disability

Deafness is complex because it encompasses biological, cultural, linguistic, and other dimensions; it is not only a physiological descriptor. This complexity is reflected in the words used to describe it. Within a medical perspective and one which focuses attention on the medical aspects of disability the World Health Organisation had initially distinguished between impairment, disability and handicap where the word "impairment" referred to "any loss or abnormality of psychological or anatomical structure or function" (Barnes, Mercer, & Shakespeare, 1999, p. 22) such as a loss of hearing. "Disability" was described as a consequence of "impairment" since it refers to "any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being" (Barnes et al., 1999, p. 23), for example, a child with deafness having restricted access to hearing all spoken language at school due to the physical reduction in hearing thresholds. "Handicap" referred to "a disadvantage for a given individual, resulting from an impairment or disability that limits or prevents the fulfilment of a role" such as the disadvantage which persons with deafness have in accessing employment. The terminology in this earlier classification is problematic since it appears to benchmark people around normality as in the use of the phrase “normal for a human being” (Barnes et al., 1999, p. 23) and suggests that persons with deafness are abnormal. This classification system focussed on what people cannot do versus what people can do. Additionally, there was “an expectation that people with disabilities would subject themselves passively and willingly to professionals” (Goode, 2007, p. 35), a perspective which is not respectful of the dignity of people who are deaf. Besides being negatively loaded, they may also be incorrect where, for example, referring to a baby who is born deaf as having a ‘hearing loss’ would suggest the loss of hearing which had existed before. However, they did not ‘lose’ their hearing; they were born not hearing. Similarly, there is the use of negatively loaded words to refer to the experience of the deafness too within the medical model by, for example, referring to “the infants who suffer hearing loss in South Africa” (Professional Board for Speech Language and Hearing Professions, 2007, p. 33) and “the excessive burden on caregivers” (Professional Board for Speech Language and Hearing Professions, 2007, p. 7).

In response to this medically dominant stance, the WHO formulated the International Classification of Function, Disability and Health (ICF) so that it could, as the guide puts it, move “from emphasizing people’s disabilities (and) … now focus on their level of health” (WHO, 2002a, p. 3) and that it “offers an international, scientific tool for the paradigm shift from the purely medical model to an integrated biopsychosocial model of human functioning and disability” (WHO, 2002a, p. 19) which “views disability as a feature of the person, directly caused by disease, trauma or other health condition, which requires medical care provided in the form of individual treatment by professionals” (WHO, 2002a, p. 8). Therefore, it seems to be more sensitive to contextual factors but remains embedded within a medical paradigm despite the reminder that

> understanding socio-cultural models of disability is of more than academic interest. Unless programmes for individuals with disabilities are designed in a culturally appropriate way, the opportunity to make real and effective change is lost…Being aware of the weaknesses (and strengths) of the surrounding community enables rehabilitation professionals to work far more effectively with and advocate in partnership with those whom they serve (Groce cited in Saloojee, 2006, p. 25).

It has been suggested that disability is a social construct which has implications for people's participation in society (Barnes, 2000) and that it may be "a form of social oppression, the appropriate response to which is one of civil rights rather than medical or social care" (Goode, 2007, p. 35). More specifically, disability is considered to be a "socially created problem and not at all an attribute of an individual … (which) … demands a political response, since the problem is created by an unaccommodating physical environment brought about by attitudes and other features of the social environment" (WHO, 2002a, p. 9) and that society is disabling (Young & Hunt, 2011). However, within this purely social model, I should suggest that it detracts from deaf people's agency because it attributes all limitations to their participation to contextual factors and does not empower deaf people to actively engage and participate in activities within the broader, albeit hearing, society. The ICF, therefore, suggests that each model on its own has limitations and therefore proposes that (WHO, 2002a, p. 9):

> disability is a complex phenomena (sic) that is both a problem at the level of a person's body, and a complex and primarily social phenomena. Disability is always an interaction between features of the person and features of the overall context in which the person lives, but some aspects of disability are almost entirely internal to the person, while another aspect is almost entirely external. In other words, both medical and social responses are appropriate to the problems associated with

> disability; we cannot wholly reject either kind of intervention. A better model of disability, in short, is one that synthesizes what is true in the medical and social models, without making the mistake each makes in reducing the whole, complex notion of disability to one of its aspects. This more useful model of disability might be called the biopsychosocial model. ICF is based on this model, an integration of medical and social. ICF provides, by this synthesis, a coherent view of different perspectives of health: biological, individual and social.

Within this view, it appears as though disability itself is not considered problematic but that the interactions may be problematic because of a mismatch in the level of participation and the activity. More specifically, the role of people's contexts is accentuated within the ICF model because people's environments and factors within their environments are recognised as being able to (Department of Social Development, Department of Women Children and People with Disabilities, & UNICEF, 2012, p. 21)

> assist or facilitate participation (facilitators) or they may limit or prevent such participation (barriers). Contextual factors may be internal, personal characteristics, such as coping styles, which can influence the extent to which a child participates in society. They may also be external factors, relating to physical and information access, as well as to policies, service delivery systems and institutional arrangements. Knowledge and attitudes are also environmental factors that have a significant impact on service provision and levels of participation.

2.8. Deafness in South Africa: Difference or Disability?

The issue of deafness as 'difference' or as 'disability' is highly contentious and the experience of deafness will differ from context to context and that the experience is not the same for all people (Corker, 1998). Barnes (2000, p. 77), in his argument for the social understanding of disability, concedes that the discussion around disability often covers “the same ground” and encourages a different way of thinking about pre-established categories and this point is especially true with regard to deafness and it appears necessary to cover the same ground but looking at the ground differently, especially in the South African context. Deafness, especially, has “posed challenges to our thinking about disability, particularly in relation to how disability should be defined” (Corker, 1998, p. 6). Historically, the trend has been to describe deafness as disability and to analyse it in terms of a pathology model, that is, to “medicalize” deafness (Penn, 1993, p. 22) and some deaf people may not ascribe to the identification as disabled, but rather as members of a different cultural and linguistic group (Ross et al., 2004). The ‘disability’ perspective says that people who are deaf have audiological thresholds which impact on their ability to engage fully within their contexts. Within this perspective, even if deaf people want or intend to use spoken language, without hearing amplification devices, they cannot physically access the sounds to learn or use the spoken variation of the language and, therefore, within this perspective, deaf people are considered disabled and not part of a different language group or minority culture. On the other hand, the ‘difference’ position is one in which Deafness is recognised as a different cultural grouping and would, therefore, imply that Deaf or deaf people who use Sign Language in settings where Sign Language is routinely used would not be considered disabled because there would no limitation on their activity and participation and it is argued that “to function in predominantly hearing society, Deaf people make enormous adaptations to be understood and to understand” (Temple & Young, 2004, p. 169), especially in South Africa where “significant barriers to communication may exist between members of the Deaf community and members of mainstream hearing society” (Van Herreweghe & Vermeerbergen, 2010, p. 126).

As referred to earlier, the context in which deafness is experienced informs that experience. The South African context with its linguistic, sociological, philosophical, historical, and educational particularities, offers a third perspective on deafness shaped by a socio-economic framework because, in this context, when discussing the ‘difference’ versus ‘disability’ stances, “the choice is in fact driven not by belief or ideology, but rather by poverty and economic constraints” (Reagan et al., 2006, p. 190). Because of the social dimension of communication (Simeonsson, 2003), differences in communication modes may contribute to an exclusion of people who are deaf from societal interactions and this exclusion is amplified because of “shame, stigma, or cultural standards” (Department of Social Development et al., 2012, p. 27). This exclusion was worsened by the segregationist policies of apartheid where people were “separated from their communities and excluded from participating in society” (Department of Social Development et al., 2012, p. 20). Deaf people were caught in a system of segregation within a larger system of segregation where schools for deaf children “were divided into European and non-European” (Penn, 1993, p. 18) and black, deaf children only had access to schools in demarcated areas for black people (Störbeck & Martin, 2010) which “were far away and mostly did not reach high levels of education” (Rasebopye, 2010, p. 508). At school, they were only taught to standard 6 or grade 8 in academic subjects and thereafter, if they continued in school, were only taught technical skills (Penn, 1993) which did not necessarily prepare deaf people for the employment sector. In South Africa, it is reported that up to 70% of deaf people may be unemployed (Ross et al., 2004) and that deaf people may have to work in lower grades of employment than hearing peers (WHO, 2013a), especially because of a limited infrastructure for many deaf people (Kiyaga & Moores, 2003). Therefore, there are “contextual factors which might either exacerbate or reduce disability” (Danermark et al., 2010, p. 257) which, in relation to deafness, may influence the experience of deafness as ‘difference’ or as ‘disability.’

Therefore, in South Africa, this debate may need to be re-evaluated in this context since, as Corker (1998) explains, the dominant culture tends to be “phonocentric” (p. 55), that is, the dominant culture tends towards oral language (Dirksen & Bauman, 2004), and because the context imposes economic, communicative and societal barriers, amongst others, without the necessary structural support for people who are deaf. The philosophical debate about whether deafness ought to be considered a disability or a difference, although an important, and ultimately, necessary one, may not fit the South African context at this juncture. By no means is it implying that the issue is not pertinent, debatable, plausible or tenable; instead, the argument is that it may not be the priority for the majority of deaf people in South Africa at this time.

Consequently, because of the aforementioned points, in the broader South African context, I propose that deafness may be considered a disability rather than a difference at this point and time in South Africa, especially as in the context where this study was conducted, deafness can be disabling. This stance may be perceived as removing deaf people’s agency and power by reinforcing the disabled label and the need to uplift disabled people. However, that is not the case. On the contrary, this stance may be useful to highlight the need for more enabling contexts for Deaf and deaf people so as to make the environments less disabling, thereby fostering opportunities for deaf people to participate more fully in society than presently. The structural context does not enable agency to fully practice a Deaf culture because of the dominance of spoken language and because of the insufficient structural support and resources such as schooling, interpreters, finance, amongst others. There appears to be a more immediate need to address tactically structural and contextual aspects of and around deafness which place it in the disability category while building a long term strategic plan which could comprehensively foster political power to achieve the desired contextual and environmental changes, thereby empowering deaf people. I suggest that in South Africa, in line with the third perspective on deafness discussed earlier which considers economic constraints (Reagan et al., 2006), and in recognising the variation in the experience of deafness within different contexts (Corker, 1998), that the ‘difference’ and ‘disability’ positions are fluid and context bound. Therefore, for deaf people who did not have access to services and those who still do not have such access, it appears as though, within the broader South African context, deafness may be disabling except in small pockets where Deaf people can, without interpreters, fully express themselves in their language.

2.9. (Deaf)inition of Deafness: A Proposal

Therefore, in this thesis, I propose a contextually mediated definition of childhood deafness in South Africa because, deafness, in the physiological sense, refers to the elevated audiological thresholds of the mechanism of hearing but this deafness can be disabling for deaf children when their geo-eco-socio-edu-culturo-historical contexts and structures do not facilitate communication with hearing and with deaf people through the acquisition and use of spoken language, of signed language, or of both. I contend that often these thresholds are not equated to functional hearing abilities as these factors contribute to the deafness as summarised in Figure 2.2.

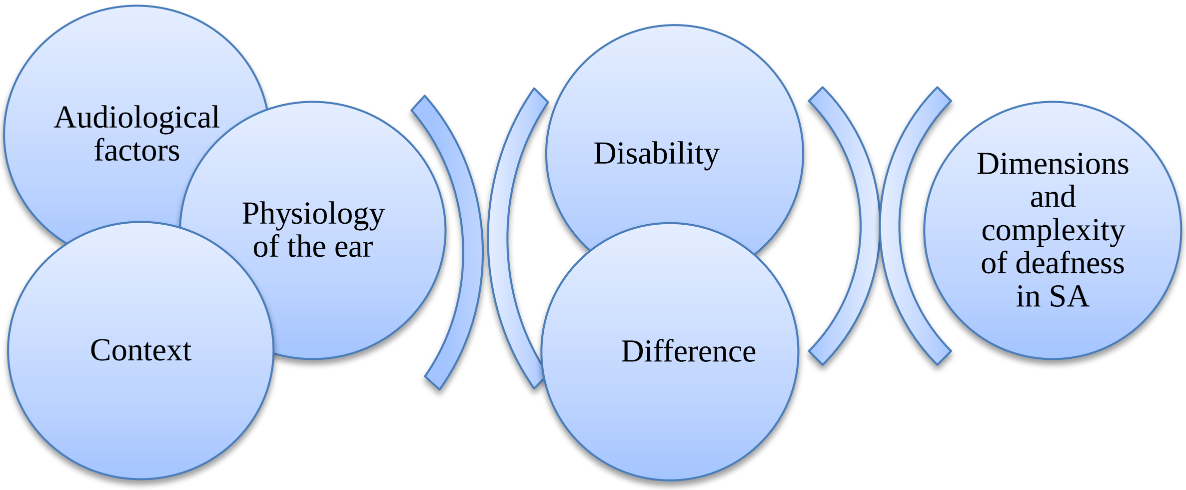


Figure 2.2. The interplay of different dimensions of deafness.

Within this contextually mediated definition of deafness, there is acknowledgement of Deaf culture but only within specific and delineated contexts which accommodate SASL and Deaf identity and the proposed empowerment offered by a language and culture specifically for Deaf people is not afforded to everyone equally in South Africa and so deafness becomes disabling in this context. This definition proposes the avoidance of negatively loaded and possibly incorrect descriptors of deafness while it is considerate of the complexity of the deafness interlinked with the different structures and actors within the experience of deafness. Therefore, for children who are deaf in South Africa, deafness is a combination of physiological and contextual factors. This thesis looks to explore the caregivers' experience of their children's deafness while considering the complexities around deafness and the demands on the caregivers.

2.10. Chapter Summary

This chapter opens the door to revealing the complexities of deafness and how it ought not to be reduced to a biological and physiological phenomenon. Instead, there appear to be other factors which interplay in the understanding of deafness and the experience of deafness because the experience of deafness appears to be influenced by contextual variables. This chapter also highlights that, for all its political aspirations of disassociation with disability, in a resource-poor context, deafness is experienced as a disability in rural South Africa. Therefore, this chapter points to the interconnectedness of deafness to where deafness is experienced and by whom.

Chapter 3: Deafness is Experienced in Context

"I had been mysteriously handcuffed to history,

my destinies indissolubly chained to those of my country"

(Rushdie, 1981, p. 11)

Figure 3.1. This photo, which was taken while driving to an interview, is representative of the way which caregivers of deaf children have to face many oncoming challenges in their caregiver role within their particular contexts in rural Mpumalanga.

Caregivers' experiences appear inextricably linked to their present realities and are shaped by the history of South Africa as reinforced by the quotation from Rushdie.

3.1. Context as a Consideration in the Exploration of the Caregiver's Experience

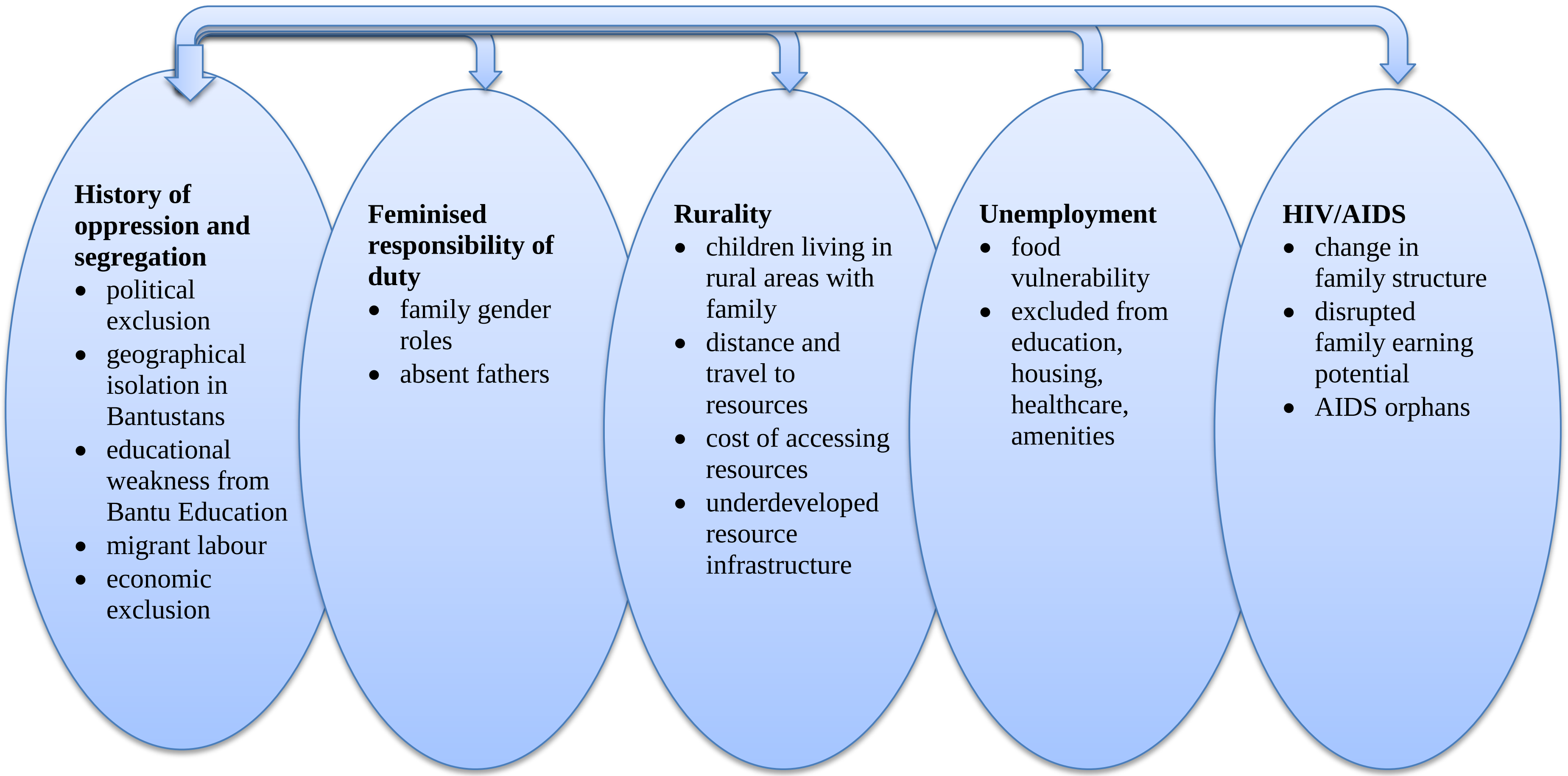
Context is integral to the experience of deafness and physiological deafness, and, as discussed in the previous chapter, is only one component of the experience of deafness. It seems as though contextual variables influence the way in which children who are deaf and how their caregivers experience that deafness. When considering the context of South Africa, it is recognised that the country has emerged from a history of legalised racism and segregation during Apartheid and is, 20 years later, still grappling with the fallout of that oppressive system. Despite the political advances since the 1994 general election, South Africa still has one of the greatest income inequalities in the world paired with an increase in inequality between races (Bradshaw, 2008). It is suggested that there is a disability-poverty nexus in South Africa in that "it is a developing context, struggling to overcome inequalities in income, employment and education" (Graham, Moodley, & Selipsky, 2013, p. 325).

Therefore, within this context, it appears necessary to explore the experience of caregivers of deaf children because their experience is worthy of attention, acknowledgement, and validation. Within this disability-poverty nexus (Groce, Kett, Lang, & Trani, 2011) and in the context of a developing country which has emerged from the socially disruptive and unstable apartheid history, caregivers' experience may take on a particular character shaped by their context, firstly, more broadly with regard to South Africa and, more specifically for rural Mpumalanga where the study was conducted. An overview of the context of childhood deafness is needed so as to explore the terrain which caregivers navigate because it reflects the demands placed on caregivers of deaf children in rural South Africa and the associated complexities in order to consider the structures which can mediate their experience.

3.2. Today's Context Reflecting History: Poverty as a Distinguishing Feature of the Landscape

From the description of South Africa and, in particular, Mpumalanga's landscape, it appears as though poverty is a distinguishing feature of this context in which deafness is lived, both by the children who are deaf and their caregivers: children become embodiments of their caregivers' poverty. Caregivers experience the consequences of poverty in themselves and in the recognition of the effects of their poverty on their children, even post-apartheid where "over the past two decades, many children born to poor households continue to suffer the indignities of poverty" (SAHRC & UNICEF, 2014, p. 17). Additionally, the Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome (HIV/AIDS) epidemic has compounded poverty in South Africa because the death from it results in a reduction in household earnings as well as additional costs related to the funeral and caring for orphaned children while healthy members' contribution to their families' income is also affected when they have to "find time and energy to care for their partners or other household relatives, further decreasing the amount of household labour available for food or income production" (Singer, 2011, pp. 18-19).

This landscape of poverty appears to have interrelated dimensions which have historical bases and modern exacerbations as depicted in Figure 3.2. This figure shows how some contextual variables, past and present, contribute to South Africa's poverty landscape. The overlap represents the fact that they do not exist in isolation and that they are all connected, reoccurring, and interrelated. No priority is assigned to one over the other because they all contributed and contribute to each other and to the overall poverty context, notwithstanding other factors such as the current, ongoing global recession.



History of oppression and segregation

- political exclusion
- geographical isolation in Bantustans
- educational weakness from Bantu Education
- migrant labour
- economic exclusion

Feminised responsibility of duty

- family gender roles
- absent fathers

Rurality

- children living in rural areas with family
- distance and travel to resources
- cost of accessing resources
- underdeveloped resource infrastructure

Unemployment

- food vulnerability
- excluded from education, housing, healthcare, amenities

HIV/AIDS

- change in family structure
- disrupted family earning potential
- AIDS orphans

Figure 3.2. The interconnected poverty factors in the South African caregiver context.

South Africa's current landscape of poverty is a reflection of its history. Apartheid purposefully sought to perpetuate the indignities of poverty by undermining people's potential to advance themselves, by, for example, denying people quality education, especially because "power is organised and manifested through knowledge … (and) … a lack of knowledge and awareness indeed leads to an overwhelming sense of powerlessness" (Van Herreweghe & Vermeerbergen, 2010, p. 135 & 136). Through a strict segregationist policy, people were classified as White, Black, Indian or Coloured which determined their access to the socio-political landscape in South Africa: "Blacks were to be relegated to the rigidly segregated occupational structures and excluded from all job categories except that of unskilled labourers and from access to an educational system that would enable them to compete with their White counterparts" (Thobejane, 2013, p. 2).

Black people were subjected to an inferior education to maintain their subordinate and marginal status in the country through the policies of Bantu Education which resulted in a "literacy crisis" for many adults in present day South Africa who may have difficulties reading (Kathard et al., 2011, p. 61). This historical legacy of a illiteracy and education crisis contributed to unemployment and poverty (Thobejane, 2013) which is still felt in South Africa at this point in time where only about 48% of people feel that they have adequate reading and writing skills (Posel & Casale, 2011). More specifically, because of the segregationist policy of Bantu Education, proficiency in the dominant language of English could not be attained for many adults in South Africa which means that they were excluded from more lucrative employment opportunities (Posel & Casale, 2011). This exclusion thereby perpetuated poverty, especially amongst women who may have had limited opportunities to attend school and who were additionally subjected to "gender oppression … in the mainly patriarchal values of the various cultural and ethnic backgrounds in the country" (Thobejane, 2013, p. 10).

The South African context is a reminder that “poverty is a diverse and dynamic concept” and that the “social, political, cultural and historical contexts of a given society” (Jansen, Moses, Mujuta, & Yu, 2013, p. 3) ought to be included in the understanding of poverty in the country. Therefore, poverty in South Africa is not only characterised by financial resource limitations but also includes limited capabilities which arise “at the individual level (such as age, health status or gender) and social level (such as access to education, gender roles and expectations)” (Graham et al., 2013, p. 327) because of South Africa’s particular history in which people can experience very vulnerable livelihoods (Goudge et al., 2009). This vulnerability appears to be especially significant at the juncture of poverty and disability, that to which Groce et al. (2011) and Graham et al. (2013) refer as the disability-poverty nexus, which would apply to the experience of deafness too.

3.3. Details of the landscape: South Africa

South Africa is a country which has been associated with a history of colonialisation and a turbulent history of legalised racial discrimination “forged by disparate educational access, divergent socio-cultural backgrounds and various historical legacies” (Hussey, 2013, p. 190) which, under apartheid, meant the exclusion of people from full participation in society and in the purposeful denial of human rights. It is home to approximately 50 million people of whom 48,2% are male and 51,7% are female (Statistics South Africa, 2012b). This population is comprised of 18.5 million (37%) children under 18 years, a child population which grew by about 6%, or about one million people, between 2002 and 2011 where about 70% of children live in the poorest 40% of households (Meintjes & Hall, 2013).

Poverty is a pervasive feature of the South African landscape where 56,8% of the population is considered poor (Statistics South Africa, 2014a) and where people may have limited capability and agency because of “poverty, and by lack of access to basic services and the capability-enhancing effects of education" (Graham et al., 2013, p. 325) and where 25% of children do not have the finances to attend educational institutions, even though they could be eligible for free education (Department of Basic Education, 2013b). Childhood and the care of children is reflective of the country's racialized history in that

> 65% of children in South Africa lived in households with at least one working adult. The other 35% (over 6.5 million children) lived in households where no adults were working. … Racial inequalities are striking: 40% of African children have no working adult at home, while 15% of Coloured children, 10% of Indian children and 3% of White children live in these circumstances (Hall, 2013, p. 90).

With regard to the care of children in South Africa, the distribution of the childhood population is skewed in that 70% of the population of children live in rural areas (Department of Health and Department of Basic Education, 2012) which may reflect the migrant labour history of South Africa's caregivers and the rural-urban duality in that caregivers may work in the urban settings while their children may reside with family in the rural areas. Consequently, in light of these complexities, 11% of children under three years are not registered at birth (Berry, Dawes, & Biersteker, 2013), especially those children in rural areas and those children who are not resident with their biological parents (de Villiers & Giese, 2008).

Reports indicate that 39% of children in South Africa are resident with their mothers, 35% reside with both biological parents, 3% reside with their fathers only (de Villiers & Giese, 2008; UNICEF, 2012) and 24,4% live with neither of their parents (Meintjes & Hall, 2013). These statistics reflect a racial character too since 42% of black South African children do not grow up in households in which their fathers are present (Meintjes & Hall, 2013). We are reminded that

> South Africa has a long history of children not living consistently in the same dwelling as their biological parents as a result of poverty, labour migration, educational opportunities or cultural practice. It is common for relatives to play a substantial role in child-rearing. Many children experience a sequence of different caregivers, are raised without fathers, or live in different households to their biological siblings (Meintjes & Hall, 2013, p. 87).

From these aforementioned reports, it appears as though women tend to be the primary and sole caregivers to children in South Africa. The last census in South Africa in 2011 revealed that women-headed households earn half the income of male-headed households and that black South Africans earn less than white South Africans (Statistics South Africa, 2012b). If anything, the poverty gap appears to be increasing (Statistics South Africa, 2015). These findings suggest that many children in South Africa are living in poor households, a finding supported by UNICEF which reports that 60% of South Africa’s children live in poverty (UNICEF, 2012) in a country where, officially, a quarter of the population is unemployed (Statistics South Africa, 2014b) although that number could be as high as 40% (Statistics South Africa, 2012b). Examples of the manifestation of this poverty are that 18% of children are reportedly hungry, only 63% have access to basic sanitation (toilets, for example) and, despite 80% of children living in households with electricity, many cannot afford that electricity and so depend on other forms of, often unsafe, energy such as paraffin, wood and coal (Department of Health and Department of Basic Education, 2012, p. 24). Hunger is experienced by many children in South Africa where more than nine million school children get meals at school because their caregivers are poor and not able to provide them with food (Department of Basic Education, 2013a) and experience severe food insecurity (Statistics South Africa, 2015).

There are reportedly almost 4 million orphaned children in South Africa, that is about 21% of children in the country (Department of Health and Department of Basic Education, 2012). Many young children are left orphaned because the adult life expectancy, on average in South Africa, is only 59.6 years (Statistics South Africa, 2013b). One of the postulated reasons for this low life expectancy in South Africa is because of AIDS as it is reported that approximately 5.26 million people (10%) have the disease although this number is believed to be a very conservative estimation because it is based on pregnant women attending ante-natal clinics (Statistics South Africa, 2013b) and on the under-reporting of deaths due to AIDS (Statistics South Africa, 2012b). The impact of AIDS has altered the structure of the nuclear and extended family due to illness and death of parents and where, because of expected gender roles, women tend to have to care for orphaned children (Singer, 2011). When describing orphaned children, there is a distinction in the way in which the children have become orphaned in light of the death of one of the parents in the presence, but non-involvement, of the other parent. Therefore,

> a maternal orphan is a child whose mother has died but whose father is alive; a paternal orphan is a child whose father has died but whose; mother is alive; a double orphan is a child whose mother and father have died (Meintjes & Hall, 2013, p. 88).

Statistically, in South Africa, 5,1% of children are double orphans, 3,3% are maternal orphans, and 12,3% are paternal orphans (Meintjes & Hall, 2013). It is postulated that the number of paternally orphaned children is due to the higher mortality in South African men and due to absentee fathers (Meintjes & Hall, 2013). Poverty is a major factor in the lives of orphaned children since more than half of all orphaned children in South Africa live in the 20% of the poorest households in the country (Meintjes & Hall, 2013).

3.4. Details of the landscape: Mpumalanga

The Mpumalanga Province, a map of which is presented in the methodology chapter 6 (Figure 6.6), is situated in the north-east of South Africa where it occupies 79 487km² of the country's 1 219 602km² area and is the fifth out of the nine provinces in terms of income per capita (Statistics South Africa, 2012b) where 43,8% of households are classified as being poor (SAHRC & UNICEF, 2014). Mpumalanga is considered rural and poor because, in this province, there is poor service infrastructure, high unemployment, limited job opportunities, and, therefore, a high reliance on state cash transfers in that 60% of households receive the child support grant (Goudge et al., 2009). In defining what constitutes a rural area, Mpumalanga fits the definition because

> 'rural' is considered to refer to remote areas with poor infrastructure, poor basic service provision (water and electricity), low levels of literacy, high levels of unemployment, limited access to health and education services, and high incidence of communicable diseases such as HIV/AIDS. These factors are compounded by restrictions in employment opportunities, lifestyle choices and access to services, and poverty (Watermeyer & Barratt, 2013, p. 3).

This province's rurality is further characterised by its position as the province with the fourth lowest population distribution of all the provinces (Statistics South Africa, 2012b) and where 24,5% of households are engaged in agriculture compared to the 19,9% average for South Africa (Statistics South Africa, 2013a). The agricultural and rural description of the province is characterised by the 152 000 households engaged in subsistence farming in the province, although these numbers are difficult to ascertain as they could be higher (Mpumalanga Department of Finance, 2014). Not everyone in the province has access to basic resources. It is reported that only 12,6% of people have access to piped water, 69,3%

have electricity, and 57% of households have access to flush toilets (Statistics South Africa, 2012a, 2012b). People who live here often do not engage in certain activities, even if they are free because they have to travel far distances to access services, such as attend hospital appointments, and they do not have the finances to pay for transport to the appointments, notwithstanding the poor public transport system infrastructure in the region: they face "an unsustainable double-burden" (Goudge et al., 2009, p. 248).

People in Mpumalanga are described as having a "vulnerable livelihood" (Goudge et al., 2009, p. 236) in that they have fewer and less secure sources of income and employment which results in them experiencing food insecurity and relying on donations from their relatives and neighbours. To compound this vulnerability, any unexpected or additional costs, such as hospital visits and any additional transport costs for these visits, only exacerbate their difficulty in meeting their costs and they, therefore, can only meet these additional costs if they get financial support from their social networks (Goudge et al., 2009). However, these social networks are not necessarily consistent or reliable because the support "can shrink or become exhausted, particularly in a context of poverty and where HIV has already undermined many households' livelihoods" (Goudge et al., 2009, p. 249). HIV and AIDS have had, and continue to have, a significant impact on poverty, especially in a context characterised by the "feminisation of rural poverty" where "poorer households become even more vulnerable, more food insecure, less able to pay for their children's education, and less in a position to afford healthcare" (Singer, 2011, p. 20).

It is reported that approximately 846 000 children, more than half (57,4%) of Mpumalanga's children live in conditions of poverty (Hall, 2013). According to the last census, it is where 4 039 939 (7,8%) of South Africa's 51 770 560 inhabitants live, 42% of whom are unemployed (Statistics South Africa, 2012b). This province is home to 8,2% of South Africa's children (UNICEF, 2012) where 30% live with both parents, 41,4% live with their mothers, 3,9% live with their fathers, while 24,9% live with neither of their parents (Meintjes & Hall, 2013). The life expectancy in Mpumalanga is lower than the already low national average. It is only 55.9 years for males and 60.1 years for females compared to the national average of 57.7 years for men and 61.4 years for females (Statistics South Africa, 2013b). With regard to orphaned children in Mpumalanga, 79 000 children (5,4%) are double orphans, 66 000 (4,5%) are maternal orphans, and 168 000 (11,4%) are paternal orphans (Meintjes & Hall, 2013) which alludes to very particular and complex caregiver roles which develop as a consequence.

3.5. Children's Deafness in South Africa: Context and Poverty Predominate

In Sub-Saharan Africa, where the prevalence of childhood deafness is the highest (WHO, 2012, p. 2) and where caregivers have lower levels of literacy (WHO, 2013b, p. 7), children who are deaf may have difficulty accessing schooling (WHO, 2013a) because, as Kiyaga and Moores (2003) point out, deafness is experienced "in the face of widespread poverty, a scarcity of funding and other resources, and a lack of trained professional personnel" (p. 20).

These limited resources with regard to children's deafness apply to the local context too in that South Africa is described as: "a country with wonderful legislation and policies, yet lacking the actual implementation and practice of these policies" (Störbeck & Moodley, 2011, p. 2). Despite the presence of various structures to support childhood deafness in the form of government financial grants, caregiver support structures such as HI HOPES (Home Intervention Hearing and language Opportunities Parent Education Services) (Störbeck & Moodley, 2011), WAB (Wits Hearing Aid Bank) (Pillay, Moonsamy, & Khoza-Shangase, 2010), and Early Hearing Detection and Intervention (EHDI) (Swanepoel et al., 2009) programmes. However, just because these structures exist, it does not mean that all caregivers and parents have access to them as they are not available across the country and to all deaf children and their caregivers. The South African context is one of juxtaposition and there is an acknowledgment of the interplay of poverty and disability because "poverty cannot be understood only in terms of deprivation of income. … Rather it may be that there is inequality of access to basic capabilities linked to that disability status … (That is), poverty is the impossibility for individuals to be and do what they value because of lack of opportunities" (Groce et al., 2011, p. 1502). Locally,

> poverty and disability need to be viewed within the context of a multidimensional or livelihoods approach, which acknowledges the poverty-related factors that impact on disability and the disability-related factors that impact on poverty (Department of Social Development et al., 2012, p. 56).

With regard to deafness in South Africa, it is estimated approximately one hundred thousand children in South Africa, that is 0,5% of children, have permanent deafness, and that 21,2% of all children who are classified as disabled are deaf (Department of Social Development et al., 2012). These numbers may seem small in comparison with the size of South Africa's population. However, as this study is looking at the qualitative and human experience, the value of the people is paramount and supersedes the quantitative value. It is estimated that approximately 6 children in every 1000, that is approximately 16 babies per day, are born with deafness or acquire very early onset deafness (Moodley & Störbeck, 2012; Swanepoel et al., 2009) compared to 2 to 4 children in every 1000 in developed countries (Moodley & Störbeck, 2012). Of the children with deafness, it is reported that the majority are born to hearing parents (Feher-Prout, 1996). It is estimated that the mean age of identification of infantile deafness in urban areas of South Africa can be about 23 months of age but in reality it can be much later, and while hearing aids can be fitted at approximately

28 months, it is reported that it can be very much later (Swanepoel et al., 2009; van der Spuy & Pottas, 2008). Deafness is reportedly more prevalent in areas of lower socio-economic status in South Africa (Swanepoel, 2006) where the age of identification of deafness in rural areas of South Africa could be as high as 6 years of age (van der Spuy & Pottas, 2008) and even extend as far as into adolescence (Olusanya, 2001, cited in Professional Board for Speech Language and Hearing Professions, 2007). These ages of identification are beyond the reportedly optimal age of 4 months of age for identification of deafness and the age of 6 months for the provision of hearing amplification (van der Spuy & Pottas, 2008). The detection period can start from two years old and extend well into the adolescent years.

Children in Mpumalanga, possibly due to its poorer resources and infrastructure, are reportedly more likely to be deaf than in other provinces. It is reported that 0,72% of all children in the province are deaf compared to the national average of 0,5% and it is suggested that this higher figure “might reflect varying exposure to specific risk factors” (Department of Social Development et al., 2012, p. 33). Also, it is reported that children in rural areas are more likely to have a disability when compared to children in urban areas and this increased chance is attributed to poverty, nutrition, toxic agents, and social factors (Department of Social Development et al., 2012). Therefore, it seems as though the context of poverty itself can be disabling and can contribute to the degree of disability, a concept linked to embodiment in which the context becomes part of people.

3.6. Deafness as an Embodiment of the Context

Caregivers’ context, power differentials, social factors, and economic relations may become physically manifest in themselves and in the people for whom they provide care. This “embodiment” is described as “a concept that refers to how we literally incorporate, biologically, the material and social world in which we live, from in utero to death” (Krieger, 2001, p. 672) and “that no aspect of our biology can be understood absent of knowledge of history and individual and societal ways of living” (Krieger, 2001, p. 672), “including our societal and ecological circumstances” (Krieger, 2005, p. 351). Through embodiment, contextual aspects such as social and cultural factors are biologically and physically manifested in people and this embodiment occurs when the individual’s biology and history interact with that individual’s societal conditions, historical background and ecological context such as poverty, environmental factors, access to health care, access to rehabilitative services and access to resources (Krieger, 2008). These contextual factors encompass a range of domains: socio-economic, cultural, environmental, and living and working conditions as well as social and community influences (Bradshaw, 2008) and can influence “help seeking for hearing difficulties, the taking up of interventions, and compliance with interventions” (Scarinci, Worrall, & Hickson, 2012).

The idea of embodiment can be extended to deafness too since socio-environmental factors may impact on hearing and the idea of embodiment could be useful in trying to understand deafness while recognising the interplay of the context and deafness. In the case of deafness, because it inhabits different paradigms, for example, biomedical, cultural, linguistic, and disability paradigms, the concept of embodiment with regard to deafness can be extended to more than just the biological aspects. Specifically, within an ecosocial approach, “humans, are simultaneously social beings and biological organisms” (Krieger, 2005) and consideration is given to the interplay of the social conditions and context in which people live while recognising the impact of history on the current context and experience (Krieger, 2001). The concept of embodiment may also be “a clue to life histories, hidden and revealed” and “a reminder of entangled consequences of diverse forms of social inequality” which are made manifest through pathways of embodiment mapped by “societal arrangements of power, property, and contingent patterns of production, consumption, and reproduction” within “multiple domains (for example, home, work, school, other public settings)” (Krieger, 2001; 2005, p. 352). More specifically, the term ‘sociosphere’ has been used to referred to refer to the space between the biology and the context, the space in which the interaction between individuals and their contexts occurs (Noble & Hetu, 1994) because the “sociosphere implicates prevailing, historically contingent conditions of society” (Noble & Hetu, 1994, p. 121) and suggests that the physiological deafness may be experienced differently within different contexts with different histories and different cultures (Noble & Hetu, 1994).

With regard to children, the social relations and power relations in which the deafness occurs may impact on the resources and support available for the caregivers of deaf children. This differential may occur because a context of poverty intensifies “social marginalisation and isolation, lack of access to education, to adequate housing, to enough nutritious food, clean water and basic sanitation, to health care and to credit, and lack of ability to participate fully in legal and political processes” (Groce et al., 2011, p. 1497). These contextual variables appear to become wholly embodied in deaf children because of the structural conditions in which caregivers’ find themselves which mediate their ability to provide for their children’s audiological, educational, linguistic, social, and other needs. Caregivers’ own educational, linguistic, financial, support systems, geographical, employment, and other socio-historical backgrounds can become embodied in their children’s deafness. Their actions and their decisions can steer the direction which their children’s deafness takes with regard to modes of communication, schooling, and hearing amplification, amongst others. The caregivers’ socio-political context can become embodied in their children. For example, during apartheid, the political discrimination caregivers’ experienced limited their financial, political, and geographical agency to act on behalf of their children. The caregivers’ agency may be dictated by the caregivers’ contexts in which they live and their context and their agency is transferred to the children in their care and the caregivers' agency is reflected in their children because this agency dictates the options available to their deaf children in terms of schooling, language, hearing amplification options, amongst others. The caregivers' contextual agency is, therefore, embodied in their deaf children.

However, the embodiment does not only occur in the child and it can be argued that the caregivers' experience becomes embodied in themselves too, a notion related to third-party disability (Scarinci et al., 2012) where the children's disability can impact on the caregivers' abilities. Additionally, the caregivers' context has an impact on their own experience and how they engage with that experience while navigating the different domains of that experience. Therefore, there is the recognition of the appreciation that deafness be considered in context and is therefore respectful of the ecosocial approach. Within the prevailing medical discourse in which deafness is often considered, recognition needs to be given to the intertwining of the prevailing social and cultural conditions and influences (Bradshaw, 2008). However, more than just looking at the children who are deaf, there is the need to explore the way that the caregivers' experience becomes manifest, especially within contexts of limited resources.

3.7. Structure: Its Relation to Childhood Deafness in South Africa

In light of the preceding considerations around the impact of context on experience, it appears necessary to consider aspects relating to structure as these may impact on the experience of deafness in South Africa. Governments in different parts of the world, including South Africa, have been accused of showing a lack of political will in providing the required structural support which can result in the structural exclusion of people and, in effect, "apartheid by design" (Imire, 1996, cited in Groce et al., 2011, p. 1497). There appears to be an "interweaving of history and structure" (Ahearn, 2001, p. 119) as in the situation of rapid socio-political change (Zhao & Cao, 2010) in South Africa’s transition out of formalised apartheid.

The concept of structure is characterised by its duality: structure shapes people’s practice and people’s practice constitutes structure (Ahearn, 2001). Therefore, although structure can sometimes be considered restrictive, it is argued that structure is necessary and can be enabling because agents can put “their structurally formed capacities to work in creative or innovative ways” (Sewell, 1992, p. 4) which suggests a paradoxical situation that to have agency, people need to operate within structures because, without these structures and in societies undergoing socio-political change, people may experience a sense of “powerlessness, alienation and confusion” (Zhao & Cao, 2010, p. 1211). However, this idea of structure presupposes that agents have that capacity within the existing structure. Notwithstanding this presupposition, it is argued that agency can be facilitated by agents’ access to resources where resources are deemed “anything that can serve as a source of power in social interactions” (Sewell, 1992, p. 9). More specifically, resources can be divided into human and nonhuman resources.

> Nonhuman resources are objects, animate or inanimate, naturally occurring or manufactured, that can be used to enhance or maintain power; human resources are physical strength, dexterity, knowledge, and emotional commitments that can be used to enhance or maintain power, including knowledge of the means of gaining, retaining, controlling, and propagating either human or nonhuman resources (Sewell, 1992, p. 9).

It is argued that even in contexts where there exist unequal distribution of resources, people still have some measure of access to human or nonhuman resources and that this access to resources empowers agents (Sewell, 1992). However, as has been highlighted earlier, caregivers in South Africa who already may have very little agency, have even less access to these human and nonhuman resources which may limit their agency even more and that may be disempowering because, “without institutional support and guidance in making developmental transitions, individuals are left largely to their own internal resources” (Côté, 1996, p. 423). Consequently, caregivers of deaf children, within the contexts of limited resources may have limited control within their structures and over their social relations which may result in limited transformative powers (Sewell, 1992) and suggests that when the structures are not enabling agency, people are constrained in their enacting of agency which may be the case for caregivers of deaf children in light of the structural context in which deafness is experienced. This sense of control is necessary in order to enact agency so that caregivers “are better equipped to seek information and services for themselves and their children” (Meadow-Orlans & Sass-Lehrer, 1995, p. 329) because, as in South Africa, this absence of structure means that “in many countries progressive human rights-based policies and programmes for person with disabilities exist on paper, but are honoured in the breach, without adequate infrastructures to ensure their effective implementation and enforcement” (Groce et al., 2011, p. 1495).

3.8. Governmental Structures and Childhood Deafness

Governments and their composites are often referred to in relation to structural dimensions (Zhao & Cao, 2010). The following section contextualises deafness in relation to governmental structures because of their political and legal influence with regard to children and specifically children who are deaf and their care. However, as is depicted later in this chapter, structures are not only these formal government entities and that there exist more fluid and non-formalised structures which also ought to be considered as structures in which caregivers navigate their experience.

3.8.1. Department of Health.

In South Africa, children who are deaf are considered to fall under the auspices of the Department of Health, notwithstanding the prior discussions around the cultural and medical aspects of Deafness and deafness. This department is meant to provide services for the screening, identification and rehabilitation of deafness, especially for children under the age of 6 years. However, there are delays in the provision of services for children who are deaf (Department of Social Development et al., 2012) and its service is reportedly "idealistic (because) the implementation of this policy is hampered due to a shortage of staff at government institutions resulting in a long waiting period for services, and a lack of transport for children to reach facilities" (Störbeck & Moodley, 2011, p. 2). Even though public health provision is free or at a means-tested rate, transport costs for hospital visits are described as "catastrophic" (Harris et al., 2011, p. S113) for many people resulting in some people having to walk significant distances to hospital visits or even foregoing appointments if they cannot afford the public transport (Harris et al., 2011). Moreover, structurally, it is proposed that "specific hearing health care service provision strategies are often unsuccessful due to a number of main barriers" (McPherson, 2014, p. 361).

In Mpumalanga, a predominantly rural area, it is reported that only 42% of children who sought rehabilitation services and only 33% of children who required assistive devices, such as hearing aids, received such services (Department of Social Development et al., 2012). Of the deaf children who attend school, 2479 are reportedly issued with hearing aids while a further 1815 are waiting for hearing aids provided by the Department of Health (Department of Women Children and People with Disabilities, 2013). It is known that in provinces such as Mpumalanga, among other rural provinces in South Africa, access to rehabilitation services, if they are sought, is often not within the district (Department of Social Development et al., 2012) which entails travel across long distances to access those rehabilitation services and there are also limited funds for transport to the different centres where services are offered (Department of Social Development et al., 2012). Mpumalanga is included in the list of three provinces with the lowest accessibility scores, especially in more rural districts (Department of Social Development et al., 2012).

The South African government concedes that "rehabilitation services are still rooted within the medical model, resulting in poor outcomes for people with disabilities, including children" (Department of Social Development et al., 2012, p. 49). Furthermore, within the public health sector, there may be delays in caregivers' seeking of hospital-based services because of their "anticipated disrespectful treatment" and the perception that their concerns were "not serious enough to warrant immediate care" (Harris et al., 2011, p. 115) at the hospitals. Structural barriers to the provision of adequate deafness-related services in the health sector within contexts of constrained resources have been suggested: these include the shortage of personnel who work specifically in deafness, the shortage of funds necessary to provide expensive hearing amplification devices, and the limited public awareness and acceptance of hearing amplification devices (McPherson, 2014). In this regard, there has been a move to offer services within a community-based rehabilitation (CBR) model in some provinces which aims to "reduce poverty by ensuring that health, education and livelihood opportunities are available to people with disabilities" and is purported to assist "mothers of disabled children with practical skills and advice to help their child at home" and "can challenge negative attitudes in rural communities and lead to greater visibility and participation by adults and children with disabilities" (Department of Social Development et al., 2012, p. 62).

More specifically in Mpumalanga, there are reportedly 29 CBR workers in the provincial department of health (Department of Social Development et al., 2012) to offer services to people in the province. However, despite these promises, children with disabilities are often still excluded from communities, suggesting that the aspirations of this policy and its implementation are not necessarily congruent, especially because of the lack of a coherent national policy with regard to its implementation (Department of Social Development et al., 2012).

With regard to an absent coherent national policy, there appears to be an absence of structure with regard to the identification of deafness in children. The absence of this structural system means that children's deafness cannot be identified early and their caregivers cannot be introduced to issues related to their children's deafness early, especially because many hearing caregivers do not have previous experience or background to deafness in children (Jackson et al., 2008). The Health Professions' Council of South Africa suggests that a well-structured EHDI service could provide direction and support to the caregivers of children who are identified as deaf in that "EHDI systems must facilitate and manage this process to ensure infants and their families will have efficient and timely access to the proposed services" (Professional Board for Speech Language and Hearing Professions, 2007, p. 33) and they "must be family-centred within a community-based model of service delivery that is culturally congruent" (Professional Board for Speech Language and Hearing Professions, 2007, p. 4). However, this system is not in place and so the screening for deafness "remains mostly unstructured, unsystematic and only available in certain hospitals" because "the vast majority of hospitals in South Africa do not provide any hearing screening services … especially since almost no universal screening programs (sic) exist in the country" (Swanepoel et al., 2009, p. 785). This insufficient screening for deafness may result in disability and reduced socio-economic participation due to the late identification of deafness (McPherson, 2012).

To compound the issue, caregivers experience considerable difficulty in accessing audiological diagnostic services at secondary and tertiary hospitals due to a shortage of the specific equipment necessary for the diagnosis of deafness in children such as auditory brainstem response and otoacoustic emission measurement equipment (Theunissen & Swanepoel, 2008) which may leave caregivers unsure about the necessary actions with regard to the suspected deafness. This absence of structure suggests that caregivers do not have recourse to resources to guide them in their actions around deafness and the subsequent information they may want with regard to the different domains of deafness. It may even contribute to that sense of “powerlessness, alienation and confusion” (Zhao & Cao, 2010, p. 1211) which was mentioned earlier.

3.8.2. Department of Education.

South Africa’s history is being lived in the present in the form of the legacy of Bantu education where, prior to the end of apartheid, “special schools were thus organised according to two segregating criteria, race and disability. In accordance with apartheid policy, schools that accommodated white disabled learners were extremely well-resourced, whilst the few schools for black disabled learners were systematically under resourced” (Department of Education, 2001, p. 9). The poor schooling infrastructure under apartheid has, as a consequence, meant that “low pass rates, violence, sexual abuse and teenage pregnancy are prevalent in numerous disadvantaged schools in South Africa” (UNICEF, 2012, p. 6).

In the post-apartheid dispensation, according to the South African Schools Act, 1996 (Act 84 of 1996), “education is compulsory for children from the age of seven to the age of 15 or Grade 9 (whichever comes first)” (Department of Basic Education, 2013b, p. 6) and compulsory school attendance is extended to children with disabilities (Department of Women Children and People with Disabilities, 2013). The Integrated National Disability Strategy of 1997 looks to provide education that is inclusive of learners with disabilities

(Department of Basic Education, 2013b) and the Education White Paper 6 – Special Needs Education wants to reduce “the barriers to learning, through targeted support structures and mechanisms that will improve the participation and retention levels of learners in the education system” (Department of Basic Education, 2013a, p. 8). The department also looks to implement the Integrated School Health Programme (ISHP) which includes health screening, health education, and psychosocial support of learners (Department of Basic Education, 2014). Within this integrated plan, learners have the right to be taught in their language of choice (Kathard et al., 2011). More specifically for deaf and Deaf learners whose preferred mode of communication is via South African Sign Language, the department has developed a new curriculum and teaching plans for Grade R to Grade 12 (Department of Basic Education, 2013a) as well as auditing procedures for this SASL programme (Department of Women Children and People with Disabilities, 2013). However, there is a concern that, when it comes to the recognition of sign language rights in education policies, there may be a mismatch between the policies and their implementation. Those who design the policies often do not have the experience of working in Deaf and deaf education and have, for example, equated deafness with blindness (Parkin, 2010).

Deaf learners make up 6,1% of all the learners with special educational needs (Department of Women Children and People with Disabilities, 2013). It is reported that 89,6% of deaf children between the ages of 7 and 15 years attend school (Department of Social Development et al., 2012). However, the percentage of school attendance drops for older children (Department of Basic Education, 2013b), even though children who receive government grants are exempt from paying school fees (Department of Health and Department of Basic Education, 2012). The Department of Education, which includes children who are deaf under the umbrella of children with disabilities, has reportedly “made progress towards ensuring that children with disabilities can access basic education, based on the policy of inclusive education" although it is acknowledged that "children with disabilities are substantially less likely to attend school than their non-disabled peers" and, that despite the progress it reports, "access to education for children with disabilities has not improved" and it reports that "communication disabilities appear to be the biggest barrier to access education" (Department of Social Development et al., 2012, p. 44). Specifically for Deaf children, "985 educators teaching deaf learners know basic SASL but have no qualifications" affecting the 44 schools for Deaf learners (Department of Women Children and People with Disabilities, 2013, p. 15). Already in 2001, the White Paper looking at special educational needs, promised that "materials and equipment, in particular devices such as hearing aids and wheelchairs, will be made progressively accessible and available to those learners who cannot gain access to learning because of a lack of appropriate resources" (Department of Education, 2001, p. 33) although it is reported that this provision is not as successful as originally intentioned (Department of Social Development et al., 2012; Störbeck & Moodley, 2011). Also, because of the constraining effects of this limited schooling infrastructure, the additional costs of getting to school, and the lack of accessibility, schooling opportunities may be restricted (Graham et al., 2013, p. 329). The limited number of schools which cater for children who are deaf means that some deaf children may have to attend schools far away from their homes and this may have an impact on the family dynamics and on the sense of home as exemplified by the case of Lorato:

> When Lorato started her primary education, it was the beginning of her being separated from her primary family, as the schools for the Deaf were all far away and inconvenient for working parents. She started at a school that was more than 110 km (about 70 miles) from her primary home, and 20 km (about 13 miles) from her secondary home (Rasebopye, 2010, p. 508).

Numerous shortcomings have been reported in the education of learners who are deaf and these shortcomings cannot be addressed in short workshops which aim to provide educators with information on educating and communicating with deaf children (Parkin, 2010). Within this context, "that many deaf children grow up understanding each other but not their teachers creates on the one hand a sense of solidarity among the children, while on the other hand it increases a sense of alienation from hearing society" (Van Herreweghe & Vermeerbergen, 2010, p. 134). These aforementioned shortcomings include the inability of 80% of teachers in schools for the Deaf being able to use SASL, a shortage of equipment specifically geared for Deaf and deaf learners, few Deaf teacher assistants, a shortage of audiologists, and no access to early childhood development programmes to foster the development of spoken language and SASL. One of the challenges to deaf and Deaf children's access to, and progress through, school included the fact that most deaf children are born to hearing parents and, therefore, do not learn language from their parents or caregivers and start school without language. This latter point again points to the support which ought to be offered to caregivers of deaf children so that they, in turn, can better support their deaf children (Department of Women Children and People with Disabilities, 2013, p. 8).

It appears as though teachers of deaf children may not have special formation in teaching deaf children in light of the specific and tailored communication needs, SASL or otherwise. Some universities offer training in deaf education, for example, the University of the Witwatersrand offers a specialisation in Deaf education which may go a long way to reduce the deficit in teaching deaf children (Magongwa, 2010). However, it is reported that children who attend schools where SASL is the medium of instruction are taught by teachers who are not necessarily proficient enough in the language (Department of Women Children and People with Disabilities, 2013) because teachers of the deaf do not need to have particular formation or qualification in deafness. It is argued that, “if educators cannot use SASL fluently, and are not appropriately qualified, Deaf learners are denied access to quality education” (Magongwa, 2010, p. 495). Even if deaf children do not use SASL, there are particular methodologies for working with deaf children which need to be considered and which many teachers of deaf children may not have (Parkin, 2010).

3.8.3. Department of Social Development.

Structural support in the form of social services is necessary to assist caregivers who are in need of support and it is argued that “social services are a vital support to families and children, including prevention and protection from abuse and neglect” (Berry et al., 2013, p. 30). Support is available in the form of the care dependency grant (CDG), the disability grant (DG), and the child support grant (CSG). Specifically related to deafness in children, caregivers can apply for the CDG instead of the DG because the DG is for adults between the ages of 18 and 59 years who have a valid identity document and proof of the disability. Caregivers of disabled children under the age of 18 years can complete the necessary documentation and are then entitled to receive financial assistance of R1350.00 per month in the form of the CDG for children who have a disability as confirmed by a state medical officer and who meet the criteria for receipt of the grant (Department of Social Development et al., 2012; South Africa Government Services, 2014). Eligibility for the grant requires that caregivers must live in South Africa and must “be a parent, primary caregiver or a foster parent appointed by the court; be a South African citizen or permanent resident; not earn more than R151 200 a year if you are single. Your combined income should not be above R302 400 a year if you are married” while the child must “be younger than 18 years; not be cared for permanently in a state institution; have a severe disability and need full-time and special care” (South Africa Government Services, 2014, n.p).

This financial assistance which the CDG offers has reportedly had positive impacts on the access to medical facilities and improved housing (Department of Social Development et al., 2012; Hall, 2013) and there has been an increase in the number of children receiving the CDG as this number grew from 5,913,719 children in 2005 to 11,227,832 children in 2012 (UNICEF, 2012), most likely because the criteria for eligibility changed, although an "estimated two million children who are eligible for the grant are not receiving it, mainly for administrative reasons" (UNICEF, 2012, p. 4) and accessibility reasons such as problems with submitting the necessary documentation and not knowing how to apply for the grant (Graham et al., 2013) which alludes to issues of limited literacy and access.

It has been found that because of situations of extreme poverty, caregivers may have to spend the CDG money on household expenses such as food rather than on their children's disability needs (Goudge et al., 2009). In light of pervasive unemployment, underemployment, and poverty, the financial assistance received in the form of social grants, there is a redirection of the grant money towards food and other household needs which means that the "value of the grant is thus eroded significantly, since there simply is not enough income in the households for individuals to be able to convert the money into meeting their basic needs as well as capability enhancement mechanisms" (Graham et al., 2013, p. 331).

In addition to caregivers' need for financial assistance as offered by this department, it also appears as though "psycho-social support for caregivers is therefore essential to promote the well-being of caregivers and … the Children's Act provides for parenting programmes that support parents to provide responsive care for young children" (Berry et al., 2013, p. 30) even though it is acknowledged that there are insufficient social workers working in the field (Department of Social Development et al., 2012). The social dimension of deafness cannot be overlooked and there is the recognition of the need for strong community and social network links. It is postulated that

> access to social security should therefore not be seen in isolation, but as a mechanism for building the capacity of the disabled child to survive and develop, and the ability of their households to extend their livelihood strategies, including increasing access to community activities and social networks (Department of Social Development et al., 2012, p. 56).

3.9. Non-Governmental Structures in Relation to Deafness

Not all structures are governmental. Other organisations may be called upon to provide input on the child and the deafness, for example after diagnosis of the deafness or if the children go to school. EHDI programmes overlap governmental and non-governmental structures (Swanepoel et al., 2009) as per the discussion earlier about the screening and identification of deafness but they also include input from HI HOPES and WAB, two examples of formal structures for children's deafness.

3.9.1. HI HOPES.

An example of support for families of deaf children is the HI HOPES (Home Intervention Hearing and language Opportunities Parent Education Services) early intervention programme which offers services to families of children between birth and three years of age who have been diagnosed with deafness and is available, at no charge, to families in the public and private healthcare sectors (Störbeck & Moodley, 2011). It is reported that

> the aim of HI HOPES is to partner with parents, informing and empowering them in order to understand all aspects of the child with a hearing loss … There is no

> indication of bias or preference of amplification or communicative modality, and parents are empowered to make decisions that will be to the benefit of their child (Störbeck & Moodley, 2011, p. 6).

This programme looks to provide input on language and cultural aspects of having a deaf child in the family and feedback from HI HOPES suggests positive responses to it (Störbeck & Moodley, 2011; Störbeck & Pittman, 2008) and appears to offer a support structure that could be beneficial to all families of deaf children. However, the programme tends to be available to people residing in the major centres of South Africa in Gauteng and the Western Cape. It also requires the very early identification of the children's deafness which is not necessarily the case in many areas of South Africa where the diagnosis of deafness is made outside of the HI HOPES age range, even if this programme were available in the rural areas. Therefore, despite its advances in providing support, especially with regard to language decisions, it is not accessible to all caregivers nor does it suit the needs of caregivers of older children where those decisions have already been made.

3.9.2. Wits HAB.

The University of the Witwatersrand Hearing Aid Bank (Wits HAB) began as an endeavour to offer hearing aids to children between the ages of 0 and 6 years who, due to delays at public hospitals or due to financial constraints, could not be provided with hearing amplification (Pillay et al., 2010) if their caregivers so chose for them. The idea of the Wits HAB was to programme hearing aids as per each individual child's audiogram and then to loan the hearing aids to children for up to 6 months to avoid delays in learning spoken language while they are on waiting lists for hearing aids. When the children's turn arrives on the waiting list for hospital-provided hearing aids and they are fitted with their own hearing aids or if the money is acquired to purchase the hearing aids privately, the loan aids are meant to be returned (Pillay et al., 2010). However, the Wits HAB is centred in Johannesburg and only offers loan aids and audiological support to people referred to the Wits HAB thereby precluding children from other areas, especially rural areas, and also precluding support for the caregivers who may not choose hearing aids for their deaf children.

3.10. Cultural Structures: The Examples of Language and Faith in South Africa

South Africa has been referred to as the Rainbow Nation because it is home to people of different languages, ethnicities, races, and beliefs. These variables may inform culture. There has been a shift in the understanding of culture from “material phenomena but rather to the cognitive organisation of such phenomena … (and that) … people carry a set of rules and assumptions in their heads … (which) … constitute what is meant by culture” (Davies, 2001, p. 150). Similarly, structures are not necessarily only material but can also be considered a virtual concept (Sewell, 1992). Therefore, culture can be described as a structurally delineated set of rules and assumptions which people have around phenomena that are not necessarily material but which structure and organise the way people interact. More specifically,

> culture is not a single variable but rather comprises multiple variables, affecting all aspects of experience. Culture is inseparable from economic, political, religious, psychological, and biological conditions. Culture is a process through which ordinary activities and conditions take on an emotional tone and a moral meaning for participants. Cultural processes include the embodiment of meaning in psychophysiological reactions, the development of interpersonal attachments, the serious performance of religious practices, common-sense interpretations, and the

> cultivation of collective and individual identity. Cultural processes frequently differ within the same ethnic or social group because of differences in age cohort, gender, political association, class, religion, ethnicity, and even personality (Kleinman & Benson, 2006, p. 1674).

Although culture is comprised of a range of variables, in terms of the South African landscape, this section will focus on the structural variables relating to language and faith particularly because they are specific variables which may be important in understanding the patterned practices which are used by people in their social milieu (Sewell, 1992), especially in South Africa which is characterised by multiple faith systems and languages. These structural considerations need to be considered as they form part of the landscape in which deafness is experienced, both by the children who are deaf and by their caregivers.

3.10.1. Faith systems.

South Africa, like many other countries, encourages religious freedom and tolerance as enshrined in the constitution of the country. As with its variety of languages and ethnicities in the same country, South Africa's landscape is characterised by a variety of faith systems. The 2011 census did not include an item on people's religious affiliation (Statistics South Africa, 2012b) but the 2001 census revealed that 83,5% of South Africans are affiliated to a faith or religious system, including Christianity, Judaism, Islam, Hinduism, African Traditional Belief Systems, and other religious affiliations (Statistics South Africa, 2004). It has been established that there are "physical, emotional, and psychological effects of spirituality and religiosity … (and that) … for many individuals, spirituality and religion are central and foundational aspects of their lives and their well-being, and thus critical elements of the counseling process and interpersonal dynamic" (Brown, Carney, Parrish, & Klem, 2013, p. 108). Religion and spirituality are described as being able to assist people in making decisions both at a personal and at a group level in order to solve problems and cope with life experiences which can alleviate symptoms of anxiety and depression, regardless of personal religious and spiritual identity (Brown et al., 2013). It is suggested that "faith gives meaning and purpose to the sacrifices the family make in caring for their deaf or hard of hearing child … (and) … families find comfort, guidance, and strength through spiritual resources" (Ahlert & Greeff, 2012, p. 402) but only if a faith system is not imposed on the caregivers. If a faith system were to be imposed on the caregivers, it could be perceived as a form of social control (Thoits, 2011) over the caregivers.

In light of the preceding discussion with regard to religion and spirituality, in South Africa, some people ascribe to African Traditional Belief Systems and it is reported that 70% to 80% of people in South Africa consult with traditional healers (Day & Gray, 2008). Within the structural dominance of the WHO, traditional medicine is described as "including diverse health practices, approaches, knowledge and beliefs incorporating plant, animal, and/or mineral based medicines, spiritual therapies, manual techniques and exercises applied singularly or in combination to maintain well-being, as well as to treat, diagnose or prevent illness" (WHO, 2002b, p. 7). However, the WHO makes a distinction in its terminology where the term 'traditional medicine' is used when referring to Africa, Latin America, South-East Asia, and/or the Western Pacific while the term 'complementary and alternative medicine' is used when referring to Europe and/or North America (and Australia) (WHO, 2002b) which may allude to a North-South divide in terms of the attitudes regarding traditional methods.

More specifically to South Africa, the use of traditional healing is passed down from "ancestors to descendants or from generations to generations, with or without written documentation, whether supported by science or not, and which are generally used in traditional health practice" (Traditional Health Practitioners Act 2004, 2005, p. 6) and a traditional healer is considered

> someone who is recognized by the community in which he lives as competent to provide health care by using vegetable, animal, and mineral substances and certain other methods based on the social, cultural, and religious background as well as the prevailing knowledge, attitudes, and beliefs regarding physical, mental, and social well-being and the causation of disease and disability in the community (Pretorius, de Klerk, & van Rensburg, 1993, p. 5).

People also seek traditional healing with regard to deafness due to a strong belief that supernatural factors can cause deafness (de Andrade & Ross, 2005; Swanepoel & Almec, 2008). Caregivers may seek traditional healing paths in the diagnosis of their children's deafness and the subsequent actions around the deafness (Louw & Avenant, 2002) while attaching meaning to disability within the traditional belief system (Saloojee, 2006) because illness and disability are believed to be culturally specific and culturally treated (Ellis, 1996; Friend-du Preez, Cameron, & Griffiths, 2009). Within the traditional belief system, illness and disability are experienced within a different dimension to the one in which allopathic medicine is practiced and the interpretation of symptoms is bound by cultural beliefs (Ellis, 1996) which means that they cannot be treated by allopathic medicine because they have a social and spiritual basis, including: bad luck/misfortune, traditional poisoning, bewitchment, bad spirits in the house or body, sexual health and reproductive problems, mental illness, and epilepsy amongst others (Nattrass, 2006). This knowledge "is stored in people's memories and quotidian activities and is expressed in stories, folklore, proverbs, myths, cultural values, belief systems, rituals, metaphors, idioms, local language artefacts" (Raza & du Plessis, 2003, p. 41).

The services of traditional healers are often sought because there is a perceived congruence between what people seek from the traditional healers and what the traditional healers can offer. People strive for an explanation from traditional healers and therefore attention is directed to "the why and looks into the anxiety which accompanies the disease. Put differently: modern medical practitioners diagnose and treat disease (abnormalities in the structure and functioning of bodily organs and functions) while traditional healers treat illness (human experience of disease)" (Pretorius et al., 1993, p. 18). At the same time, people may engage in medical pluralism where traditional and allopathic routes are followed with regard to deafness (de Andrade & Ross, 2005). However, despite the accepted benefit which people derive from receiving traditional treatments with regard to deafness, some have proved to be ineffective and even harmful and people ought to be aware of these too (de Andrade & Ross, 2005) in the same way that not all allopathic medicine is always beneficial.

Therefore, it is important to understand how people internalise and accept deafness to "anticipate and understand the decisions of culturally diverse families … (and) … to adjust service delivery to the family's beliefs about disability, health and healing" (Louw & Avenant, 2002, p. 147), regardless of the religion, faith system, or belief.

3.10.2. Causality, culture, and rumour as structural components of faith systems.

In looking to provide support to caregivers of deaf children within the context of South African and supposedly framed within the notion of ubuntu or African humanism, a concept which will be elucidated in the next chapter, it is necessary to explore notions of causality, culture, and rumour so as to better understand caregivers' navigation of the faith landscape. Cultural processes need to be included in the exploration of deafness so as not to lose the human dimension of deafness (Corker, 1998). Disability, it is argued, "is shaped by the human circumstances in which it exists" (Ingstad & Reynolds-Whyte, 1995, p. ix) and "a range of barriers and facilitators in the person's life context" (Schneider, Eide, Amin, MacLachlan, & Mannan, 2013, p. 1). Proximal causes are biological and organic while distal causes are societal, environmental and political and there has been a shift from a "monocausal to a multifactorial account of disease causation, which involved not only the agent but also the host and the environment" (Krieger, 2008, p. 223) including an analysis of the power relations, that is: class, race and gender inequality, as well as the material conditions, that is: processes, production, and the consumption of goods in society. Therefore, there is an argument that causality does not have a linear or a direct relationship with the manifest disability. Instead, there are numerous variables which may affect the presentation of a disease or disability, many of which appear, on the surface, unrelated, but which may be very directly related. Within the biomedical paradigm, the 'what' and 'how' of the illness is important while in the traditional paradigm, the focus is on the 'why' (Ellis, 1996). Within the traditional African context, there is always a reason for an illness and "the reason is the most important aspect of the disease – more important than an exposition of the illness itself. In the African traditional setting 'Why am I ill?' is more important than 'What is the nature of my illness?'" (Kubukelli, 1999, p. 24). Because of this very strong cultural influence on the meaning of illness, decisions around causality appear to be culturally driven.

Rumour and gossip may interact in the process of establishing the reason for the disability, an important question within the traditional paradigm (Kaler, 2009) where rumour refers to the lack of veracity in an account which is widely circulated in the community but which has not yet been proven to be true while gossip is described as something that was told in secret and in confidence and therefore alludes to an element of truth upon which moral judgements are made (Stadler, 2003). This rumour and gossip may impact on way the disability is accepted, especially if the cause or the reason for the disability is incorrectly ascribed but especially because rumours and gossip are difficult to disprove which tends to add weight to their perceived, even if unfounded, veracity (Stadler, 2003). In South Africa, "gossip has immense social power; it is almost impossible to trace the source of the story and control its flow … (and it can) construct moral texts that shape responses" (Stadler, 2003, p. 359). Moreover, rumours can guide people's behaviour, even if the rumour is not necessarily believed to be true because "even the most superficially bizarre rumours can be credible if they can explain conjunctions between day-to-day experiences and larger historical processes in which the people who disseminate the rumours are involved" (Kaler, 2009, p. 1714). Therefore, members of people's social network can exert social control when they "monitor, encourage, persuade, remind, or pressure" (Thoits, 2011) people which applies to the social control experienced by caregivers of deaf children when, due to rumours, they engage in certain practices, such as faith based practices or traditional healing, even if they are in disagreement with them or if they do not believe in those practices.

3.10.3. Language and culture as structural entities.

Language and social actions structure people's interactions where "language does not merely reflect an already existing social reality; it also helps to create that reality" (Ahearn, 2001, p. 111) and language is a central component of culture and the transmission of what culture means (Davies, 2001). South Africa is in a particularly interesting position in its interaction with a multilingual population because, despite the equal status ascribed to all of South Africa's 11 languages in the constitution, that is, Sepedi, Sesotho, Setswana, siSwati, Tshivenda, Xitsonga, Afrikaans, English, isiNdebele, isiXhosa and isiZulu (Constitution of the Republic of South Africa, 1996). English is the dominant language (Hussey, 2013; Kathard et al., 2011; Posel & Casale, 2011; Thobejane, 2013) and this dominance is internalised with the knowledge that language and power are intricately intertwined and that language can reinforce power and domination (Ahearn, 2001). Within these power dynamics, English is considered a language “spoken by the elite and the successful, while African languages are considered to be low in status, most useful in the private sphere of social and cultural interactions” (Posel & Casale, 2011, p. 450).

Multilingual considerations take on a different flavour in South Africa when compared to other multilingual settings because the research in other countries tends to focus on multilingual immigrant communities such as in the United States of America, the United Kingdom of Great Britain, and Australia (Penn, 2002) where English is the dominant language and immigrant languages need to be accommodated. However, South Africa’s position is very different in that English is the dominant language and the other 10 official languages are not used by immigrant communities to South Africa but by South Africans themselves within structures which are English dominant. That is, accommodation is made to the other 10 South African languages as though they are foreign languages when these less dominant languages are used in formally structured settings such as government, hospital visits, and schools, amongst others. Therefore, South Africans, in their use of their South African home languages are treated as though they are immigrants in their own country.

The dominance of English over other languages is a historical legacy in South Africa where language was a way of “alienating the majority of the population from the political and economic core of the country” (Posel & Casale, 2011, p. 450) by relocating black people to eight homelands within South Africa based on ethnicity and language (Thobejane, 2013) so that, even in a post-apartheid context, “previously disadvantaged groups of people continue to be marginalised and to experience this power imbalance” (Hussey, 2013, p. 190). This point is particularly relevant since it has been found that there is a positive relationship between dominant language skills and market labour outcomes in South Africa where people who speak English have higher average monthly earnings than those people who are not proficient in English (Posel & Casale, 2011). Therefore, it seems as though English is a structural entity in people's contexts in which they have to manoeuvre so as to achieve better outcomes, for example, in the completing the necessary forms when applying for state financial assistance, for securing higher paid employment, or for accessing information resources, amongst others.

Within this context, speech-language therapy and audiology services perpetuate that dominance in that most practitioners are not first language speakers of the various other languages of South Africa (Swanepoel, 2006). This dominance means that within medical interactions, under which many audiological interactions occur, "patients may even blame themselves for their own linguistic inability rather than hold health professionals accountable for the decreased quality of care" (Hussey, 2013, p. 190). There is a reminder that this hegemony of one language over another can "marginalise those who may not be able to acquire English easily: older patients and people with low socio-economic circumstances or poor inter-cultural and linguistic exposure (characteristic of rural areas)" (Hussey, 2013, p. 193). It has been suggested that interpreters can facilitate cross-cultural and multilingual consultations because of their proficiency in another language and their cultural identification with the people who attend for these consultations (Penn, 2002). Interpreters, as is discussed elsewhere in this thesis, do more than just interpret one language into another; they also mediate the contextual meaning and knowledge between the speaker and the listener. Within interactions with clients, audiologists ought to take the advice that, when calling upon people to serve as interpreters, competence or partial competence in a second language is not sufficient qualification to serve as interpreters and there is the call to train interpreters appropriately (Hagan et al., 2013). Therefore, it is insufficient to just call on anyone to serve as an interpreter in a consultation with someone of a different language. Unfortunately, the South African experience is replete with examples of calling upon people who are available such as "family members (often small children), cleaners, administrative staff, other patients or any ad hoc bilingual" (p. 192) to serve as interpreters which raises ethical concerns around ensuring confidentiality and about being legally accountable for mistakes (Hussey, 2013).

3.11. Accounting for context

Particularly in the field of deafness, there is the need to account for the political, cultural, social, and linguistic dimensions highlighted in Chapter 2. Within the predominant medical paradigm, there has been a call for practitioners to be more culturally competent (Kleinman & Benson, 2006) so as to "gain a better understanding of a patient's experience" (Hussey, 2013, p. 193). However, cultural competency ought not be reduced "to a technical skill for which clinicians can be trained to develop expertise" replete with a list of "do's and don'ts" as it may run the risk of stereotyping people (Kleinman & Benson, 2006, p. 1673) instead of garnering a personal sensitivity with other people. Crucially, culture is "not a monolithic phenomenon" (Penn, 2002, p. 96) nor is it homogenous or static (Kleinman & Benson, 2006). In order to more fully understand people and their experience, it seems appropriate to tune into people's "family, gender, artefact, history, geography, religion, education, myths, and attitudes" (Penn, 2002, p. 96), as well as the economic, political, psychological, and biological (Kleinman & Benson, 2006) variables within their contexts.

In audiology, specifically, it is suggested that audiologists and others who work in multicultural and multilingual South Africa ought to show cultural competence (Penn, 2002; Swanepoel, 2006; Swanepoel & Almec, 2008) in their interactions. There is the assertion that

> it is within this multiracial, multilingual, and multicultural context that the field of audiology in South Africa has emerged over the second half of the previous century as a hearing healthcare profession aimed at providing quality services to meet the diverse needs of the entire population (Swanepoel, 2006, p. 262).

However, this aforementioned reference remains embedded within the biomedical paradigm by referring to “healthcare” and does, therefore, not open itself up completely to a more personal and social approach to deafness although it appears to be an attempt at consolidating the contextual and the biomedical considerations. Furthermore, when describing the field of audiology, it has been said that

> South Africa is characterized as a multicultural society and has great diversity in geography, language and culture. Currently, the majority of early interventionists belong to a minority cultural group and cultural mismatches between professionals and the clients they serve exist, which is further compounded by language barriers (Louw & Avenant, 2002, p. 146).

Notwithstanding its reference to social factors, the biomedical perspective is perpetuated by the use of the term “interventionists” while it also problematizes South Africa’s multicultural society by referring to language “barriers” instead of alternatives such as ‘differences’ or ‘diversity.’ Furthermore, besides the call for more culturally competent and family sensitive interactions in audiology, the biomedical paradigm is entrenched by referring to “hearing loss” in the following reference, despite the reservations around the use of that term raised earlier in this thesis:

> These differences necessitate professionals to develop cultural competence and become committed to honouring cultural diversity through the services provided to families of young Black children with hearing loss. However, each family is unique and should be regarded as an individual unit with its own values, beliefs, practices and needs (Louw & Avenant, 2002, p. 145).

Moreover, this reference reflects a wider literature which seems to dwell on differences between people which could cognitively entrench the notion of difference and othering, especially in reference to ‘Black’ children which excludes any cultural competence in the interactions with people of different races in South Africa including immigrant communities who may not be black. There seems to be the suggestion that race is equated with culture which is not necessarily the case and so this conflation of race and culture suggest that in interactions with people of different races, erroneous cultural attributions could be made which could be damaging to the interactions especially because, as stated earlier, "cultural processes frequently differ within the same ethnic or social group because of differences in age cohort, gender, political association, class, religion, ethnicity, and even personality" (Kleinman & Benson, 2006, p. 1674).

However, there is a suggested Western bias and paternalistic stance when making reference to people of other cultures as exemplified by this reference to culture as a cause for ignorance when interacting with people from other cultures on the topic of disability: "especially in developing countries where concerns have been raised of cultural-based ignorance and resistance towards childhood disabilities" (Swanepoel & Almec, 2008, p. S48). It is proffered

> that the burgeoning area of narrative medicine is particularly fruitful as a cross-cultural focus point as it has the potential to minimise the cultural barriers which may exist in more structured clinical interview settings … (and) … that the multiple roles of the interpreter may extend to that of facilitator through the narrative genre for effective clinical interactions (Penn, 2002, pp. 95-96).

There is a call to recognise the value of the narrative in within clinical interactions and to be more sensitive to the multi-lingual and multi-cultural dimensions of these interactions while paying special attention to the potentially valuable contribution of interpreters (Penn, 2002). The role of the interpreter could be extended to one of a "cultural broker" who is described "as a go-between, one who advocates or intervenes on behalf of another individual or group … from diverse backgrounds" (Andrews et al., 2010, pp. 129-

130). The value and contribution of the culture broker is reinforced throughout this thesis, although within this thesis, I make reference to a ‘mediator’ rather than ‘broker’ because the role is one in which they consider the audience and the context to mediate meaning, not just transfer information from one party to another. Notwithstanding the recognition of the value of the narrative and the interpreter within interactions within diverse settings, the focus appears to be on clinical interactions which may limit the application of such recommendations to other, non-clinical interactions. Also, again reference is made to “barriers” which may negatively load the idea of cultural diversity and may suggest the need to overcome “barriers” rather than engage with diversity and appropriate it within interactions.

Therefore, context appears to be an essential component of experience and according to the psycho-social ecological theory, there exist different levels of influence on children’s development and that “human development takes place through processes of progressively more complex reciprocal interaction between an active, evolving biopsychological human organism and the person, objects, and symbols in its immediate environment” (Bronfenbrenner, 1994, p. 38) or context, which, “like concentric onion peels, the ecological environment is a series of successive layers, each surrounding a smaller sphere” (Hook, 2009, p. 504). These layers represent different environmental systems of development as depicted in the adapted Figure 3.3 (Bronfenbrenner, 1994; Hook, 2009) where accommodation is made for the interaction between levels and for the movement between the levels through ecological transitions during the lifespan while acknowledging the meaning which people ascribe to their contexts (Hook, 2009).

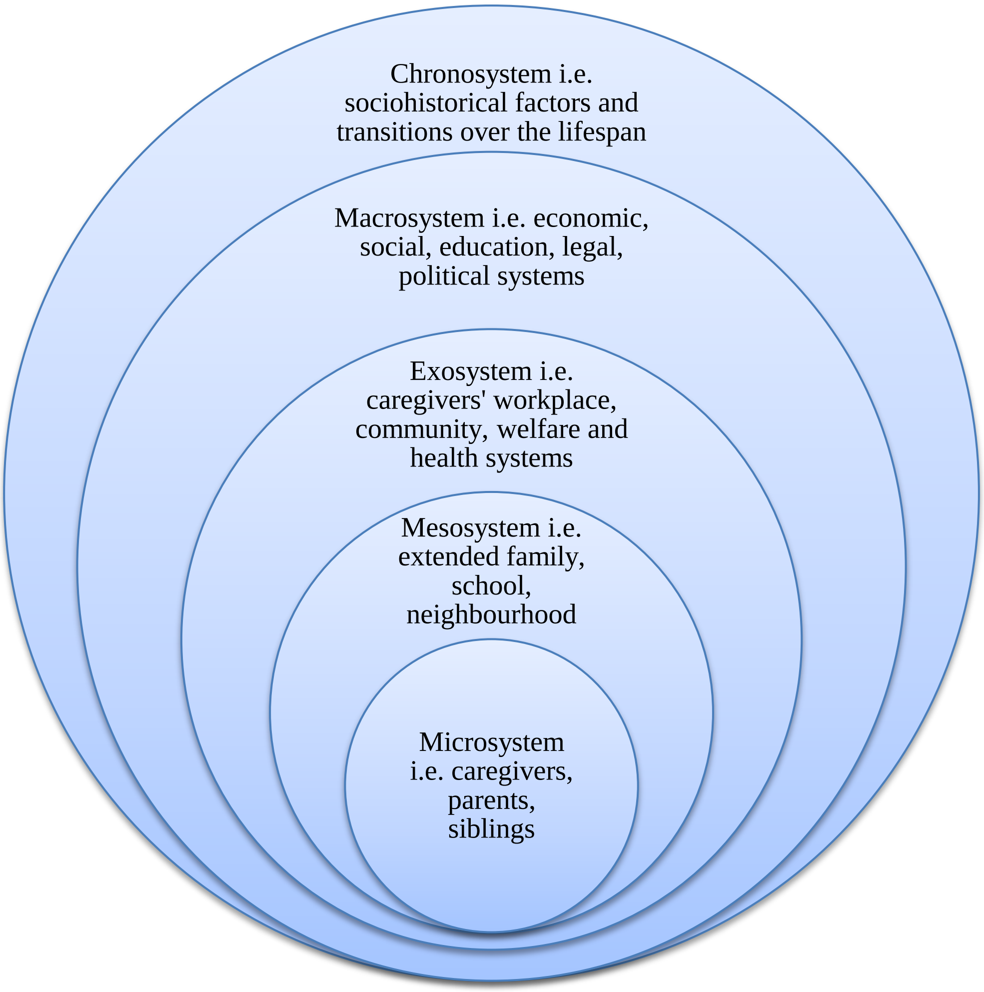


Figure 3.3. Bronfenbrenner's levels of ecological influence on human development

Ecological theory's recognition of the importance of context and the interaction between people and their contexts can be extended to deafness too as this chapter has revealed that contextual factors impact on the experience of deafness as do the material interactions between people and their contexts while acknowledging the meaning which people attach to experience, a point also made in this thesis. However, in using a purely ecological approach, it appears as though the levels or layers of influence envelope the other layers which creates a sense of a hierarchy of influence which may suggest that these levels of influence, regardless of the interactions between them, are discrete and that the components of those levels cannot exist in more than one level. This layered level approach presumes that some levels have more weight and influence rather than recognising that at different times, in different contexts with different agents and structures, some of the components within the layers and some layers may exert more influence and may occur higher in the hierarchy of levels; caregivers may ascribe a different value to the same domain at different times and different contexts. It means that one template of ecological hierarchy cannot be flatly imposed on the caregivers' experience because it is different for caregivers of different backgrounds and at different times when caregivers fulfil multiple and different roles at different times and contexts. For example the same person can, simultaneously, not discretely, be aunt to a deaf child for whom she has assumed the caregiver role while being mother to her own children, wife to her husband, daughter and daughter-in-law. Because caregivers exhibit different degrees of agency within different structures, a universal hierarchical model may not fully explain their experience since the agents may be the same, but their agency with regard to the different domains may not be the same in different contexts with their particular structural characteristics.

Related to the ecological approach, the ecosocial approach (Krieger, 2001) espouses that biology and people’s contexts interact and that these contexts, present and past, determine people’s biological state in the form of embodiment, topics which were discussed earlier in this chapter. With regard to audiology, attempts have been made to describe deafness within an ecological model (Noble & Hetu, 1994) and even an ecohealth model (Borg, 1998). These approaches could be useful in understanding the interplay between context and deafness because they also recognise the value of the context on the experience of deafness. Importantly, there is the recognition of individualist contexts which promote the individual’s response to deafness and collectivist contexts which promote the society’s response to deafness (Noble & Hetu, 1994) while also recognising that it is not just the context, but the interaction between people and their contexts which matters because “ecology is the science of the interaction between the individual and the environment” (Borg, 1998). Tenets of these approaches could be very useful in the understanding of context as highlighted earlier. However, these approaches have been described within an epidemiology framework and remain quite oriented towards the medical paradigm where there is an epidemiological interest in causative inferences but where “many of the exposures epidemiologists are interested in coexist and are jointly embodied - not necessarily because they are causally connected, per se, but because they are entangled by the ways people actually live in their societal context, replete with constraints as well as possibilities” (Krieger, 2007, p. 661).

Therefore, in recognition of the value and contribution of the ecological and ecosocial perspectives, I suggest that a contextual and interactional approach appears more respectful of the caregivers of deaf children in that recognition is given to interactional nature of the different domains simultaneously. It is imperative and respectful to consider these meaning laden contexts because they influence people’s experience and the interpretation of that experience and they include socio-economic contexts (historical, economic, social, political, poverty, employment, education, and geographical elements), sociocultural contexts (family structure and dynamics, language, arts, religious practices, values, traditions, customs, child rearing practices, beliefs, history of oppression, prejudice), and individual contexts (age, gender, size, appearance, physical, psychological and emotional state, education, and occupation) (Andrews et al., 2010, p. 81S & 55S). These contextual considerations can apply to deafness too as outlined in Figure 3.4 (Andrews et al., 2010; Denzin & Lincoln, 2011; Kleinman & Benson, 2006; Penn, 2002).

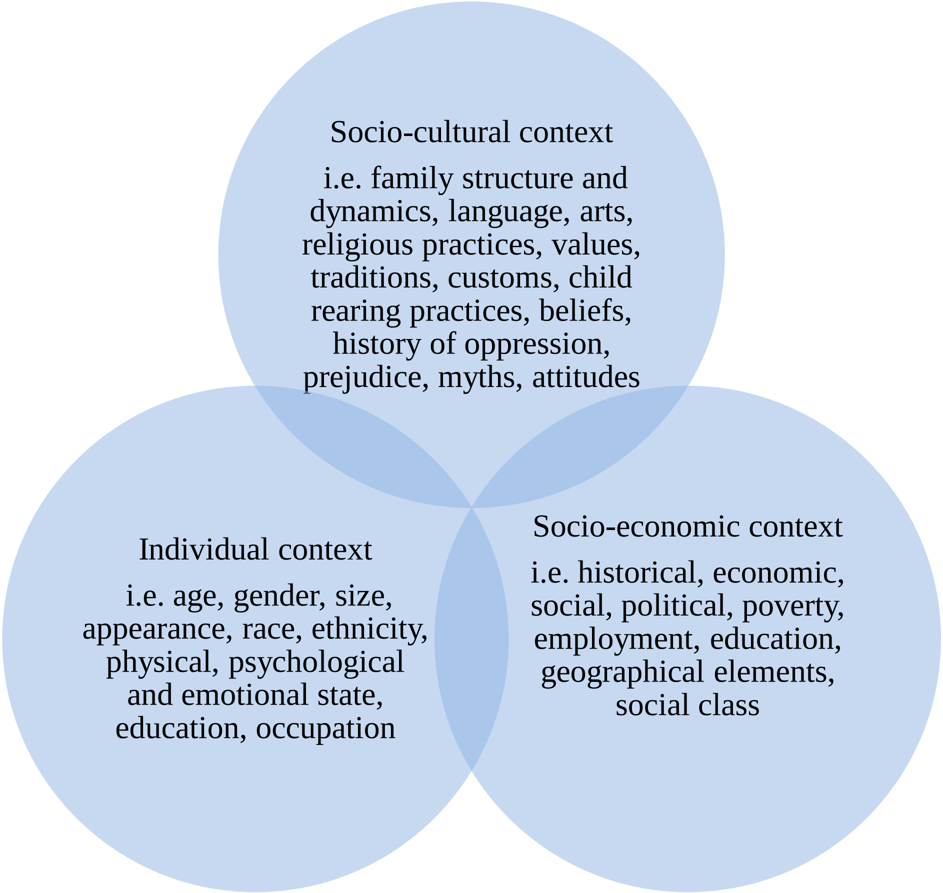


Figure 3.4. Contextual considerations in the caregivers' experience

This figure shows that no particular hierarchy is ascribed to any one of the contexts while also recognising that they do not exist in isolation, for example, the individual context is shaped by the socio-economic and socio-cultural contexts and these two afore mentioned contexts are populated by the individuals. Therefore, the context and the individual cannot and ought not to be disaggregated as they occupy different positions simultaneously and are contingent on each other.

3.12. Chapter Summary

Therefore, I suggest that, in order to more fully and wholly connect with deafness in South Africa where deafness is often conflated with disability and where deafness is an experience of deafness is an embodiment of the context, there is the need to show a contextually attuned sensitivity that transcends just language and culture. This attuned sensitivity promotes the recognition that different contextual factors carry different weight and value to different caregivers and so there ought not to be a relegation of contextual factors to the periphery of caregivers' experience. The recognition that these domains interact simultaneously, not discretely, means that one domain can be influenced by different contextual variables. By exploring caregivers' experience where they live and through the use of a qualitative method, a language and culture mediator, and ethnographic interviews, I propose that it offers an opportunity for audiologists to understand the things that matter most with regard to deafness, people who are deaf, and the significant others of deaf people while also creating an opportunity for audiologists to reflect on themselves, their practice, and their interactions and relations with the people with whom they engage. In other words, I suggest a contextually attuned, respectful, sensitivity based on a mediated analysis and interpretation of people's experience of multi-faceted domains.

Chapter 4: Caregivers of Deaf Children

“We are our grandmothers’ prayers.

We are our grandfathers’ dreamings.

We are the breath of our ancestors.”

(Barnwell, 1993, p. 128)

Figure 4.1. This photograph represents the recognition for the caregivers’ need for support to address their contextual challenges related to, for example, unemployment and poverty.

It also symbolizes that the structures which are meant to support caregivers may not be fully available to caregivers in this rural context. The quotation above the photograph represents the manifestation of history on the caregivers of deaf children’s’ call for support today.

4.1. Recognition of the Caregivers' Experience and their Human Right to be Recognised

It is acknowledged that "the health and well-being of caregivers is the single most important contributor to ensure child health and survival, and to create conditions that enable children to meet their developmental potential" while "caregivers living in adverse conditions face a broad range of challenges that may affect their ability to be effective parents and to promote early child development" (Tomlinson, 2013, p. 56). Similarly, it acknowledged that the rights of people with deafness have to be respected (McPherson, 2011) because people who have access to the necessary and required deafness-related support and hearing amplification feel that their human rights are more fully recognised (McPherson, 2014). Nonetheless, despite acknowledging the children's experience, the children's needs, the impact on their children's well-being, and the deaf children's human rights, attention ought to be focussed on the caregivers themselves, not only as providers of care to children, but as caregivers in their own right and there is a call to make the position and experience of caregivers more "visible" (Munford, 1994, p. 268). Caregivers' human rights ought to be recognised and they need to be accorded the right to be heard. It has been suggested that research ought not only look at caregivers as "passive participants" who pose a "professional/practice problem" (Munford, 1994, p. 268) but that we recognise their agency and their resilience (Young, 1999, p. 170) and, therefore, accord them the human dignity and value to be recognised and acknowledged. Focus ought to be directed to "underpinning values such as democratisation, service user empowerment, and the redistribution of unequal power relations" (Petriwskyj, Gibson, & Webby, 2014, p. 119) so as to empower people to the status of citizens where this citizenship approach tries to foster participation within their delineated contexts (Petriwskyj et al., 2014).

However, when it comes to deafness, caregivers may not always have agency as it is argued that there are "unique challenges faced by hearing parents of deaf children" (Poon & Zaidman-Zait, 2014, p. 176) and they may confront structural obstacles in their enactment of agency related to the forms of present and past structures which can impede their enactment of agency. In trying to enact agency, caregivers may not have the self-efficacy (Bandura, 1982), a concept which will be explored later in this chapter, to do so. Therefore, there is a call for attention to be directed at caregivers too because "the focus has been on mortality and morbidity, and less on the broader components of caregiving such as mental health, social and emotional support, accessing social grants, and parenting skills" (Tomlinson, 2013, p. 58). This focus on the caregivers is necessary because there is the need to support caregivers with regard to the

> adjustment to the diagnosis; planning for the future as well as the present; securing appropriate programmes, services, and equipment; and dealing with additional financial and childcare pressures … (as well as) decisions about communication mode, hearing aids, and speech training … (and) … future school placement options (Meadow-Orlans & Sass-Lehrer, 1995, p. 315)

More specifically, it seems necessary to extend the exploration to include other primary caregivers of deaf children, not only biological parents. The existing research seems to focus on parents' experiences which does not account for the reality in South Africa where the primary caregivers of deaf children can be other people besides the children's biological parents (as per these few reference examples although, throughout the thesis and in the reference list, there are further references: Antonopoulou, Hadjikakou, Stampoltzis, & Nicolaou, 2012; Coleman & Karraker, 1997; Hintermair, 2006; Jackson et al., 2008; T. L. Jones & Prinz, 2005; Meadow-Orlans & Sass-Lehrer, 1995; Pipp-Siegel, Sedey, &

Yoshinaga-Itano, 2002; Poon & Zaidman-Zait, 2014; Swanepoel & Almec, 2008; van der Spuy & Pottas, 2008).

4.2. Caregivers' Experience: Multidimensional Considerations

Broadly, caregivers can be said to offer formal and informal care where formal care refers to paid work by professionally trained care workers while informal care is "generally provided by untrained social network members (family or friends), usually in the absence of any monetary compensation" (Timonen, 2009, p. 307) except for the possibility of social assistance in the form of a financial grant (van den Berg, Fiebig, & Hall, 2014). Informal caregivers tend to submit to the structural and power-laden "expectations attached to gender, marital, or family status" (Timonen, 2009) and "may also feel a sense of obligation or duty to provide care" (van den Berg et al., 2014, p. 124) with little external support for a role which caregivers may assume unexpectedly (Kidman & Thurman, 2014) and with little preparation, planning, or choice (Raina et al., 2004) especially for women in Africa who, while carrying the responsibilities for childcare, housekeeping, and the health of their families, may have their own needs overlooked by themselves and by their families (Mundell, Visser, Makin, Forsyth, & Sikkema, 2012).

It seems as though the caregiver role is multidimensional and complex in that caregivers have to navigate a variety of challenges and still find a sense of positivity within their experience. The caregiver role for children is dynamic because different roles and responsibilities are assumed over time and at different stages in the children's lives (Raina et al., 2004). Moreover, within a context of poverty, unsupportive communities and continued financial difficulties may curtail "the amount of personal control that they feel they are able to exercise" (Coleman & Karraker, 1997, p. 63).

Notwithstanding these very real challenges, especially within a context of poverty and limited resources such as in South Africa, the focus appears to be on these challenges. There appears to be little reference to the positive experiences related to caregiving which can include the sense of satisfaction, altruism (van den Berg et al., 2014), enlightenment, and exhilaration (Coleman & Karraker, 1997) as well as the personal gratification and the sense that they are fulfilling their social responsibility, especially because caregiving "confirms social norms and generates social approval" (Lin, Fee, & Wu, 2011, p. 4). This social approval is skewed in terms of gender which means that "because women are socialized to nurture, they provide more help with hands-on tasks and longer hours of care than men" but "when men carry out caregiving tasks, they are more likely than women to be praised for their care provision" (Lin et al., 2011, p. 6). Over and above the social recognition, for some caregivers, the role may provide "purpose and meaning in life, which in turn guards against anxiety and existential despair" (Thoits, 2011, p. 148), especially if there is a sense of control or mastery in consistently, frequently, and repeatedly fulfilling the necessary and required role obligations (Thoits, 2011). This gendered role is further observed in the types of support caregivers receive where "mothers of children with disabilities place a high value on emotional support and exhibit lower levels of stress if they receive support from professionals, whereas fathers are likely to seek information rather than emotional support and are less likely than their wives to be affected by professional support services" (Meadow-Orlans & Sass-Lehrer, 1995, p. 319).

Research into informal caregivers has focussed on the burden of their role and reports "that caregiving is exhausting, demanding and stressful, and therefore will have detrimental effects on physical and mental health. Scholars suggest that health impacts are particularly profound when caregiving is prolonged and support from other informal caregivers is absent" while also considering "the economic, social and emotional costs of caregiving" (Timonen, 2009, p. 312). Additionally, caregivers fulfill multiple roles in their lives including the roles associated with their families and places of work (Raina et al., 2004) as well as in their communities and social groupings. They, therefore, are said to experience caregiver burden which is described as "the physical, emotional, social, and financial hardship associated with caregiving" (Kidman & Thurman, 2014, p. 235) and includes objective and subjective components where the objective component includes the observable effects on, for example, the caregivers' financial or social situations while the subjective component describes the caregivers' perception of their roles (Kidman & Thurman, 2014). These different components impact on the caregivers' role and responsibility while they navigate their multiple roles and identities.

Caregivers who experience a higher burden of care are in greater need of support in order to protect their own physical and mental wellbeing, not to mention the wellbeing of those to whom they are caregivers (Kidman & Thurman, 2014). They may not access support from, for example family, friends, lay counsellors, or churches because "the sense of family obligation and family boundaries often keep caregivers from using these services" (Lin et al., 2011, p. 24). The caregivers' wellbeing is influenced by a range of factors which include the "characteristics of the caregiver, the recipient of care, their shared history, and the social, economic and cultural contexts within which they find themselves combine to create an infinite variety of circumstances from which stress may both originate and be managed" (Raina et al., 2004, p. 2). Therefore, it is important to consider a range of personal and contextual factors which can contribute to caregivers' wellbeing and to their agency which can include deference to authority, their previous experiences, life experiences, and consultation fatigue (Petriwskyj et al., 2014, p. 122). This consideration is especially necessary within contexts where support systems are weak and where caregivers encounter environmental stressors, they may have a reduced sense of efficacy in their caregiver responsibilities towards their children (Coleman & Karraker, 1997). More specifically, "social environments may place constraints on what people do or may aid them to behave optimally" (Bandura, 1982, p. 131).

4.3. Considering the Caregivers' Context: The South African Experience

There is a reminder that "caregiving does not occur in isolation from one's social and experiential past or present, thus it must be considered within this context" (Raina et al., 2004, p. 9). Therefore, it is necessary to acknowledge caregivers' "cultural identity, geographic location, ethnic/racial background" (Poon & Zaidman-Zait, 2014, p. 181) and to consider the diversity in caregivers' "spirituality, views on health and disability, child rearing, help-seeking, and family structure" (Moeller, Carr, Seaver, Stredler-Brown, & Holzinger, 2013, p. 432), not to mention the other contextual factors which were highlighted in Chapter 3, for example, historical factors, amongst others. Therefore, there is also a call to recognise caregiver burnout and to make the necessary referrals in light of the caregivers' needs (Albino & Berry, 2013) and conditions of poverty in which they and their families live, especially because of the significant responsibilities of care which they carry.

When considering context, in South Africa, it is reported that caregivers may have to confront challenges in caring for children such as "material deprivation, low levels of education, lack of access to jobs and services, social isolation, mental and physical ill health, and domestic violence" while cognizant of the "epidemics of HIV, alcohol, drug abuse and under nutrition compounded by non-communicable diseases and poor access to basic services and educational opportunities" (Tomlinson, 2013, p. 56). Also, as has been highlighted earlier in this thesis, access to literacy was compromised during apartheid and the consequences of poor literacy development may extend to caregivers' restricted access to health literacy, the dominant discourse in which the literature around deafness is often presented.

Additionally, the caregiver context in South Africa is characterised by the ineffable consequences of HIV/AIDS and it is reported that of the 4 million orphaned children in South Africa (Department of Health and Department of Basic Education, 2012), about 2 million children are AIDS orphans (Kidman & Thurman, 2014) which may compound the caregiver burden related to poverty and food insecurity, especially amongst caregivers who live in rural parts of the country and even more so for those caregivers who may themselves have HIV/AIDS (Kidman & Thurman, 2014). Within Mpumalanga specifically, it is reported that there has been a fall in the average life expectancy from 72 years of age to 60 years for women and 66 years of age to 52 years for men in approximately 10 years (Goudge et al., 2009). Therefore, the caregiver burden is accentuated when they have concerns about their wellbeing and possible death which, in the absence of other caregivers' assuming that role, may leave their children in child-headed homes. In the wake of the HIV/AIDS pandemic it is reported that as many as 82 000 children live in about 47 000 child only households in South Africa (Meintjes & Hall, 2013).

In South Africa, caregivers of children with disabilities may experience isolation from their communities because of "persisting stereotypes of disability which continue to exclude adults and children with disabilities from mainstream society" (Department of Social Development et al., 2012, p. 20) and "children with disabilities are frequently viewed by society as objects of pity and deserving (only) of charity" (Department of Social Development et al., 2012, p. 14) rather than cooperation. Especially within rural settings, caregivers and families of children with disabilities are directly linked to the child, in other words, they are extensions of the children and they share in the disability experience where

> people with disabilities are not a visible population because many of them are not on the streets, in the workplace or in the taxi. Children with disabilities are still found locked away by ashamed families. … Disability obstructs livelihoods, incurs a wide range of costs, and plunges entire households deeper into poverty because the family foregoes income generation opportunities to provide care (Sherry, 2013, n.p.).

Within a context of limited resources, caregivers may face situations where sustaining life and the family may take precedence over other matters such as deafness (Swanepoel, 2006). Therefore, caregivers of children with disabilities appear vulnerable and could benefit from support, such as the psycho-social support from counselling, over and above the financial support which they may receive from the government (Albino & Berry, 2013). Caregivers can benefit from validation of their role because, when it comes to disability, there may be a diminishing of the caregivers' role because it "does not relate to any notion of production and is not measured in economic terms" and is not "rated as an economic activity contributing to the well-being of society" (Munford, 1994, p. 276).

4.3.1. The assumption of the caregiver role in the South African context.

Many children in South Africa grow up living with other relatives, not necessarily with their biological parents (Meintjes & Hall, 2013). Although the legal terminology refers to a caregiver as someone other than a parent or a guardian, in the South African context caregivers tend to be the people who assume the care of children, be it through assignment of the role or by assumption of the role. This assumption of the caregiver role is not necessarily always a formal and legal arrangement as the Department of Social Development admits that the formalisation of the transfer of the caregiver role within the extended family "requires a report by a social worker to the children's court, and it is a time-consuming and often delayed process, with huge backlogs reported" (de Villiers & Giese, 2008, p. 9). Therefore, the following definition of caregivers is offered which seems to fit the South African context: “Primary caregivers may be biological or foster parents, grandparents and others responsible for the day-to-day care of the child at home” (Berry et al., 2013, p. 28). Within the South African context, the stereotypical notion of the nuclear family is broadened where kinship may be extended beyond the concept of the conjugally based family (Makoni, 2008) and the idea of caregiver is extended so that the “terms alloparent, allomother, or allomaternal caretaker are used to describe individuals such as father, older siblings, grandparents, uncles, and aunts who provide care and resources to offspring” (Bock & Johnson, 2008, p. 133). This idea that the caregiver can be anyone in the family may reflect the notion that everyone seems to share in the responsibility of child rearing, a notion which is also found in relation to deaf children where research has shown that, in South Africa, extended families are also involved in the care of deaf children (Louw & Avenant, 2002). According to custom, it is believed that “all children are accepted as part of the house into which they are born” (de Villiers & Giese, 2008, p. 6). The caregiver role may also not be completely fixed because of child mobility in South Africa which is ascribed to the death of children’s parents as well as “cultural norms, educational opportunities, the need for children to provide care to ill or elderly family members, and the need for children to be cared for by others” (de Villiers & Giese, 2008, p. 21). Grandparents, especially, have had to assume the responsibility for the duty of care for their grandchildren whose parents may have left, died or moved. It is reported that the extended family, especially grandparents, look after 90% of AIDS orphans in Sub-Saharan Africa (Ice, Zidron, & Juma, 2008) which places many grandparents in very difficult financial positions, especially because they have to provide for raising children and their roles have become extended so that,

> while grandparents in Africa are traditionally active participants in the care of grandchildren, they are taking on a new and greater level of responsibility as they

> become the sole caregivers for multiple children. In many cases, as they lose their adult children, the elderly not only increase their responsibility but also lose their main source of economic support (Ice et al., 2008, p. 112).

4.3.2. Structural definitions of caregiving: Children's Act, 2005 (Act No. 38 of 2005).

In light of the complexities of the South African context, it appears as though the designation of caregiver may take on different forms. According to law, in South Africa, a child is defined as "a person under the age of 18 years" (Children's Act, 2006, p. 12). According to the act, parental responsibilities are: "to care for the child; to maintain contact with the child; to act as guardian of the child; and to contribute to the maintenance of the child" (p. 25). With regard to the care of the child, the act calls for, amongst others (p. 25): "a suitable place to live; living conditions that are conducive to the child's health, well-being and development; and the necessary financial support" as well as the "safeguarding and promoting the well-being of the child and protecting the child from maltreatment, abuse, neglect, degradation, discrimination, exploitation and any other physical, emotional or moral harm or hazards."

The act also calls for "guiding, directing and securing the child's education and upbringing, including religious and cultural education and upbringing, in a manner appropriate to the child's age, maturity and stage of development" and the "guiding, advising and assisting the child in decisions to be taken by the child in a manner appropriate to the child's age, maturity and stage of development." It calls for "maintaining a sound relationship with the child" while, especially with regard to this study, "accommodating any special needs that the child may have." However, in light of the situation in South Africa in terms of its apartheid history, migrant labour and high rate of communicable disease, a child is not necessarily cared for by a parent and so it needs to be acknowledged that a caregiver, guardian or family member may assume parental responsibilities.

In terms of the act, a caregiver is described as “any person other than a parent or guardian, who factually cares for a child” and may include “a foster parent” or “a person who cares for a child with the implied or express consent of a parent or guardian of the child” (Children's Act, 2006, p. 11). The act includes the child’s parent in its definition of family, but also acknowledges that other family members may assume “parental responsibilities and rights in respect of the child” such as “a grandparent, brother, sister, uncle, aunt or cousin of the child” or “any other person with whom the child has developed a significant relationship, based on psychological or emotional attachment, which resembles a family relationship” (Children's Act, 2006, p. 14) and parental responsibilities are extended to the child’s guardian if the child does not have a parent (Children's Act, 2006).

4.3.3. Caregivers’ duty of support to their children: socio-legal aspects.

Legally, persons between birth and seven years of age, are referred to as infants and are only referred to as children between the ages of seven and 18 after which the person is known as a major (de Villiers & Giese, 2008). The mother is given guardianship of a child born out of wedlock while guardianship is shared by both parents if the parents are married under any system of marriage; if one of the married parents were to die, the guardianship is assumed by the surviving parent (de Villiers & Giese, 2008). If children are orphans, be they double orphans, maternal orphans or paternal orphans (Meintjes & Hall, 2013), then common law requires that the courts appoint a guardian to manage any aspects of the estate while under customary law, an orphaned child is always supposed to have a guardian in the form of the head of the family, usually the head of the father’s family (de Villiers & Giese, 2008). However, it is suggested that “urbanisation … and the impact of a labour economy on the movement and living arrangements of people, as well as widespread poverty have changed social practices" (de Villiers & Giese, 2008, p. 5). The role of grandparents is also defined by common law and customary law where under common law, grandparents have a duty to support their grandchildren while customary law extends that duty of support to blood relatives and marital relatives (de Villiers & Giese, 2008).

Constitutionally, the duty of support towards children does not automatically end at the age of majority but rather extends until children are able to support themselves independently, an extension which could apply to children who have disabilities. Also, that duty of support is revived should children, who were previously able to support themselves, are no longer be able to do so, even if they have reached the age of majority (de Villiers & Giese, 2008). The law seems to provide for the basic levels of support in terms of food, housing, clothing, medical care, and education but recognises that "these needs may vary from case to case and will depend on the age and other circumstances of the child" (de Villiers & Giese, 2008, p. 6). This recognition of the varied needs suggests that, for children who are deaf, different levels or types of support are needed. This duty of support is transferred to a guardian in the event that children are orphaned and this transfer can be officially by the courts or through customary law, notwithstanding that the law recognises that there are family complexities and cultural factors which need to be considered (de Villiers & Giese, 2008).

Any social insurance benefits designated for children can be collected by the people responsible for their duty of support because it is accepted that "these benefits are payable in the first instance for the maintenance of the child" (de Villiers & Giese, 2008, p. 7). However, even at government level, it is recognised that the policy does not meet the practice. For example, a report by the Department of Social Development (de Villiers & Giese, 2008, p. 7) concedes that, in situations of widespread poverty, "difficult family circumstances may easily incline a caregiver to use the child's monies for other more pressing needs." Another complication in the collection and in the use of monies set aside for children for whom the monies were designated, is the customary law expectation that the money will be used to meet families' benefit and not necessarily for the benefit of the children for whom the money was allocated (de Villiers & Giese, 2008).

4.4. Self-efficacy: a dance between belief and ability

People display self-efficacy when they successfully coordinate the cognitive, behavioural, and social resources available to them to achieve control over events in their lives and in their particular contexts (Bandura, 1982; Coleman & Karraker, 1997). In his work on self-efficacy, Bandura (1982) posits that people's belief about their efficacy and the action are related. Specifically, with regard to parents, and by extension, caregivers, parental self-efficacy is "the expectation caregivers hold about their ability to parent successfully" (T. L. Jones & Prinz, 2005, p. 342) and the "perceived ability to exercise positive influence on the behaviour and development of one's children … and carry out the designated role behaviours" (Coleman & Karraker, 1997, p. 58). Parenting and parenting competence "is multiply and complexly determined" (Hess, Teti, & Hussey-Gardner, 2004, p. 424) by proximal and distal factors (Hess et al., 2004; Krieger, 2008) where proximal factors include self-efficacy perceptions and distal factors include socioeconomic status. It is argued that "self-efficacy expectations are tied to one's perceived skills and outcome expectations are more environmentally based, incorporating both knowledge of requisite behaviours and perceptions of whether or not the social system will be supportive of one's actions" (Coleman & Karraker, 1997, pp. 49-50). Moreover, Bandura (1997) argued that self-efficacy was a mechanism of agency within people's environments, that is, within the structures which people navigate. That is, in relation to self-efficacy, agency is defined as "acts done intentionally that reflect an individual's perception that they are exercising influence over what they do …, the beliefs that what the person does will produce the intended outcomes" (T. L. Jones & Prinz, 2005, p. 342).

Caregivers who, due to contextual challenges to their parental self-efficacy (Coleman & Karraker, 1997) and unfamiliarity with certain events may have to, in an act of proxy control, hand over their parental responsibilities to others whom they perceive as more able, self-efficacious, empowered, and influential (Bandura, 1982). Because "self-percepts of efficacy operate as cognitive mediators of action," (Bandura, 1982, p. 126), people with positive self-efficacy have been found to be more adept at complex decision making, have better interpersonal relationships, display more assertive behaviour, and may have greater perseverance when confronted by challenging situations while those with low self-efficacy have greater self-doubt, more anxiety, learned helplessness, and higher stress (Coleman & Karraker, 1997). Therefore, caregivers who have low self-efficacy, when confronted with difficult, challenging, or stressful situations in their contexts, may withdraw from those situations when the demands placed on them exceed their ability to cope (Coleman & Karraker, 1997), exceed their capabilities, or when they experience the possible subsequent sense of futility, despondency, and resignation (Bandura, 1982) thereby surrendering completely (Hess et al., 2004). Proxy control may occur when there exist challenges to caregivers' interactive capacities with their children when they have difficulty interpreting and responding to their children (Hess et al., 2004) as in the case of hearing caregivers of deaf children who often use different language modalities to those of their children.

The need for proxy control (Bandura, 1982) seems to occur especially when caregivers experience high levels of stress (Coleman & Karraker, 1997), have children with special needs, and when caregivers find themselves in situations of socioeconomic disadvantage (T. L. Jones & Prinz, 2005) and "people grudgingly relinquish control to technical specialists and to public officials" (Bandura, 1982, p. 144). Therefore, the ideal seems to be to strive for the fostering of self-efficacy in caregivers so that they can "experience a sense of personal empowerment in their parental role which facilitates the management of the multifaceted tasks of parenting and fosters enjoyment in the process … rendering it a deeply meaningful experience" (Coleman & Karraker, 1997, p. 78).

4.5. Caregivers and Their Children's Deafness

In light of the structures within which caregivers navigate their roles as highlighted in the previous sections of this chapter and in earlier chapters, it is important to consider the caregiver aspects as they relate to deafness particularly. In Chapter 3 and in the earlier sections of this chapter, the context in which deafness is experienced was highlighted as a cornerstone of the experience, both for the deaf children and for the caregivers of deaf children. The burden of care as it relates to the objective and subjective components of the caregiver role has been set out earlier, as was the recognition of the limited, but acknowledged, positive aspects of the caregiver role as it pertains to children with disabilities.

The diagnosis of deafness may be experienced as "a critical life event for parents, and it is known that high stress experience can arise from it" (Hintermair, 2006, p. 495), especially for hearing parents of deaf children, notwithstanding the calls from Deaf advocates for deafness to be normalised. After this diagnosis, caregivers of deaf children may have to engage in activities such as

> finding and obtaining early intervention services, modifying communication strategies, medical and educational decision making, working with professionals across a range of disciplines, learning about technological supports, working with the

> child to enhance developmental outcomes, and dealing with additional financial pressures (Poon & Zaidman-Zait, 2014, p. 176).

It is suggested that the diagnosis of deafness in children of hearing parents or caregivers may have implications for the bonding because they are having to bond with their children while having other people involved in their lives (Young & Tattersall, 2007) such as doctors, audiologists, speech-language therapists, amongst others. Also, caregivers may find that they have extra demands on their time in relation to their deaf children. Activities such as attending hearing aid appointments and therapy appointments may take away from time that the caregivers are expected to be performing duties at home and within their families, especially when it comes to having to balance their time spent with their other children (Jackson & Turnbull, 2004). Additionally, some caregivers may feel rejected by their deaf children and they may have doubts about their worthiness as caregivers of deaf children (Pipp-Siegel et al., 2002). Caregivers may particularly find it difficult in circumstances where their children have physical or cognitive disabilities in addition to deafness or in circumstances where there are communication differences between the children and their parents (Hintermair, 2006; Pipp-Siegel et al., 2002). Due to these issues, and also because of the specific language, culture, and identity aspects of deafness (Young & Hunt, 2011), caregivers may have to call on social and personal resources in order to meet their caregiver responsibilities. These social resources consist of "natural networks (partners, children, their own parents, relatives, friends, acquaintances)" and "artificial networks (new contacts with other parents/parents' groups in the same situation, contact with deaf adults and professionals)" (Hintermair, 2006, p. 496) whereas personal resources "are the psychological characteristics and strengths that help people to cope with difficult situations in life (e.g., optimism, sense of coherence, hardiness, self-efficacy, self-esteem), and the specific competence in dealing with the child’s hearing loss acquired in the interval after diagnosis” (Hintermair, 2006, p. 496). Caregivers benefit from these social and personal support resources to reduce the impact of the caregiver burden which may be associated with being caregivers to children who are deaf within contexts of limited resources and poverty, especially when these caregiver roles have been unexpectedly assumed (Raina et al., 2004).

4.6. Support for Caregivers - Dimensions of Support

In keeping with this thesis’ assertion that context ought to be considered in the understanding of phenomena, support is understood as “acts that reflect responsiveness to another’s needs” (Cutrona, 1996, cited in Poon & Zaidman-Zait, 2014, p. 177) which “is best viewed as a complex process unfolding in an ecological context” (Vaux, 1990, p. 507). This support and the benefit from appears to be contextual and variable over time and over the life course (Williams, Barclay, & Schmied, 2004) and contextual variables such as financial stability, employment, professional resources, and religious beliefs have been found to offer support (Ahlert & Greeff, 2012).

Support consists of emotional components which include, amongst others, expressions of love, value, encouragement, and esteem; informational components, that is advice and feedback; and instrumental components including material and practical assistance (Thoits, 2011) which may impact on the caregivers’ positive and negative experiences of caregiving (van den Berg et al., 2014). The benefit and the value of the support is also mediated by the characteristics of the recipients of the support, “such as their affective state, appraisals of need, self and the resources they are offered, and the action they take” and the characteristics of the provider of the support which “include appraisals of need and self, the willingness of the action they take, and the outcome of their actions for themselves and their relationship with the recipient” (Williams et al., 2004, p. 949). However, if people are forced to ask for support from those who are aware of their situation, "they may feel resentment and betrayal, and perceptions of available support again will be seriously compromised" (Thoits, 2011, p. 151). In light of this contextual sensitivity, it is acknowledged that social support can be influenced by factors related to poverty such as the geographical setting and pattern of housing, single parent status, and social roles when the chronic need for support associated with these factors may erode that support base and exhaust support sources (Vaux, 1990), especially when those support structures are poor themselves (Graham et al., 2013).

Demonstrations of support can occur over time or in response to a stress event. These "everyday" (Thoits, 2011, p. 150) expressions of support reflect support in which there is the fulfilment of basic social needs over a prolonged time and occur every day and in ordinary ways and do not necessarily need to be overt or grandiose and can occur when everyday emotional, informational, and instrumental acts are shared with, for example, "spouses, neighbours, co-workers, church members, and others" (Thoits, 2011, p. 150). An especially valuable aspect of support is the need to recount experiences and discuss them with other people because they can ventilate their feelings and express themselves (Thoits, 2011). These conversations and expressions of support reflect the caregivers' sense that they are loved or cared for, have a sense of attachment with others, are able to confide in another person, have a sense of self-esteem, and sense of security in the received support (Williams et al., 2004). These everyday expressions of support in which people are able to talk about their lives and experiences are sometimes overlooked although they are beneficial in that these

> informal discussions with others about impending problems at home, at work, or in other role domains may pinpoint ways to prevent the occurrence of a stressor or de-escalate the appraisal of imminent problems from possible threats to manageable challenges … These forms of emotional, informational, and instrumental assistance

> swapped in everyday interactions are so minor, so commonplace, and so taken for granted as to be virtually invisible as support provisions (Thoits, 2011, p. 150).

“Stress-related” (Thoits, 2011, p. 150) support refers to the supportive buffering in response to specific episodes and times of stress (Williams et al., 2004) or an “intensified ongoing strain … where the demands created by the exigent situation exceed the usual level of demands in the person’s life and are perceived by the person as taking his or her abilities to cope” (Thoits, 2011, p. 151). This stress-related support tends to be more obvious and visible, as opposed to the everyday stress support mentioned earlier and tends to extend to structures outside of people’s close family and community networks (Thoits, 2011). When accessing this stress-related support, there is the suggestion that consideration ought to be given to the skills demonstrated in accessing the support such as “choosing a place, time and person, expressing distress, self-disclosing, articulating needs, eliciting the appropriate mode of support and showing appreciation” (Vaux, 1990, p. 515) while recognising that in these stress-related events, “expectations of reciprocity in everyday support probably are also suspended temporarily; network members recognize that the individual’s attention and effort must focus on dealing with the immediate situation” (Thoits, 2011, p. 151).

4.7. Peer Support – A Special Connection Between ‘Similar Others’

When support is offered by people who have undergone similar experiences, it is seems as though it is especially valued and internalised. Despite the intimacy, proximity and accessibility of significant others within family, community, and friendship circles, if they do not directly share in the experience which requires support, they may not identify with that experience and so their advice may be considered generic, inappropriate, naïve, or unrealistic (Thoits, 2011). Therefore, it seems as though the support from similar others or peers can be especially beneficial because it can enhance caregivers' self-efficacy when they see similar others achieve success in their actions, they are able to vicariously experience the others' success and thereby have a model of effecting strategies for addressing their particular needs (Bandura, 1982). This support from similar others is especially valuable because,

> from previous experience, similar others have an in-depth understanding of the many dimensions and nuances of the stressful situation. Given this, a similar other is able to take the role of the distressed person and imaginatively anticipate his or her emotional reactions and practical concerns …. Having 'been there' themselves, similar others can tolerate expressions of distress and validate the normalcy of the person's emotional reactions and worries, rather than deny, criticize, or attempt to change them because they are upsetting or threatening to hear. … Direct experiential knowledge is the key to their provisions of effective emotional sustenance as well as active coping assistance … Due to past experience, similar others can provide coping assistance that is closely tailored to the exigencies of the problematic situation and known to be effective in solving problems (Thoits, 2011, p. 154).

The similarity of the experience and the associated empathy appears to lend weight to the value of the received support because "building upon shared interests and concerns, parent sessions can provide a natural setting for developing relationships with other parents and feelings of belonging to a cohesive group" (Meadow-Orlans & Sass-Lehrer, 1995, p. 329). The similarity relates to the experience and is not constrained by social characteristics such as age, gender, race, ethnicity, and socio-economic status. Nonetheless, the greater the social and experiential similarity the greater the value of the support because the "social similarity should boost the utility of the experience-based support they provide" (Thoits, 2011, p. 154) which again points to the value and necessity for the contextual sensitivity which support resources ought to demonstrate (Williams et al., 2004).

4.8. Support Considerations for Caregivers of Deaf Children

In this thesis, I recognise the contextual factors which may contribute to the need for support for caregivers of children in general in South Africa considering the structural limitations which caregivers need to negotiate. However, in addition to caregivers' general need for support, in light of the particularities associated with being caregivers to children who are deaf, they may experience a greater need for support because of the added dimension to the caregiver role which results from the children's deafness. Moreover, in light of the poor structural support for caregivers of deaf children and for deaf children themselves, caregivers find that they have to navigate a novel landscape. They may find a situation where

> social institutions like education, the workplace and the family are often poorly regulated, inadequately linked, or are actually failing … (and) … individuals seem to require more personal resources and a heightened awareness to make their way through this uncharted and often hostile territory (Côté, 1996, p. 424).

Social support is considered a very strong factor in the caregivers' adjustment to deafness, even when accounting for the degree of the children's deafness and the caregivers' life situations and stressors (Jackson & Turnbull, 2004). It is argued that, with regard to,

> deaf and hard of hearing children, and their parents in particular, … the social support that parents experience from their spouse, family, and friends as well as from professionals and people with similar hearing problems greatly contributes to enabling parents to cope better with the child's disability both emotionally and practically (Hintermair, 2009, p. 301).

4.9. Caregivers are hearing and their children are deaf – the possibility for mismatch

Caregivers, even those who are caregivers to other children, may find that they are experienced in raising children and have support structures in this regard, but may find that the experience of being caregivers to deaf children is quite different because of the specific and possibly novel experience of being caregivers to deaf children. It has been found that caregivers of deaf children are under extreme pressure to make the most suitable decisions with regard to their children and may be unsure of how to respond to their deaf children, even becoming overprotective of their deaf children, or at the other extreme, more punitive towards them (Antonopoulou et al., 2012).

It is estimated that 90% of deaf children are born to hearing families (Feher-Prout, 1996; Meadow-Orlans & Sass-Lehrer, 1995) which suggests that there may be incongruences in the communication modes between deaf and hearing members of the family, and caregivers may find that they experience additional stress from the extra time and effort that is needed for learning a different communication mode with their deaf children (Jackson & Turnbull, 2004), a stress not necessarily experienced by deaf caregivers of deaf children (Antonopoulou et al., 2012). Also, it may suggest unfulfilled communication needs between family members, including caregivers, and deaf children in the family.

Moreover, in terms of identity, there are significant implications for hearing caregivers of deaf children because there is a reported sense of alienation between them where the

> Deaf community is often regarded as the ‘family of choice’ replacing the ‘family of origin,’ even when other members of the same Deaf community do not have the same ethnic background. The main reason for this seems to lie in the fact that considerable communication barriers within the family of origin become surmountable in the family of choice (Van Herreweghe & Vermeerbergen, 2010, p. 134).

Therefore, Deaf children may have a culture and language that is different to their caregivers' culture and language and Deaf children may acquire these from their friends and not from their parents or caregivers (M. A. Jones, 2002). There even appears to be a role reversal in the teaching and learning of language where, when it comes to SASL, the children may teach their caregivers in what is referred to as a prefigurative culture where "the young can teach and guide their parents to the point of their parents becoming subservient to them in various ways" (Côté, 1996, p. 419).

It is suggested that, within Deaf culture, Deaf people may feel more connected to the Deaf culture than they do with their families and neighbours. Moreover, hearing caregivers may face opprobrium and "may find themselves the target of harsh words because of the choices they have made for their deaf children, which deaf adults may view as inappropriate" for which hearing care personnel "need a high level of sensitivity and diplomacy to balance discrepant needs and views" (Meadow-Orlans & Sass-Lehrer, 1995). Some Deaf people may assume a sense of responsibility over deaf children of hearing parents and feel "that somehow the Deaf culture is more of a parent to a Deaf child than the child's hearing family" (M. A. Jones, 2002, p. 51). Dolnick (1993, cited in M. A. Jones, 2002, p. 51) puts it very bluntly: "(Hearing parents) have to accept that the (Deaf) child can never be one hundred percent theirs." This recognition that they are connected to their children through their role as caregivers while still being disconnected from their children because of their children's deafness may be very difficult for caregivers to internalise and it challenges the notion of how families are constituted and operate. To compound the situation, it is suggested that "there is a fundamental change in the relation between parent and child, where the authority of the parent can be questioned and where the child can actually give direction to the parent" (Côté, 1996, p. 419).

A compounding difficulty for caregivers may be the existential predicament which may arise from a dis-identification with their own children if they are hearing and their children are deaf. It has been suggested that deaf children of deaf parents may have better relationships than hearing caregivers and their deaf children because there is an understanding and a connection between themselves (Hintermair, 2006). Similarly, caregivers realise that, if the deaf children have hearing siblings, this dis-identification applies to the siblings too which may cause anxiety and distress in the caregivers and negative comparisons by the caregivers between the deaf and hearing children (Antonopoulou et al., 2012) which can be attenuated when deaf and hearing children are engaged in activities which emphasise togetherness within the immediate and extended family such as family time, routines, traditions, and celebrations (Ahlert & Greeff, 2012).

Besides the logistical and practical adjustment to their children’s deafness, hearing caregivers of deaf children may have difficulty understanding the experience of being deaf and growing up deaf and it is suggested that there is an advantage when the caregivers and their children are deaf which because “it is important to be able to share the child’s experience” (Hintermair, 2006, p. 509). It is suggested that hearing caregivers may engage in a “search for their child’s world” because they can experience “anxieties over not understanding what it *meant* for their child to be deaf” (Young, 1999, p. 162). Caregivers, before having deaf children, may not be aware of themselves as hearing people because it is just taken for granted. In Young’s (1999, p. 169) study, she found that, for her participants, a

> powerful experience was that of becoming conscious that they had a *hearing* identity. If the vast majority of people can hear and that is regarded as the norm, then to describe oneself as `hearing’ is just not relevant. However, for these parents, that aspect of themselves became relevant.

4.10. Caregivers' potential experience of third-party disability

Despite the limitations of the medically dominant paradigm in which deafness may occur, as highlighted earlier in this thesis, within this medically dominant paradigm, the ICF recognises the contextual and situational dimensions of ability and disability (WHO, 2002a) and there is now recognition of the impact of the disability on significant others, that is, a third-party disability (WHO, 2007) which is the "disability and functioning of family members … due to the health condition of significant others" (WHO, 2007, p. 264) and "that in the absence of targeted interventions aimed at enhancing the independence and participation of people with disabilities, …, family members and disabled people themselves are not freed up to participate more fully socially and economically" (Graham et al., 2013, p. 333). This concept of third-party disability appears very appropriate when discussing the effect their children's deafness has on caregivers, especially when compounded by the disabling effects of poverty. The third-party disability seems to manifest itself in various domains of the caregivers' life because they be excluded from or limited in their social participation because of their caregiver responsibilities and duties highlighted earlier in this chapter, not to mention their communication disability in communicating with their deaf children and even their deaf children's deaf friends.

This area of third-party disability appears to be under-investigated at this time and the WHO concedes the need for further study (WHO, 2007). This thesis suggests that childhood deafness may become embodied as a third-party disability amongst caregivers of deaf children, especially amongst caregivers from contexts of poverty, limited resources, and limited access. A search for the term 'third-party disability' returned very few items and these only related to research on the spouses of older deaf people (for example Scarinci, Worrall, & Hickson, 2009; Scarinci et al., 2012) and research on spouses of people with aphasia (Grawburg, Howe, Worrall, & Scarinci, 2013). With regard to deafness, in the aforementioned studies on the spouses of older deaf people, it was found that the spouses experienced "effects involving lifestyle changes, communication difficulties, and emotional consequences. Communication difficulties between the couple were the central source of stress reported by spouses" (Scarinci et al., 2012, p. 707) and it is suggested that, "acknowledging and understanding the effect of the hearing impairment on not only the person with the hearing impairment, but also his or her spouse, is central to family-centred practice" (Scarinci et al., 2012, p. 698). With regard to spouses, it is acknowledged that, "clients and their significant others form a partnership, and therefore it is important to treat them as a partnership rather than focusing exclusively on the client with hearing impairment" (Scarinci, Worrall, & Hickson, 2008, p. 150) because deafness can have emotional effects on spouses of deaf people too (Scarinci et al., 2008).

Therefore, by extrapolation, if these effects are seen in spouses, it appears as though caregivers of deaf children too may experience third-party disability especially because they exercise more influence on their children than spouses may influence over each other. In research on third-party disability in hearing spouses of deaf people, it has been found that spouses may feel communicatively disabled when trying to communicate with their deaf spouses, especially as they get older (Scarinci et al., 2012). Similarly, caregivers of deaf children may feel that they are communicatively disabled when they have difficulty communicating with their deaf children, especially in cases where caregivers may be elderly grandparents, as is often the case in South Africa or when the topics which they want to discuss are more complex in terms of its subject matter, content, and linguistic structure.

There is a recognition that there may also be discrimination against people who are associated with a disabled person, more specifically, caregivers of people with disabilities, especially in South Africa in relation to supernatural beliefs and rumours around deafness. Associative discrimination is defined as "direct discrimination against someone because they associate with another person who possesses a protected characteristic" which, in terms of the practicalities of being a caregiver "could have implications in relation to requests for time off or flexible working" (University of Sheffield, n.d). Therefore, it seems as though there could be an associative discrimination against caregivers of deaf children who may need to take time off work or have to forego work opportunities because of their caregiver roles which could, therefore suggest a third-party disabling effect of the children's deafness.

4.11. The medical focus predominates in support for caregivers of deaf children

There is a call for an adjustment in the engagement with caregivers and Munford (1994, p. 278) asks: "How are we to ensure that policy makers understand the daily lived experiences of caregivers and the people they personally assist? What is society's commitment to supporting caregivers?" and suggests that "the answer to this question is intricately related to the ways in which society values the lives of people with disabilities." Within the medically dominant discourse with regard to the children's deafness and the diagnosis, habilitation and rehabilitation of that deafness, there is the need to focus on the caregivers of deaf children in their own right and for their wellbeing. The World Health Organisation, for example, published a document entitled "The importance of caregiver-child interactions for the survival and healthy development of young children" (WHO Department of Child and Adololescent Health and Development, 2004) where the document perpetuates the idea that the health and well-being of the children is paramount and that the caregivers' wellbeing is only considered because of the impact their wellbeing has on their children's wellbeing, not because they are worthy of wellbeing themselves. Little attention is paid to the needs of the caregivers themselves which appears to make the relationship between caregivers and their children one sided, even parasitic. Caregivers may be stranded in the vying for prominence between the medical and social ideologies. It may be that caregivers are

> caught between two social discourses about deafness - one deeply ingrained (deafness as handicap), one new and difficult to grasp (deafness as culture). Given that most parents will have had little or no previous experience of deafness and will have grown up with the usual social understanding of deafness as a handicap, the implications of this view are not going to be easily shed (Young, 1999, p. 168).

This medical focus on the diagnosis of children’s deafness means that “there is evidence that our screening endeavours have far outstripped our habilitation efforts, leaving parents with a diagnosis but without support” (Kurtzer-White & Luterman, 2003, p. 232) which suggests the need for the strengthening of the caregivers’ position and wellbeing.

Also, within this medical dominance, caregivers are required to display health literacy which may be compromised because of their limited literacy as described earlier. The structural absence of health literacy support suggests that caregivers of deaf people may experience particular challenges in communicating with other people about their children’s deafness. Health literacy is described as “the degree to which an individual can obtain, process, and understand basic health information and services needed to make appropriate health decisions” (Nair & Cienkowski, 2010, p. 71) and includes the ability to read. Literacy demands may compromise the understanding of audiological information, such as the audiogram, especially because of the linguistic complexity and the necessary advanced reading abilities which, in a context of structural restrictions to literacy development such as the one in which this project was conducted, may impact on the successful transmission of information and, more crucially exclude people from empowered participation in decision-making processes (Nair & Cienkowski, 2010).

4.12. Ubuntu and social dimensions

Social support is beneficial for hearing caregivers of deaf children and they appear to be better able to address the challenges they encounter with regard to their children's deafness than caregivers with fewer support mechanisms (Poon & Zaidman-Zait, 2014). Within the context of South Africa, this social support could be described as 'ubuntu' when considered in light of the suggestion that caregiving ought to be a shared experience and "that it is 'absurd' and 'myopic' to view care as a private family matter" (Edgar, 1992, cited in Munford, 1994, p. 279).

Specifically in the South African context, when it comes to discussions around social support, it appears necessary to discuss the concept of 'ubuntu.' Ubuntu has been described as African humanism, a philosophy recognising the humanity of other people which is even included in the South African constitution and is connected to the proverb '*umuntu ngumuntu ngabantu*', that is, a person is a person through other persons (Gade, 2011) or more specifically, "I am because we are: I can only be a person through other persons" (van den Heuwel, et al., 2006 cited in Gade, 2011, p. 313). It is related to a sense of collectivism where there "is an assumption that groups bind and mutually obligate individuals" (Oyserman, Coon, & Kemmelmeier, 2002, p. 5). It is a contextually sensitive philosophy since "social context, situational constraints, and social roles figure prominently in person perception … and meaning is contextualised" (Oyserman et al., 2002, p. 5). Because of the dominant discourse of deafness within the medical domain, it is necessary to consider this very social concept of ubuntu within that dominant discourse. Hanks (2009, p. 132) suggests that

> our commitment to technology, individuality, and arrogance has left us with an ersatz sense of fulfilment and a longing for authentic connection. We are empty, alone, and

> afraid. We yearn for the as yet unnamed, and we know deep in our hearts that there has to be more.

Ubuntu recognises the collective humanity, that which makes us human, that which considers the individual within the broader context of the community. Within collectivism, there is the assumption that there is “concern for group harmony;” that there is a “turning to close others for decision help;” that there is a consideration of others “as an integral part of the self;” and a recognition there are “duties and sacrifices being a group member entails” (Gade, 2011, p. 9). It is suggested that ubuntu mediates the harmonious meeting of differences and similarities in people (Andrews et al., 2010) because, as a collective philosophy, there is an assumption that the “self changes according to context or situation” (Gade, 2011, p. 9). Therefore, it suggests a focus on the shared experience of people and the interconnectedness of people rather than on the individual differences in people. However, there is the warning: “Nevertheless, it is important not to advocate for ubuntu uncritically, as it is in the recontextualisation of the philosophical ideas and their ideological take up, within the parameters of power and context, that distortion, myths and misappropriation occurs” (Swanson, 2007, p. 59) which can result in a romanticised idea of ubuntu.

It is difficult to reconcile the poverty and disparity in South Africa if ubuntu is supposedly and popularly believed to be a cornerstone of South African society. The idea of ubuntu suggests that the collective good is to the benefit of the individual too. Because ubuntu is the recognition of people’s humanity in others it would suggest that ubuntu would ensure the provision of free services, assistance, therapy and hearing aids at the point of contact for people who seek those services. It would also suggest that people would assist and support each other. Various political factors, which themselves are contrary to the values of ubuntu, such as corruption, excessive government spending, underinvestment in education and health, and large military spending, affect the material ability to provide the necessary services (Benatar, Daar, & Singer, 2003, p. 114). Ubuntu could be a buffer against these disparities and could serve to activate the collective assistance but the material reality often denies that humanity from being expressed. There is the reminder that, "medicine is becoming increasingly linked to and influenced by market forces" (Benatar et al., 2003, p. 115) instead of the focus on humanity and is an indication that, despite the strong foundation in ubuntu in South Africa, financial considerations play a significant role in the provision of services and suggests in the possibility of a disconnection between people and the services which they may seek. Within the medical domain, ubuntu is compromised because the

> ubiquity of managed care has boxed us into a medical model of care delivery, focused on stability and maintenance and mathematical cost analyses as opposed to health and healing. Our clinical clients are no longer unique individuals with infinite potentialities. They have been reduced to finite numerical codes of predictable behaviours... and our interactions have been limited to the number of sessions for which insurance is willing to pay. As therapists, we have begun to view our clients only from within the confines of their diagnoses, dehumanizing the person (and ourselves) along the way (Hanks, 2009, pp. 118-119).

Marxist philosophy argues that it is people's material condition that dictates their experience of the world and Marx suggested that economic determinism and class conflict are the ways in which members of society relate with the world (Almgren, 2007). Within this economic and class bound interaction, people have subsistence needs which need to be met in order to survive (Benatar et al., 2003). Therefore, within contexts of limited resources, there may be insufficient money to pay for deafness related services and poverty may dictate that people have to re-direct their spending to fulfil survival needs (Graham et al., 2013; Harris et al., 2011). If people do not have access to these subsistence needs because of their material conditions, ubuntu is compromised, and it, therefore, appears necessary to consider the overarching and pervasive social and material contexts in which caregivers of deaf children find themselves; it becomes obvious that they form part of a broader landscape of social, societal, economic, historical and material interactions. If there is a synchronicity between these different elements, an opportunity is created for the revival of ubuntu and to attain “the freedom to develop one’s full potential” (Benatar et al., 2003, p. 124).

Ubuntu is also necessary for communities’ and people’s acceptance of deafness and of the caregiver role. Caregivers need support and validation in their caregiver role in South Africa and they may risk being excluded from the tenets of ubuntu because “negative perceptions of children may be rooted in religious beliefs that disability is an embodiment of evil or the result of bewitchment. Disability is also seen by some as punishment for the sins of parents” (Department of Social Development et al., 2012, p. 71). In light of these negative perceptions, it is argued that support is not always positive and that it may also hinder the caregivers’ acceptance of their children’s deafness (Hintermair, 2009). It is also reported that support is less available when “people are seen as more blameworthy or responsible for their problems” (Thoits, 2011, p. 151) which, in light of the suspicions around supernatural causes of deafness that people may have with regard to deafness in South Africa, may imply that social support or ubuntu may be less forthcoming. Therefore, within communities where acceptance and integration of deafness may be limited, caregivers may experience anxieties about their deaf children’s future, including their deaf children’s prospects for getting married and concerns about their deaf children securing employment in adulthood (Young, 1999, p. 163).

4.13. Professional practice aspects

Support for caregivers of deaf children can be formal, for example from people who work in deafness, or informal, for example from friends and family (Poon & Zaidman-Zait, 2014). In the provision of professional support to caregivers of deaf children it is important to interrogate aspects of this formal support as it contrasts with informal support where the former is considered an artificial network because it is comprised of new contacts specifically related to the caregivers' children's deafness (Hintermair, 2006) while the latter is considered a natural network as it includes people already known to the caregivers (Hintermair, 2006). There is the suggestion that in order to optimise support for caregivers, a combination of both is necessary since the "care and development of children is the responsibility of both the public and private spheres – including the family and extended family networks, as well as the health system, early childhood education centres, and the formal schooling system" (Tomlinson, 2013, p. 58).

Because of the need for contextually attuned practice in the field of deafness, cognizance ought to be given to the culturally appropriate and competent interactions which are respectful of traditions and preferences, historical factors, and "an understanding of individual difference and diversity among individuals, not just groups" (Petriwskyj et al., 2014, p. 128). Additionally, the potential power differentials between the professionals and the people with whom they interact ought to be considered because, when it comes to support for caregivers, it appears as though caregivers have anxieties about how these support structures "have the authority to determine how their lives will be constructed" (Munford, 1994, p. 274) and, therefore, professionals must "assume all families as responsible, trustworthy people and treat them as such" (Moeller et al., 2013, p. 432). Support needs to be offered in such a way that it corresponds with the caregivers' needs or goals (Poon & Zaidman-Zait, 2014). There is a responsibility to foster caregivers' psychological empowerment by giving advice and support with regard to both the available resources and those deemed necessary (Hintermair, 2006, p. 508) and to offer referrals to other professionals, for example, mental health services (Moeller et al., 2013). Also, it is necessary to highlight the contextually similar support which can come from informal support sources such as relatives, friends, neighbours, community members (Poon & Zaidman-Zait, 2014), peers or similar others (Thoits, 2011), community organisations, extended family, religious affiliations, and play groups (Moeller et al., 2013).

In setting therapeutic goals, these ought to be set within a humanistic interaction which is not fixed within the medical model but, instead, offers a mutually negotiated, attuned, and respectful sensitivity to the caregivers' context and personhood. Additionally, goals ought to be set and co-constructed with caregivers in order to enhance caregivers' self-efficacy so that they can feel more competent in their ability (Coleman & Karraker, 1997). One of those goals could be the need for effective communication between caregivers and their deaf children (Hintermair, 2006) which appears to warrant input from speech, language and hearing professionals because it has been found that early diagnosis and subsequent support may be beneficial to both deaf children and their caregivers (Hintermair, 2006). However, in light of the specific South African context described earlier, this need may not necessarily be met and so it is essential that caregivers are involved in the therapeutic goal setting (Poon & Zaidman-Zait, 2014) within a relationship between caregivers and professionals that builds on the caregivers' existing strengths and which is "characterized by reciprocity, mutual trust, respect, honesty, shared tasks, and open communication" (Moeller et al., 2013, p. 432). Caregivers ought to be empowered to deal with "discrimination, oppression, and stereotyping" (Moeller et al., 2013, p. 432) which may be associated with the fulfilment of their caregiver roles. Therefore, being mindful of the potential to bolster the caregivers' agency, they can be encouraged to create opportunities for personal and social development through social anxiety reduction activities, skills training, and the design of context specific interaction programmes, especially in understaffed areas (Vaux, 1990).

4.14. Community of Practice (COP)

Bandura (1982, p. 143) proposes that “people do not live their lives as social isolates.” Relatedly, communities of practice (COPs) are “an aggregate of people who come together around mutual engagement in an endeavour. Ways of doing things, ways of talking, beliefs, values, power relations—in short, practices—emerge in the course of this mutual endeavour” (Lave & Wenger, 1991, p. 464, cited in Ahearn, 2001, p. 111) and “are comprised of individuals who share common concern or enthusiasm about a topic or problem and who deepen their knowledge and expertise about the area by frequently interacting with one another” (Moodie et al., 2011, p. 14). The concept of ‘communities of practice’ suggests that caregivers of deaf children can offer support to other caregivers of deaf children because they have experience in deafness. These COPs can be a blend of formal and informal support in order to best understand the experience of deafness because within a COP, “as meanings are co-constructed, social reality is also constructed” (Ahearn, 2001, p. 111) and, through a combination of tacit knowledge and experience, “can optimize the creation and dissemination of knowledge” (Moodie et al., 2011, p. 14). By fostering these COPs, there is an improved chance of a collaborative approach to deafness where caregivers work together with audiologists and others in the contribution towards the knowledge base relating to deafness, especially within particular contexts where the tacit knowledge and experience can merge with theory and pre-established knowledge to fine-tune that knowledge, apply it and evaluate it within the contexts in which the caregivers live. Therefore, it seems as though a COP can enhance caregivers’ agency because they contribute to the COP through their experience and knowledge. This enhancement of agency can come about due to an enhancement of caregivers’ self-efficacy and their collective efficacy (Bandura, 1982) within their communities and contexts. Specifically, within contexts where structures are weak or absent and in ecologically disadvantaged contexts, “the community creates the social structure that is imperative for knowledge creation, collective learning, inquiry, relationships, and trust" (Moodie et al., 2011, p. 14). However, collective endeavours can bring about change in people's circumstances, especially when self-efficacy is high, "through the mutual effort of people who have the skills, the sense of collective efficacy, and the incentives to shape the direction of their future environment" (Bandura, 1982, p. 143).

Research suggests that there is a need to facilitate the strength of caregivers' social resources by strengthening the contact between caregivers and their communities (Moeller et al., 2013) and, crucially, with "other parents of deaf and hard of hearing children, deaf and hard of hearing adults" (Hintermair, 2006, p. 508). This interaction with other caregivers may offer them support by virtue of the shared experience of being caregivers to deaf children. In caregivers' interactions with deaf adults, they can garner an understanding of their children's deafness and the implications of their children's deafness (Young, 1999) and these deaf adults may serve as mentors to hearing caregivers of deaf children (Jackson & Turnbull, 2004). By facilitating positive experiences, professionals can "support families to feel optimistic about the child's future and to establish and maintain high expectations for the child's development" (Moeller et al., 2013, p. 433). It therefore suggests the need for the creation of support groups constituted by caregivers of deaf children because it is reported that caregivers can benefit from the exchange of experiences with similar others in that they show greater confidence in their caregiver skills (Ahlert & Greeff, 2012).

Support groups could offer the opportunity to benefit from the identification with similar others, the learning of coping behaviours and attitudes which could be imitated so as to increase their sense of control (Thoits, 2011) and thereby, vicariously, the development of self-efficacy (Coleman & Karraker, 1997). Very importantly, caregivers of deaf children who find themselves distressed with regard to a domain of their caregiver experience may find that

> the sheer existence of peers who have coped effectively with the stressor generates hope; the distressed individual can envision himself or herself in the future … As a positive emotion, hope counteracts felt tension and upset, and envisioning a desired 'possible self' motivates striving toward that goal (Thoits, 2011, p. 154).

4.14.1. Embodiment of the Role, Burden, and Support.

As discussed earlier, people's contexts can and do become embodied in themselves within their biological state and wellbeing (Krieger, 2005). This embodiment can apply to caregivers of deaf children too, where the concepts referred to in this chapter become part of the caregivers' experience in very tangible ways. Therefore, from the preceding sections, it can be seen that their children's deafness can become embodied within the caregivers too which suggests that caregivers merit attention and support with regard to their caregiver experience and highlights the human rights dimension to the caregivers' experience and the need to consider the impact of their roles and responsibilities.

4.14.2. Embodiment of the caregiver role and burden.

It seems as though the caregiver role and possible burden can become physically embodied in the caregivers. Caregivers have reported that they experience negative effects on their physical and emotional wellbeing (van den Berg et al., 2014) where, for example, caregivers of orphans have reported "higher perceived stress and depression, more chronic illness, worse nutrition and greater health declines over time" (Kidman & Thurman, 2014, p. 241), especially in contexts of poor socio-economic status (Raina et al., 2004). Because of the demands on their time, informal caregivers may experience limitations on engaging in paid, full-time employment because of the demands on them at home (van den Berg et al., 2014) which may result in greater food insecurity and lower household incomes (Kidman &

Thurman, 2014) in already vulnerable households (Harris et al., 2011). This consequential inability to engage in employment, for example, can become embodied as a third-party disability (WHO, 2007) where the caregivers' responsibilities and duties to the children to whom they provide care limit and disable their engagement in activities in which they may have otherwise participated were they not caregivers. Caregivers may embody their caregiver role and burden which, as pointed out earlier, may result in the likelihood for poor mental and physical wellbeing; in other words, they experience disability resulting from their caregiver role and burden. People with disabilities may have limitations placed on their full social and economic participation (Graham et al., 2013) which caregivers, even though they are not recognised legally or formally as having a disability, may also experience which supports the argument that they experience a third-party disability. Additionally, caregivers' sense of low self-efficacy in their role can become embodied physically and emotionally in caregivers because they feel as though they cannot fulfil their caregiver roles and responsibilities (Coleman & Karraker, 1997).

4.14.3. Embodiment of the support people receive.

This third-party disability embodiment can be mitigated. There may be lower levels of anxiety, depression, and physiological reactivity to caregivers' burden as well as enhanced physical and physiological wellbeing when people perceive support from their significant others and society at large, when they perceive a sense of their mastery or control over their circumstances, and when they experience a sense of belonging and companionship instead of loneliness (Thoits, 2011). In the same way that caregivers may embody their burden and role, the support which they receive similarly becomes embodied and "there are many potential ways that relationships can affect bodily and emotional well-being" (Thoits, 2011, p. 147) and it is recognised that the support or absence of it can be embodied "through emotionally induced effects on immune system functioning” (Williams et al., 2004, p. 956). It is also reported that support can alleviate psychological distress when it is contextually relevant (Williams et al., 2004) but that it can also become embodied in the psychological distress that comes from feeling “indebted, unjustly over rewarded, too dependent, over controlled, or incompetent in the eyes of support providers” (Thoits, 2011). The psychological distress and physiological arousal tend to be reduced when caregivers can ventilate and talk about their experiences while receiving validation of their experience, especially from similar others and from significant others because they feel as though they really matter and have a sense of belonging and acceptance (Thoits, 2011). This embodiment of the absence of support could be especially noticeable in vulnerable groups of people such as people who have limited resources, people who live far from support and resource services, women-headed households, children with special needs, older people, and people with disabilities, amongst others (Schneider et al., 2013).

4.15. Chapter Summary

From this chapter it can be seen that within the South African context, the role of the caregiver is multi-dimensional and is a product of the context, including historical, legal, and cultural aspects. Parents are not the only caregivers of deaf children and so the variations in the people who assume the caregiver role suggests that there has to be contextually relevant support where, for example, an older grandparent who did not attend school and is not in formal employment may not have access to the same support as a younger father who has schooling and employment. Notwithstanding the potential challenges to their fulfilment of their caregiver roles when their children do not have special needs, it can be seen that caregivers of deaf children have deafness-specific support needs which ought to be addressed because of the potential for the embodiment of all of the related factors in the caregivers.

Chapter 5: The Turn for Qualitative Research in Audiology

> “Now here is my secret, very simply: you can only see things clearly with your heart.
> What is essential is invisible to the eye.”
> (de Saint-Exupéry, 2000, p. 72)

Figure 5.1. In trying to understand and appreciate the human and personal dimensions of deafness which may be invisible in quantitative approaches, there is a call for a new road to be travelled when researching deafness, a road which is not necessarily easy to travel and which may follow an irregular and bumpy route.

5.1. People are Not Numbers

Deafness ought not to be reduced to calculations and descriptors of deafness. The application of a qualitative approach to the field of audiology has the potential to shed light on the complexity of deafness within a context of poverty and inequality because there is

> the need for more nuanced analysis that reflects the complex world within which poverty among persons with disabilities must be considered. … In other words, it is not simply more research on the links between disability and poverty that we need, but more research that explores what poverty means at the level of the individual, the household, the community and broader society (Groce et al., 2011, p. 1509).

I propose that, in the study of audiology, there be consideration for the human aspects of audiology and a consideration of the contexts and the experiences surrounding audiological aspects so as not to reduce audiology and its study to measurable entities, but to include personal and human ones too. This thesis is, in its qualitative rather than quantitative approach to exploring the experience of caregivers of deaf children, therefore concerned with the lives behind the numbers, measurements, and statistics, the human dimension; that which is essential.

5.2. The Need for Qualitative Research in Audiology and in Exploring Caregivers' Experience

There have been criticisms against the objectification of the study of deafness and the depersonalisation and exclusion from the process of research production that is associated with deafness (Young & Hunt, 2011). Therefore, to get more personal and inclusive insights into deafness, there is the need for a qualitative turn in the research focus with regard to deafness. It is important, necessary, valuable, and ethical to show interest in people's "experiences, circumstances, and situations" (Hesse-Biber & Leavy, 2011, p. 4), as is the case in this thesis with regard to caregivers of deaf children in the Ehlanzeni District of Mpumalanga. The key features of qualitative methods appear to be congruent with the requirements of this study in that it this study is looking at the subjective meanings of experience from the caregivers and from their perspective while also considering the role and perspective of the researcher in the research process (Spencer, Ritchie, Lewis, & Dillon, 2003). In this study, as is expected of qualitative studies, the researcher has a prolonged relationship with the setting and did not create an experimental setting, but, rather, looked to perform a contextually sensitive analysis while capturing the rich and complex data from thick descriptions of the context and by capturing the participants' voices.

Qualitative research's tendency to be "concerned with the particular situations and experiences of the individuals participating in the study" (Yardley, 2000, p. 215) and its focus on "exploring and understanding the meaning individual or groups ascribe to a social or human problem … typically collected in the participant's setting … building from particulars to general themes, and the researcher making interpretation of the meaning of the data" (Creswell, 2009, p. 4) points to its centeredness on people. In the aforementioned reference from Creswell (2009), the inclusion of the word 'problem' is of concern and suggests that even qualitative research, in an effort to legitimise itself within a quantitative hegemony, runs the risk of problematizing the phenomenon of interest and setting it aside as something aberrant.

Qualitative research recognises and gives value to the personal dimensions of the area of interest to provide a fuller description of a phenomenon. This fuller picture is created by legitimately recognising qualitative research as

> a situated activity that locates the observer in the world. Qualitative research consists of a set of interpretive, material practices that make the world visible. These practices

> transform the world. They turn the world into a series of representations…, attempting to make sense of interpret phenomena in terms of the meanings people bring to them (Denzin & Lincoln, 2011, p. 3).

Although the formation and practice in audiology had had quite positivist and quantitative leanings in the need to quantify and measure deafness, in practice, I have found that audiologists are called upon to be able to do more than measure deafness and provide rehabilitative services, especially within a society, such as ours, which is characterised by poverty and inequality. We are often called upon to see the client holistically and interact accordingly and qualitative research encourages such a holistic approach (Hesse-Biber & Leavy, 2011). Therefore, this multifaceted approach may be necessary when conducting research with people who are deaf and with their families which suggests that a qualitative approach may be beneficial in studies within the discipline of audiology. The attention to qualitative aspects of audiology research "ensures that background, meanings, motives, reactions, and outcomes are assessed from many angles, especially because audiology is interdisciplinary and has borrowed perspectives, knowledge, and skills from disciplines such as medicine, physiology, engineering, psychology, sociology, and pedagogy in order to better understand" deafness (Knudsen et al., 2012, p. 90).

The qualitative researcher is described as one who does not neglect or relegate naturally occurring data and sees the value in these naturally occurring phenomena (Silverman, 2011) and is interested in shining light on the complexity of the phenomena under study, phenomena which are often insufficiently understood, novel and "newly being seen as important" (Spencer, Ritchie, Lewis, et al., 2003, p. 34), characteristics of the caregivers' experience. The motivation for a qualitative approach was reinforced by my intention to explore the insider perspective of being primary caregivers of deaf children rather than studying the deaf children themselves and thereby validating the caregivers' experience in the process of the study and in its outcomes. Besides validating their experience, the qualitative approach shows participants that they matter. By showing that they matter, their significance and purpose can be enhanced (Thoits, 2011). Also, a qualitative research approach appeared best suited for this study because its focus was not, for example, the measurable deafness, statistical calculations of probability and regression but rather the texture of the caregivers' accounts, especially within their particular context, that is, an exploration of "action-in-context" (Holstein & Gubrium, 2011).

5.3. Qualitative research as a tool to explore caregivers' of deaf children's experience in context

South Africa's particularly turbulent history and context suggests that caregivers may have particular experiences and even the experience of caregivers from Mpumalanga will have its particular essence, especially within the context of poverty because, up to now, evidence "remains anecdotal and the complex relationships that exist between poverty and disability remain ill-defined and under researched" (Groce et al., 2011, p. 1493). There is variation in caregivers' experience based on their context and it cannot be assumed that the experience is the same everywhere and so, within the field of audiology, there is a rather recent acknowledgement that context is an important variable in the provision of audiology services and that "some aspects of hearing disability are not universal but rather vary regionally" (Knudsen et al., 2012, p. 90) and that the participants' historical and cultural settings are of importance (Creswell, 2009) which propels the agenda for qualitative studies within the field. Due recognition ought to be given to the participants' context and researchers ought to look at the "normative, ideological, historical, linguistic and socio-economic influences on the beliefs, objectives, expectations and talk of all participants" (Yardley, 2000, p. 220). Consequently,

> unlike quantitative researchers who seek causal determination, prediction, and generalisation of findings, qualitative researchers seek instead illumination, understanding, and extrapolation to similar situations (Golafshani, 2003, p. 600).

When conducting research in which people are the focus, there is the need to consider the context (Ahearn, 2001) so that the research does not present a romanticised or anecdotal account of people's experience (Silverman, 2011). Qualitative research, therefore, can fill that liminal space between reality and the participants' representation of their reality because "a qualitative-humanistic bent, then, seeks neither purely novelistic reportage nor purely abstract conceptualizing. (The aim) is judiciously to combine them, providing the vividness of 'what it is like'" (Lofland, 1971, p. 7).

Because qualitative research embeds itself within the participants' contexts, there is a promise of a close fit between research and practice (Yardley, 2000) and it could be a vehicle to provide a voice to the caregivers of deaf children so that people benefit directly from research (Bloor, 2011). Then, with that voice and information, theory and research can inform the practice of audiology, even though it is acknowledged that it is not always the overt intention of research to formulate policy but rather to provide a novel exploration of an existing phenomenon (Spencer, Ritchie, Lewis, et al., 2003) More specifically, within contexts of major social change, as would be the case in South Africa's transition out of legislated apartheid, there is the need to explore concepts around human agency and social structures and "to investigate how practices can either reproduce or transform the very structures that shape them" (Ahearn, 2001, p. 110).

5.4. Qualitative Research as a Segue from the Medical and Quantitative Approaches to Deafness

Although there may have been a medicalised and positivist background to research in audiology where the predominant focus has been on quantitative methods (Knudsen et al., 2012), I feel that there is a need for a segue into qualitative approaches so that the information pertaining to aspects dealt with in audiology can more closely reflect the voice of the caregivers of deaf children. This segue does not suggest the replacement of the one approach by the other but, instead, calls for the two approaches to complement each other and build on each other in order to give a broader and a deeper understanding of deafness and the different dimensions of the experience around deafness. The dominance of quantitative research in audiology and deafness (Knudsen et al., 2012) can make it difficult to operationalise quantitative findings because these findings may not necessarily account for meaning, experience, or context and it is suggested that “rather than imposing a definition on a context in which it might not fit, we should derive definition from context to ensure fit” (Williams et al., 2004, p. 957) in the way which a qualitative approach can accomplish.

Qualitative research is recommended for providing a more holistic understanding of experience, especially because “most methods have been restricted to close-ended questions, surveys, or scales” (Jackson et al., 2008, p. 83). This quantitative focus does not necessarily place the emphasis on the depth of the experience, as exemplified by a study on maternal views about deafness in Nigeria which only surveyed the participants via a ‘yes’, ‘no’ and ‘not sure’ questionnaire and did not involve a thick description of the mothers’ views (Olusanya, Luxon, & Wirz, 2006). Another example of the limited in-depth analysis of experience is a study conducted in South Africa (Swanepoel & Almec, 2008) in which only mothers were surveyed. Research in this area has been dominated by the experiences of parents (Jackson et al., 2008) and has not considered that other people may assume that parental role as caregivers of deaf children. The contextual reality in South Africa is that other people may be caregivers of deaf children, not necessarily only mothers and so it is important and necessary to broaden the research focus to include caregivers who may not be mothers.

Even research into caregivers of deaf children seems to remain within the quantitative domain where questionnaires and other measures are administered as exemplified in a study by Hintermair (2006, p. 493) which limits the qualitative dimension to “an array of different questionnaires (PSI, SDQ, SOC, F-SozU, etc.)” to explore parental resources when, instead, a deeper and possibly more qualitative approach could have been taken and added to the findings. Similarly, a study by Ahlert and Greef (2012) used a correlation and regression analyses within a quantitative approach to explore resilience but included two open-ended questions in their study to further explore strengths and challenges for family resilience in which, through a factor analysis, they found that family and social support were useful resources in mediating parents’ and families’ response to childhood deafness. However, although these two questions can give a glimpse into some qualitative components to experiences around deafness, there is an indication that there is the need for further exploration of the experiential and qualitative components. Evidence of this quantitative predominance was recently found by Poon and Zaidman-Zait (2014) when they conducted a review of social support for parents of deaf children and this review of the literature revealed that, of the studies which they reviewed, “18 involved a quantitative research design, 6 were qualitative, and 2 were mixed methods” (p. 179).

Quantitative approaches are useful and informative, but the use of qualitative approaches could yield information that can contribute to the understanding of deafness and can reveal information on aspects that may have been overlooked by a quantitative approach because a qualitative approach “illustrates multiple aspects of human actions and demonstrates paradoxes and contradictions" (Knudsen et al., 2012, p. 84). Esposito (2001, p. 570) feels that quantitative researchers use instruments which "are frozen in time while, in contrast, qualitative researchers seek to reflect a dynamic social world that is constantly changing." Additionally, qualitative research "crosscuts disciplines, fields and subject matter" (Denzin & Lincoln, 2011, p. 3) and embraces an interdisciplinary approach which respects "diverse perspectives and practices for generating knowledge" (Hesse-Biber & Leavy, 2011, p. 4) and it, therefore, appears appropriate for this thesis as it cuts across different domains of the caregivers' experience. By recognising that experience is not devoid of cultural and linguistic influences (Silverman, 2011) caregivers' experience can be contextualised in terms of place, time, and existing knowledge, especially because it is reported that many studies on caregiving have been conducted using questionnaires and that there is a need for a deeper exploration of the dynamic nature of the caregiver role (Raina et al., 2004).

Within the medical paradigm, there lies promise in the branch of social medicine studies which consider end-user centeredness (Chiegil, Zungu, & Jooste, 2014) and the purported offer of patient-focused interventions (Coulter & Ellins, 2006). However, despite these promising moves, they still remain embedded within a medical paradigm and the language these approaches employ reinforces the medical dominance. By referring to end-users, it limits and constrains the focus to the people who are attending for medical services rather than looking more broadly and accepting that they are not the end-users; the services do not end with them but extend to their significant others, families, communities, and societies. Similarly, although proponents of 'patient-focussed interventions' say that "patient-focused interventions are those that recognise the role of patients as active participants in the process of securing appropriate, effective, safe and responsive healthcare" (Coulter & Ellins, 2006, p. 7), the terminology alludes to the perpetuating of the person as a patient, as being under the treatment of a medically trained professional rather than engaging in an equal relationship. The use of the word ‘intervention’ has quite forceful connotations which does not promote the idea of choice but, rather, reinforces imposition and does so, as per the definition, within the healthcare paradigm. Therefore, to move away from these negatively loaded associations with quantitative research with people, this thesis calls for more qualitative approaches to studying deafness because quantitative research tends to require the researcher to be detached from the participants in order to, supposedly, ensure objectivity (Morse, 2011), a detachment which is not congruent with a person-focussed approach advocated by qualitative researchers. Instead, because the qualitative researcher is often involved in the emotional experience of their participants (Morse, 2011) and engaging with them “in an emotional and mental sense” (J. S. Jones, 2010, p. 7), it may provide a more personable and humanist approach to studying experiences of deafness. The adoption of a more qualitative approach within the dominant medical paradigm would be congruent with its own call for, “Nothing about me without me” (Coulter, 2010, p. 473) which was advocated at a global medical seminar in 1998 which explored the involvement of patients in improving the quality of health care.

5.5. Considerations in the conducting of qualitative research

The turn of qualitative approaches to the study of audiological topics means that it has to contend with the possible methodological criticisms levelled against it by quantitative researchers. The limits of generalisation are more delineated within the qualitative approach, (Ritchie, Spencer, & O'Connor, 2003) because it does not rely on statistical factors to make it generalizable (Spencer, Ritchie, Lewis, et al., 2003) but, instead, looks to give a description and insight into the current experience within a specific setting (Lacey & Luff, 2009) which has its own contextual and researcher variables (Spencer, Ritchie, Lewis, et al., 2003). This study, similarly, is contextualised in terms of history, time, population, caregivers' backgrounds, the children's deafness characteristics, and available resources, amongst others and these factors have been detailed in the methodology chapters of this thesis so as to "enhance the external validity of the research by providing sufficient information for users to extrapolate and be in a better position to make their own transferability judgments" (Miyata & Kai cited in Sin, 2010, p. 307) without perpetuating the notion that within this qualitative orientation, "knowledge lacks all authority" (Bloor, 2011, p. 401).

Within a qualitative approach, there is often no predetermined decision on the number of participants which should be recruited or interviews which should be conducted because in qualitative studies, samples tend to be quite small (Hesse-Biber & Leavy, 2011) which tend to include participants who are able to share information on a particular area of interest (Davies, 2001) as was the case in this study. The emphasis on the number of participants may derive from the historical dominance of positivist research and it often dominates the discussion around sampling in qualitative research (Guest, Bunce, & Johnson, 2006) but, within qualitative research practice, the focus does not tend to be as prescriptive on the number of participants because the analysis is on the meaning rather than the statistical rigidity required for quantitative projects (Ritchie, Lewis, & Elam, 2003). The reason for not emphasising the need for a large sample size is because "there will come a point where very little new evidence is obtained from each additional fieldwork unit… There is therefore a point of diminishing return where increasing the sample size no longer contributes new evidence" (Ritchie, Lewis, et al., 2003, p. 82), that is, sampling to saturation (Guest et al., 2006; Hesse-Biber & Leavy, 2011). Because the data which are to be analysed are the participants' lengthy interviews, in order to prevent the analysis of these lengthy interviews from becoming too unwieldy or diluted, the sample size is legitimately small (Ritchie, Lewis, et al., 2003). These strategies are detailed in the methodology chapter of this thesis.

5.6. The Value of Qualitative Research

The value of a qualitative turn to research in this aspect of audiology could lie in the promotion of practitioner-oriented social research (Bloor, 2011) which, admittedly, is a medicalised notion and possesses intimations of ‘fixing’ and reflects the historical preponderance of discussing deafness and topics related to deafness within health discourses. However, because of this medical preponderance and dominance, I have to engage in the language with which medically oriented audiologists may converse so as to convince the positivists about the value and integral contribution of qualitative approaches to the study and interaction with people. I recognise that the results of the study may be of interest to practitioners in the medical and allied medical field and so this project offers a different perspective besides the medical one to people who are accustomed to that medical and medicalised paradigm. By offering a different discourse around deafness to all readers, not only medical and allied medical practitioners, this project could reinforce an appreciation for the qualitative aspects of deafness and stimulate a new discourse in health circles “since discourse, ideas and beliefs are an intrinsic part of our experience of health and illness, then this experience can be substantially altered by research which contributes to a change in the way we think or talk about health” (Yardley, 2000, p. 223) so that there is a move away from discourses around “medical prevention and ‘cure’ …(and) a paternalistic system of professional evaluation of needs for assistance” (Yardley, 2000, p. 223). This change in the discourse could go some way towards elevating research in deafness from the constraints of the positivist and medical domains so that within these domains, there is a “redescription using some categories from a particular framework” which could serve as an “antidote to the common-sense and often mistaken explanations for human behaviour” within a “space for thinking afresh about something (Parker, 2004, p. 7) and which may “contribute to the accumulating body of knowledge for the use of other researchers” (Parker, 2004, p. 7). More specifically, by adopting and implementing a qualitative approach to research with people, we are reminded that "what is demanded by social research, here and elsewhere, is a slowing down of, and the giving of reflexive attention to, normal processes of perception and cognition; in order both to increase accuracy and to provide for the communication of evidence" (Hammersley, 2010, p. 567).

It is argued that qualitative research is a collaborative process where participation involves an active process of engagement with the study and the study methods and gives participants an opportunity to create meaning or to clarify meaning for themselves rather being the passive objects of interest and study while recognising that "the meaning of all phenomena is created through interpretation and discussion, action and interaction" (Yardley, 2000, p. 217). Therefore, methods such as interviews, can be transformative, therapeutic and beneficial through the reflexivity which comes from talking about the participants' experience (Funk & Stajduhar, 2009; Squire, 2009) more than just worrying about their experience in that, through the interview, caregivers have the space for problem solving and for visualising things differently. Notwithstanding this potential benefit, there is also the recognition that not everyone may be comfortable discussing their challenges or expressing their needs so as not to appear as though they are placing their needs above others' although research has shown that this reluctance may not be beneficial (Petriwskyj et al., 2014). Therefore, with the turn to qualitative research, participants can experience benefit from their participation instead of just being objects of interest and instruments of data production (Holstein & Gubrium, 2004; Parker, 2004).

5.7. Qualitative research as a human rights prerogative

The inclusive and participatory character of qualitative research may hold potential human rights implications in that qualitative research shows "the ability to respond to the needs and preferences of the person" so as to create a space for "people's experiences to be the interpretative framework through which to understand the data produced and their implications (Young & Hunt, 2011, p. 12) especially in South Africa where, "two decades after the dismantling of apartheid, widespread inequality still exists in South Africa" (SAHRC & UNICEF, 2014, p. 17). Even though qualitative research can incur more financial costs and require more time in order to get unambiguous interpretation of context specific information (Williams et al., 2004), researchers and practitioners have the ethical and human rights duty to understand people's experience fully without hiding behind these costs as an excuse for not conducting this kind of research. There is a need to demonstrate respect and bolster dignity while engaging with people who have diverse perspectives (Petriwskyj et al., 2014) and this human rights focus can go a long way towards such endeavours.

The qualitative paradigm with its social focus could go a long way to garnering a "greater awareness of and attention to changing and conflicting interpersonal relationships, and greater concern with justice and the political implications of the research endeavour … in the context of extreme vulnerability within which many of us work" (Molyneux & Geissler, 2008, p. 691). Moreover, it has the potential to focus on the human rights prerogative in addressing stereotypes, citizenship principles, failures in communication, unequal power relationships, inclusion, and representation (Petriwskyj et al., 2014) and this human rights emphasis is necessary in the fields of deafness and audiology (McPherson, 2014). A qualitative approach "has the advantage of empowering participants …(where) each participant determines his or her own meanings and constructions that offer flexibility when studying individual, diverse perspectives" (Jackson et al., 2008, p. 83). Over and above the audiological practice and social policy implications, this qualitative stance to the exploration of caregivers' experience has the potential to highlight the experience of caregivers of deaf children who are at risk of remaining a hidden population (Singer, 1999) within the research arena because their deaf children may remain the focus of study which excludes and diminishes their participation, their needs and their contribution. This study, therefore, through the use of ethnographic interviews, was an attempt at including the participation of the caregivers within the research landscape; they have the right to be heard.

5.8. Chapter Summary

Qualitative research offers the opportunity to co-inhabit the research space and to extend the frontiers of research into deafness, not by any notions of usurping quantitative methods, but rather by giving a fuller, more human, all-encompassing, context sensitive, and participatory picture of deafness and its related dimensions such as the experience of caregivers of deaf children.

Chapter 6: Methodology

"I wonder to myself a lot;

'Now is it true, or is it not,

That what is which and which is what?'"

(Milne, p. 100)

Figure 6.1. The method, as in the photograph above, had to be considerate of the caregivers' context and had to navigate the particular landscape in which this study was set.

The journey followed a meandering path of personal experience in which many questions had to be asked of the research, meta-analytically, to ensure that the study was respectful of the caregivers of deaf children who participated in the interviews, sometimes sidestepping puddles and other times wading through them, but all the time accounting for them.

6.1. Introduction to the Methodology

In this section of the thesis, an account is presented of how the data for this study were collected, analysed and interpreted. The procedures outlined here were informed by the particular backdrop to the study as well as the qualitative approach to this study.

6.2. Research Question

What is the experience of primary caregivers of deaf children in the Ehlanzeni District of Mpumalanga?

6.3. Research Aim within the Thesis

To explore the experience of caregivers of deaf children in the Ehlanzeni District of Mpumalanga.

6.4. Research Design - A Qualitative Research Design

As discussed in Chapter 1 and Chapter 5, this study was oriented towards a qualitative research design. It is acknowledged that in social research, more specifically within the qualitative domain, that an eclectic and pragmatic approach is useful, one which is sensitive to the participants and which is cognizant of contextual factors (Krauss, 2005; Snape & Spencer, 2003; Williams et al., 2004). Therefore, to this end, a combination of methods was used to gather information around the experience of caregivers of deaf children in the Ehlanzeni District. A holistic approach to qualitative research is encouraged to provide a fuller and richer analysis and interpretation (Hesse-Biber & Leavy, 2011) and, therefore, ethnographic observations and reflective research notes were employed in addition to the individual and group interviews. This project adopted an ethnographic orientation by following “first person” (Baszanger & Dodier, 2004, p. 10) accounts of caregivers’ lives and by connecting my findings with the participants' "backdrop," thereby making the study, more specifically, an "in situ" (Baszanger & Dodier, 2004, p. 12) study. The Framework Analysis (Ritchie, Spencer, et al., 2003), which will be explained later, lends itself to a holistic and thorough method of analysis in keeping with the interrogative nature of the data collection.

6.5. Participants

In keeping with the qualitative orientation, this project sought to explore the caregivers' reflections on their experience by speaking to them directly and, therefore, the participant recruitment reflects that qualitative and first person (Baszanger & Dodier, 2004) focus while also acknowledging that, within a qualitative orientation, insight into phenomena and experiences is derived from the interaction between the researcher, language and culture mediators, and the participants in the study (Lincoln et al., 2011) as depicted in Figure 6.2 in which is depicted the interrelationship between the different actors in the research project.

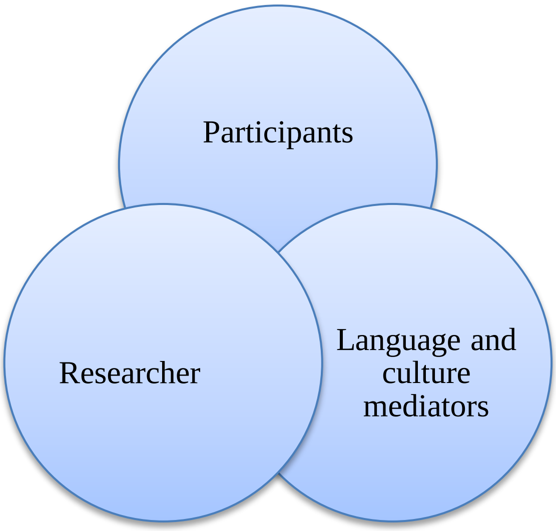


Figure 6.2. Participants, researchers, and language and culture mediators as co-constructors of meaning in qualitative research.

6.5.1. Inclusion criteria for the caregivers' participation in the study.

With regard to the inclusion criteria for the caregivers' participation in the interviews, participants were:

- primary caregivers of the deaf children, that is, the persons most responsible for the care of the deaf children, those who assumed the principal responsibility for the child. I included caregivers who were not biological relations to the child but who may have been transferred the role of caregiver of that child as per the description of the caregiver set out in Chapter 4. For inclusion in this study, the caregivers were required to be people and not institutions to which the caregiver role had been assigned, for example, schools, social workers, and orphanages so as to explore the caregivers' personal experience rather than the experience of the institution. For inclusion, the children in their care did not have to be of any specific age but had to be considered children as per the legal description which was discussed in Chapter 4 (Children's Act, 2006).
- caregivers to children with bilateral, permanent deafness. This study was focussed on the particular experience around bilateral, permanent deafness, and, although caregiving around transient deafness and around unilateral deafness has its own dynamics, the focus was on the experience of caregivers whose children have bilateral, permanent deafness. For the purposes of this study, symmetry of the thresholds of hearing were not considered because, as per the next inclusion criterion, the caregivers' children tended to have severe deafness.
- caregivers to children who were formally diagnosed as deaf to a degree that hearing aid amplification was considered, prescribed, or worn and for whom, with or without such amplification, speech at a conversational level and loud sounds cannot be heard.

- not excluded on the basis of nationality, race, ethnicity, gender, disability, age, schooling, employment status or language (Ritchie, Lewis, et al., 2003), thereby creating an opportunity to get a more encompassing idea of the caregiving in that district.
- caregivers to children who were not exclusively deaf, that is to say, children could present with deafness and other factors such as blindness, mobility difficulties, and developmental delay, although deafness had to be present for inclusion in the study. By being open to other aspects, a more sensitive idea of caregiving of deaf children could be sought which accounts for other possible aspects of their experience, not just their children's deafness.
- to live in the Ehlanzeni District of Mpumalanga. Caregivers needed to have an established settlement in the district although the participants did not have to always have lived here and their children did not have to attend school here to be included in the study. A time frame was not specified for how long the caregivers had to have lived in the district since this study would look at the caregivers' experience in that district, regardless of whether they had recently settled in the district or had moved into the district so as to include an exploration of those aspects in relation to their caregiver experience.

6.5.2. Sampling Considerations.

In the recruitment of caregivers of deaf children in the Ehlanzeni District, as summarised in Figure 6.3, a non-probability sampling method (Ritchie, Lewis, et al., 2003) was selected to invite participants to participate in this study. In this method, there was a deliberate selection of potential participants who best reflected the study's intentions and there was no requirement for the sample to be statistically representative (Ritchie, Lewis, et al., 2003) because of the in-depth and experiential focus of this study which was more concerned with “the depth of understanding generated” (Goudge et al., 2009, p. 235). Within this non-probability method, I chose a purposive, convenience sampling strategy because the participants recruited through this purposive sampling strategy, by virtue of their position (Hesse-Biber & Leavy, 2011) as caregivers of deaf children themselves, were in a position to share insights into the experience of being caregivers to deaf children in this district of Mpumalanga and it was based on “who is available, who has some specialized knowledge of the setting, and who is willing to serve in that role” (Hesse-Biber & Leavy, 2011, p. 46). Additionally, I also employed a snowball sampling technique where research contacts led to others based on their personal networks (Hesse-Biber & Leavy, 2011) in order to invite new participants through the participants who had already agreed to participate or had already been interviewed. This snowball strategy seemed quite effective, especially because the participants who had already been interviewed seemed to allay the potential participants’ anxieties about being interviewed. For example, after the interview with Participant 6, she phoned Participant 16M, the mother of a deaf girl, to invite her to participate and told her that she had been interviewed and that there was no cause for anxiety.

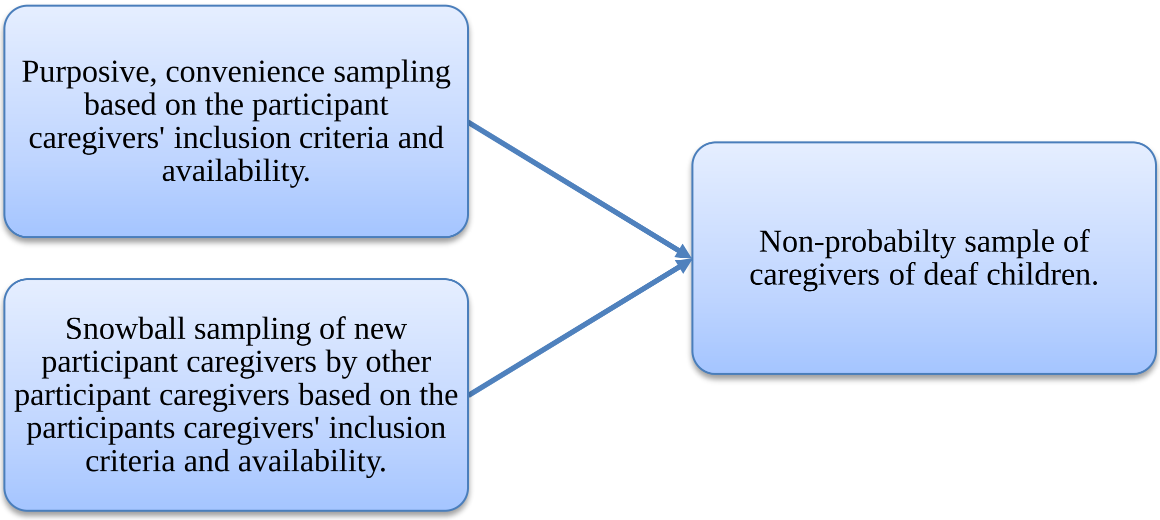


Figure 6.3. Composition of the non-probability sample.

6.5.3. Accessing participant caregivers: purposive, convenience sampling.

In line with the guidelines in the literature (Hesse-Biber & Leavy, 2011), my goal was to enlist both formal and informal assistance in gaining access to participants. I gained access to the participants in my study via various routes. Some proved more successful than others. Based on meetings with potential access sources, I was able to make contact with potential participants, who then, themselves invited other caregivers to participate in the interviews. As this was a community-based study and because of its more qualitative orientation, I set out to recruit not solely from medical and audiological services and sought other possible sources. I made contact with a local youth centre, an adult caregiver training facility, a day centre for children with special needs, a local district hospital, and the local school for children with special needs. The representatives from the local youth centre and adult caregiver training facility said that they were unable to assist because they did not know anyone who was deaf and that they were not able to be involved in the study because of other commitments.

I approached the manager at a day centre for children with special needs who expressed interest in the study and agreed to invite participants for this study. However, prior to the start of the data collection phase of the study, she expressed no interest to continue participation in the study, did not reply to my correspondence, and subsequently withdrew the involvement of this centre because she said that participation in the study held no benefit to her.

While I was trying to source bases from which to recruit participants, contact was made with the audiologist at a local district hospital, Themba Hospital in rural Kabokweni who said that she saw adults in her clinic and that children are usually referred to the bigger hospital in Nelspruit, which is about 30 kilometres from Themba Hospital or Emalahleni, which is about 240 kilometres away. Therefore, because she sees adults at her clinic, she could not serve as formal gatekeeper to approach potential participants.

I also met with the occupational therapist and principal of the local, rural school for children with special educational needs, Kamagugu Inclusive School in Kabokweni. More information about the school is included in Appendix A. The occupational therapist was also the school's liaison for people wanting to conduct research at the school and she agreed to serve as the gatekeeper to invite participants who wanted to be interviewed for my study. Permission to conduct research was obtained from the principal of the school as in Appendix B.

Each learner at the school has a message book for their caregivers in which messages are written to caregivers about various topics related to their children, for example, upcoming events, tasks, announcements. Since this was the usual and apparently successful way of communicating with the caregivers, I asked the occupational therapist to include a message to the caregivers of the deaf children at the school in each of the deaf children's message book informing them about my study and inviting them to participate. The information letter was sent in each deaf child's message book for his or her caregiver to read. Those caregivers who agreed to participate in the study returned the slip to the school indicating their agreement. The caregivers were asked to return the letters within a week.

The names and contact details of those who had agreed to participate in the study were collated by the occupational therapist and given to me for me to contact the caregivers. I only contacted them once they had agreed to participate so as to avoid coercion into the study and to avoid cold calling potential participants. The occupational therapist, on behalf of the school, acted as the gatekeeper (Hesse-Biber & Leavy, 2011) between me and the potential participants. From this recruitment through the school, 13 caregivers returned indicated that they were willing to participate in the study. From those 13 caregivers who had agreed, in principle to participate, eight were interviewed. The other five had changed their minds about participating and were, therefore, thanked for having considered participation and no further contact was made with them.

Contact was also made with the two South African Sign Language teachers' assistants at the school who are deaf themselves and they said that they knew of some caregivers of deaf children who may want to participate in the study whom they could invite to participate in the study. The one teachers' assistant invited two caregivers to participate in the study to which they agreed.

6.5.4. Accessing participant caregivers: snowball sampling procedure.

Seven new participants were recruited for the study through snowball sampling by the eight participants who had been recruited through the school. When contact was made with the school-recruited participants or after each interview with the participants recruited through Kamagugu Inclusive School, the language and culture mediator asked the caregivers if they knew of any other caregivers of deaf children who may have been interested in participating in the study. In order to ensure the privacy of the new potential participants, the language and culture mediator did not ask for the contact details of these new potential participants. Instead, she asked the caregivers who had been recruited through the school to contact the potential participants and ask them whether we could contact them to arrange for an interview, if they wanted to participate. We did not contact them directly without first having had the go-ahead to do so from the participants who had already been interviewed and who made contact with the potential participants. I offered, in order to save the newly recruited participants' telephone costs, that the language and cultural mediator would phone the new participants if they had indicated to the existing participants that they were willing to be interviewed. The potential participants also had the choice to phone me, rather than me phoning them, and were therefore also given my telephone number to contact me if they wanted to be interviewed, thereby giving them some agency and choice in making contact with me. In order to save them money in phoning me, they sent me text messages with their telephone numbers so that I could phone them without them incurring costs for the phone calls. From this snowball strategy, seven participants were recruited, of whom one child was from Kamagugu Inclusive School but was not on the original list from the school. Two other participants recruited via other participants had had their children at Kamagugu Inclusive School but their children were not attending school there any longer.

6.5.5. Sampling till saturation.

There was no predetermined decision on the number of participants which should be recruited or interviews which should be conducted. Instead, sampling was carried out until saturation, especially because the sample was homogenous in terms of the inclusion criteria yet diverse in the final makeup of the sample. It has been suggested that studies which use in-depth interview techniques interview at least 12 participants in order to reach data saturation when the sample is quite homogenous and when the interview guide is quite similar in structure across the interviews (Guest et al., 2006). This homogeneity extended to the participants in this study and in the interview guide because they all shared in their role as caregivers of deaf children even though the sample included deaf caregivers, a blind caregiver, mothers, a father, aunts and grandmothers.

Interviews were conducted to the point of data saturation (Guest et al., 2006) which is described as “the point in data collection and analysis when new information produces little or no change to the codebook” (Guest et al., 2006, p. 65). In other words, new participants were interviewed until each new interview started revealing similar themes to the interviews which had already been conducted. The second saturation point was reached with regard to the availability of participants, that is, of the convenience sample, the people who had availed themselves to be participants in the study (Hesse-Biber & Leavy, 2011). It appears as though these two saturation points merged in the sampling saturation point as depicted in Figure 6.4. That is to say that even if more people had come forward, the decision would have been taken not to interview them and to use the information from the sample thus far because it reflected caregivers of different ages, relationships to their children, employment and other factors, and could yield information pertinent to this study although it was less representative of gender variation.

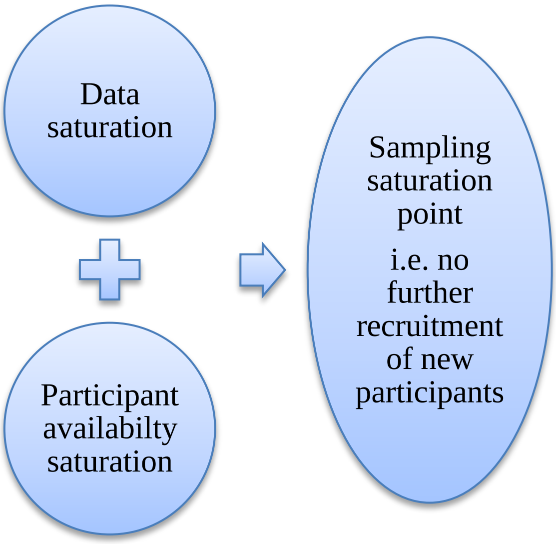


Figure 6.4. Sampling to saturation.

6.5.6. Participant-Caregivers' Demographics.

Based on these aforementioned criteria and the sampling strategies, 19 interviews were conducted with 20 participants from across the Ehlanzeni District and appear to represent a predominantly rural spread. The participants' demographics are summarised in Table 6.1.

Interview 16 which is recorded as Participant 16 comprised of a mother and father pair who chose to be interviewed together. The participant who lived in Nelspruit had moved to Nelspruit from a rural area of Ngondwana as her child was attending Kamagugu Inclusive School and so she would still be reflecting the experience of the rural context and the move to Nelspruit, in itself, was part of that experience. Similarly, Participant 2 had moved to the area from Zimbabwe and then Bushbuckridge. Participants' ages ranged from 25 years of age to 55 years of age, although the one grandmother looked older than 55 years of age but she did not know her age. The children in their care ranged from 11 months of age till 18 years of age. Ten of the participants who were interviewed did not have spouses.

Table 6.1. Participant Caregivers' Demographic Summary (n=20)

Participant Number	Relationship To The Child	Home	Participant's Age In Years	Child's Age In Years	Recruitment Source	Employment	Highest Level Of Schooling
1	Mother	Tekwane South	48	13	Kamagugu Inclusive School	Unemployed	Did not finish high school
2	Aunt	Ka-Nyamazane	40	12	Kamagugu Inclusive School	Personal assistant at a firm in Nelspruit	Secretarial diploma
3	Mother	Shabalala	33	10	Kamagugu Inclusive School	Formally unemployed but has a spaza (informal) shop in her house	Grade 11
4	Aunt	Phola	27	12	Participant 3	Formally unemployed but assists as a home based care volunteer in her village and has hair dresser salon in her garage	Grade 12
5	Aunt	Phola	42	13	Participant 4	Unemployed	Grade 12
6	Mother	Recently moved to Nelspruit from Ngondwana	35	8	Kamagugu Inclusive School	Planner at paper factory	Grade 12 but busy studying N4 Electrical and Diploma in Management and Technology
7	Grandmother	Matsulu	51	18	Teachers' assistant at Kamagugu Inclusive School	Unemployed	Did not attend school
8	Mother	Matsulu	26	0.11	Teachers' assistant at Kamagugu Inclusive School	Unemployed	Grade 10
9	Mother	Matsulu	28	7	Participant 8 and Participant 9's sister (whom I shall refer to as 'N')	Unemployed	Grade 11

Participant Number	Relationship To The Child	Home	Participant's Age In Years	Child's Age In Years	Recruitment Source	Employment	Highest Level Of Schooling
10	Mother	Matsulu	38	14	Participant 8	Unemployed	Grade 7
11	Grandmother	Umjindi	52	9	Participant 12	Unemployed	Did not attend school
12	Mother	Umjindi	30	11	Kamagugu Inclusive School	Unemployed but finds occasional casual employment	Grade 12
13	Grandmother	Matsulu	Does not know her age.	18	Participant 8 and Participant 9's sister (whom I shall refer to as 'N')	Unemployed	Standard 1 (Grade 3)
14	Grandmother	Matsulu	55	18	Participant 13	Unemployed	Did not attend school
15	Mother	Matsulu	37	12	Participant 8 and Participant 9's sister (whom I shall refer to as 'N')	Formally unemployed but assists as a home based care volunteer in her village.	Grade 11
16	Mother and Father	Brondal	Father 32 and Mother 25	3	Participant 6	Father: Business development officer on a farm. Mother: Unemployed.	Father: National Diploma in HR, Assessor course NQ15. Mother: Tourism course
17	Aunt	Kabokweni	42	17	Kamagugu Inclusive School	Unemployed	Grade 11
18	Aunt	Sibuyile	32	12	Kamagugu Inclusive School	Child care assistant at a crèche in Nelspruit	Grade 12
19	Mother	Kamajika	37	18	Kamagugu Inclusive School	Fruit picker on an avocado plantation	Grade 12

Of the participants, 10 were biological mothers to deaf children, 4 were grandmothers, 5 were aunts, and 1 was a father. Of the 20 participants in the 19 individual interviews, 15 of the participants were formally unemployed. Three participants had not attended formal schooling and 8 had not completed school. Eight participants had obtained a Grade 12 qualification but only 4 of them had obtained some form of post-school qualification as is graphically summarised in Figure 6.5. Please note that in this figure, the schooling number exceeds 20 because it includes caregivers' post-school qualifications.

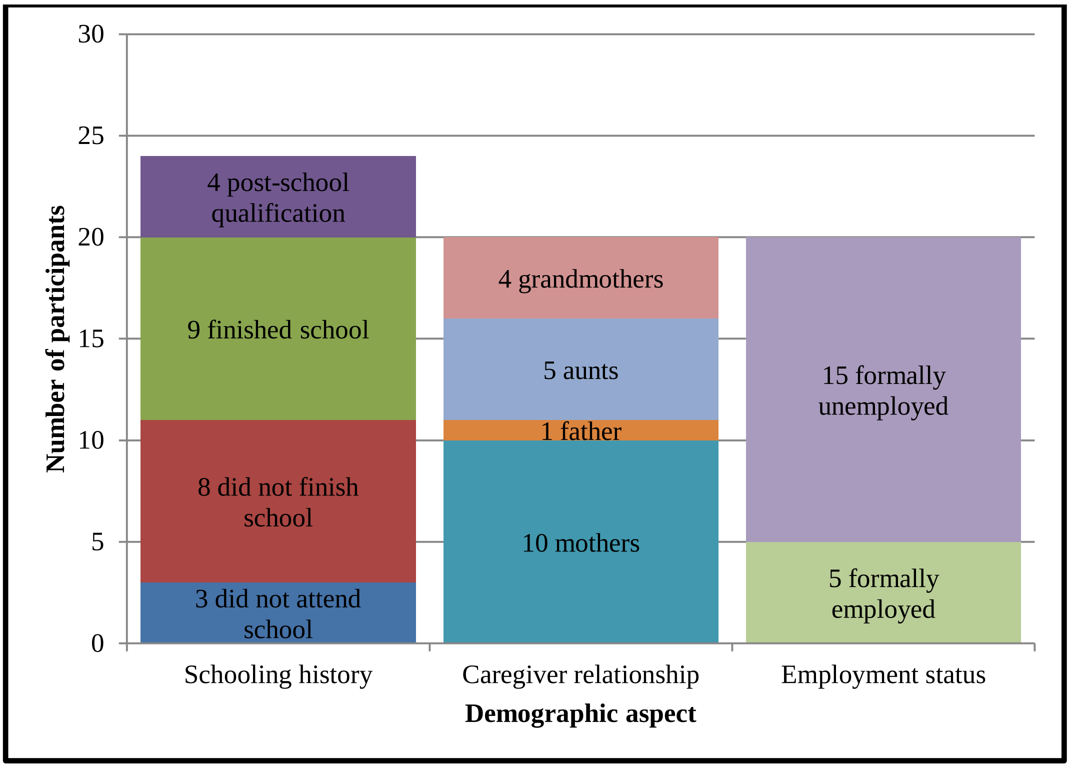


Figure 6.5. Graphic summary of the schooling, caregiver, and employment demographic factors of the participant caregivers.

Table 6.2 provides a description of the people with whom the participants live and points to the variations in extended family living arrangements in South Africa (de Villiers & Giese, 2008).

Table 6.2. Description of the people who live with caregivers in their homes

Participant	Participants and the people who live with them.
1: Mother	deaf daughter and other children.
2: Aunt	her biological daughter (14 years old), her biological son (17 years old), the child's grandmother, and the deaf nephew.
3: Mother	her husband, deaf daughter, and younger hearing son.
4: Aunt	her daughters and her deaf niece who boards at a school away from home during term.
5: Aunt	her husband, deaf nephew, and her own children.
6: Mother	her husband, her older son, and her deaf son.
7: Grandmother	the deaf child's great-grandmother, uncle, the deaf child and two other children.
8: Mother	the deaf child's grandmother, 3 of the mother's siblings, nephews and nieces, (including 2 sets of twins), and her deaf son.
9: Mother	the deaf child's grandmother, grandfather, her sister, her nephews, and her deaf child.
10: Mother	the deaf child's grandmother, 3 of the mother's siblings, her nephews and nieces, her other children (including 2 sets of twins), and her deaf daughter.
11: Grandmother	the deaf child, his uncle and the uncle's twin children.
12: Mother	her partner, her brother, her deaf child, another child, her uncle, her aunt, and the aunt's 6 children.
13: Grandmother	her son, the son's fiancé, the deaf child, and 3 other children.
14: Grandmother	the deaf granddaughter and 8 other children. Her husband is working in Rustenburg.
15: Mother	her deaf son and a new-born baby.
16: Mother	her husband, her husband's brother, the child's grandmother, the deaf child and another child.
17: Aunt	her husband, 2 step-children (her husband's children), 4 of her and her husband's children, and her deaf nephew.
18: Aunt	her husband, 6 children, and her deaf nephew.
19: Mother	her father, the deaf child and 2 other children.

6.6. The Language and Culture Mediators as Participants in This Study

This qualitatively orientated study was conducted as a collaborative and co-constructed exploration between the researcher and the participants (Lincoln et al., 2011) of the caregivers' experience of childhood deafness. Therefore, because of this co-construction, a description of the language and culture mediators is included at this point as they are considered to have participated in the research too through their engagement with the caregivers of deaf children and through their clarification and reflections of the interview data. The involvement of the language and culture mediator "offers greater possibility for construction of nuance and meaning, particularly where cultural parameters influence the collection and meaning of sensitive data from vulnerable populations" (Larkin, Casterlé, & Schotsmans, 2007, p. 468). Furthermore and very importantly, the language and culture mediator plays a major role in mediating in the ethical interactions with participants because, "they do not simply neutrally observe and adhere to formal externally derived ethical rules, but instead play a vital, creative, and under-recognised role in research and ethics practice" (Molyneux & Geissler, 2008, p. 688).

6.7. Considerations in the selection of the principal language and culture mediator

In order to reflect more closely and earnestly on participants' lived experience of being caregivers to deaf children and because it seemed ethical and prudent, I incorporated the services of a language and culture mediator as the principal fieldworker for this project. From my previous work in this geographical area and from the preliminary exploration of the setting for this study I anticipated predominantly black, female, siSwati speaking participants. Therefore, I actively sought to include a female language and culture mediator because it is suggested that there is a closer affinity between female participants and female interviewers (Lewis, 2003) as I am a white, non-first language siSwati speaking, urban, university educated, male researcher which is in contrast to the description of the likely participants. The recruitment of a language and culture mediator in the role of fieldworker who had some resemblance with the participants would also allow for a truer interpretation of the data because this collaborative reflection on the interviews with the language and culture mediator was to provide a more contextually interpretive understanding of what participants had said because of the interlinking of language and culture (Fontana & Frey, 2000) offered by the language and culture mediator.

In selecting the fieldworker who was also the language and culture mediator for the study, certain considerations were taken into account. The predominance of siSwati in this district suggested that it was preferable to recruit the services of a fieldworker who was fluent in both siSwati and English, one of the languages I speak and in which the thesis would be written. It was preferable that the fieldworker had a local and first language experience of siSwati so as to be able to have an understanding of the metaphors and idiomatic expressions of the language which could have come up in the interviews and which she would need to be able to convey, not only literally, but figuratively too, so as not to lose the meaning of what the participants were saying in the interviews, especially because it is accepted that "language is not defined as a conduit that merely conveys information and it is not a transparent vehicle carrying only referential information" (Ahearn, 2001, p. 111).

There may have been limitations to using a fieldworker who is very similar to the participants since this familiarity may suggest to the participants that they did not need to provide as much detail to what they were sharing in the interviews because they could assume that the fieldworker knew what the participant meant when that may not have been the case (Davies, 2001) and these shared understandings could lead to less detailed responses from participants (Miller & Glassner, 2004). In order to reduce this threat, the fieldworker was advised to seek clarification when needed and to state from the outset that our interest was the participants’ experience and for the participants to speak freely on the topic. Therefore, it was suggested that, from the start of the interview, the language and culture mediator explain the aims of the study to the participants (Davies, 2001) in order to get elaboration on topics arising from the interviews.

6.7.1. Description of ‘P’, the principal language and culture mediator.

The principal language and culture mediator employed as the fieldworker for this study, P, was introduced to me through the Health Communication Project in Mpumalanga where she was working as a language and culture mediator on some of its research projects. P seemed to closely resemble my anticipated demographic description of the participants besides being caregiver to a deaf child. During the data collection phase, she had a school-going child who was 5 years old which, again, suggests an identification with the caregiver dynamics, albeit that her child is not deaf. Therefore, she seemed to share certain characteristics with the participants in terms of her race, gender, language, geography and parental background. At the time of the start of the individual interviews, P was a 26 year old, single mother who had completed Grade 12 in 2005 at dual medium English and siSwati school. P also completed a National Diploma in Computer Literacy in 2009. She had worked in an orphanage for 3 years before she changed employment and went to work at a local clinic, first as a data capturer and then later as a laboratory assistant. Thereafter she started working for the Health Communication Project where she gained experience interviewing, transcribing and translating which seemed very useful for my study. I was very fortunate that, during my data collection phases, P was not working on other projects which meant that she did not have to split her attention across different projects and interviews.

Because interactions with participants “are heavily laden with social, cultural, and political meanings” (Bucholtz, 2007, p. 802) I asked P to be the fieldworker to conduct the interviews in siSwati and to transcribe them. Because of her contextual knowledge, I also asked her to translate the interviews from siSwati into English and to engage with me in understanding the interviews and then, later, the transcriptions, thereby also serving as a language and culture mediator. Therefore, P served a more complex role than the pure literal interpretation of siSwati into English and vice versa. Her role as language and culture mediator meant that she considered not only the literal meaning of what was conveyed, but also mediated or brokered meaning from what participants said in the interviews and she also mediated between the participants and me and then between the different participants themselves.

6.7.2. Collaboration with the principal language and culture mediator.

P, in her role as the fieldworker and the language and culture mediator, interviewed the participants, transcribed their interviews and translated them. She mediated between me and the participants or anyone else with whom we came into contact who may have been of a different background or language to me. Her role encompassed more than just being a research assistant and she, instead, fulfilled a collaborative role in this study. P served as the point of contact between me and the research participants when interacting with participants and making arrangements for the interviews as well as representing me, my project and the university. From the outset I tried to involve her as much as possible in the process of the research project so that she could feel part of it and thereby feel as though her contribution was not just in the practicalities of the research. I wanted her to feel that she was an integral part of the project. To these ends, we reflected on the interviews, the participants, deafness, the setting of this study, and even the contrast with other settings. I felt that her contribution was very valuable, not purely as a fieldworker but as a collaborator with insight into the context. Therefore, P played a multifaceted role as she was invited to be involved in the post-interview reflections (more details of which are included in Appendix C with regard to language and culture mediation) so that we could analyse the interviews in relation to the particular context so as to enrich my “understanding of the participants’ accounts, of the language they use and of nuances and subtexts” (Lewis, 2003, p. 65).

6.7.3. Assistant language and culture mediators.

Although P was the principal language and culture mediator, during the data collection phase, the teachers’ assistant, whom I shall refer to as ‘F’, from Kamagugu Inclusive School and Participant 8 and Participant 10’s hearing sister, to whom I shall refer as ‘N,’ also played critical roles in the study in the collection of data and on providing input on the caregivers’ interviews. I acknowledge their identities and their roles within the interviews (Hammersley, 2010) while accepting that these contribute to the co-construction of meaning. This influence is acknowledged, and, for that reason, as I describe later in this chapter, I oriented them to this particular study and its aims.

6.7.3.1. ‘F’ – teachers’ assistant at Kamagugu School.

I requested F’s assistance in conducting the individual interviews with the deaf participants because my South African Sign Language proficiency would be insufficient for conducting the interview and also my dialectal variation from Gauteng. F is a deaf man who was 32 years old at the time of the data collection phase and he has a reported longstanding history and engagement with the deaf community in this district. His responsibilities at school include supporting the teachers who teach the children in South African Sign Language. I was informed that he has a Grade 10 qualification and that he has completed courses and workshops in his role as a teachers’ assistant. F is married to a woman who is also deaf although their child is hearing.

Although earlier I stated that P's gender could be seen as an advantage during the interviews, in F's case, I could not recruit a female deaf person to assist with the interviews. There is a female teachers' assistant at the school too but she was not available to conduct the interviews. However, F's acquaintance with the participants could be seen as a enhancing the comfort which the deaf participants could have experienced in being interviewed by him. He appeared very aware of the lighting and seating requirements for the video recording of the interview and advised me with regard to those matters which I took into consideration in recording the interviews.

6.7.3.2. 'N' – Participant 8 and Participant 10's sister.

N is Participant 8 and Participant 10's sister. Even though she is hearing and has hearing twin children, she appears to be very attuned to deafness, especially since she is the daughter of a deaf woman and she has three deaf siblings, and of her three deaf siblings, two have deaf children. She described her home language as South African Sign Language since that is what she learnt from her mother who uses it as do her sisters although she lives in a siSwati speaking region. She and I communicated in English predominantly, although I sometimes spoke to her in isiZulu and she replied in siSwati. The deaf teachers' assistant who had conducted the individual interviews with the individual deaf caregivers, Participant 8 and Participant 10, was not called upon to assist in the group interview because N, who is hearing, was asked to interpret instead. During the round of individual interviews it became apparent that N was fluent in South African Sign Language and could serve as the link between the hearing participants and her deaf sisters in the group interview. Therefore, in the group interview, she interpreted for Participant 10 because F would not be able to do so because, due to his deafness, he would not be able to hear the hearing participants' responses in the group discussion and interpret these spoken responses into SASL. Therefore, enlisting

N’s services meant that deaf participants who communicate via SASL could be included in the group interviews so that a broader caregiver perspective could be tapped in the group interviews.

6.8. The principal researcher as participant in the study

As has been described elsewhere in this thesis, within this qualitative study, it is accepted that the researcher is a collaborator in the study and that the researcher’s background has an impact on the way the study is conducted and interpreted (Davies, 2001; Lincoln et al., 2011) and it is, therefore, suggested that researchers provide their backgrounds, experiences, identity, perspectives, and standpoints so as to contextualise the researchers’ position within qualitative studies (Temple & Young, 2004; Young & Hunt, 2011) but without using it as an opportunity for confessing (Fontana & Frey, 2000) to personal immersion in the study.

I am conducting this study for my PhD in the Department of Speech Pathology and Audiology, School of Human and Community Development, in the Faculty of Humanities at the University of the Witwatersrand where I am also employed as an audiologist, lecturer, clinical supervisor, and researcher and where I had also undertaken my undergraduate studies from 1995-1998. My location in the School of Human and Community Development and in the Faculty of Humanities may have orientated my perspective of audiology towards a humanistic and qualitative leaning. However, notwithstanding this possible influence, there was no expectation, coercion, or pressure from this department, school, and faculty to conduct a study with this orientation and perspective. I have worked alongside deaf and Deaf people since 1999 in various settings in South Africa and seven years in the United Kingdom of Great Britain and have presented at conferences locally and internationally. This experience of working in different settings has informed my interest in the contextual influence on the experience of deafness and Deafness.

I am hearing and I am the eldest son of hearing, immigrant parents from Portugal. My mother tongue is Portuguese which is spoken in our home and in our multi-generational family, although I attended English schools and university and consider English my dominant language. I am conversant in isiZulu and Afrikaans and have some SASL knowledge. This experience of a multilingual upbringing has fostered a sensitivity for other people's multilingual needs and experiences, probably because of my experience of translating Portuguese into English and vice-versa for family and friends who may have had limited English language abilities.

I have published and supervised in the areas of Deafness, deaf education, traditional healing and deafness, ototoxicity, culturally sensitive practice, hearing aid rehabilitation, and auditory processing, amongst others. This varied spectrum of research areas may have influenced my multi-faceted appreciation for the caregivers' experience which I explored in this study with regard to the different domains of their experience, not just the audiological interest. My interest in the human experience of deafness as well as the humanistic and ethical practice of audiology with people who are deaf and Deaf and their families and significant others has been one of the motivators for my current and previous research endeavours.

Therefore, I acknowledge that these factors may and would have influenced various aspects of the study, either in terms of my response to them or other people's response to me and I recognise that it adds to the multiple layers of engagement in qualitative research.

6.9. Ethical Considerations

The ethical considerations around this project had to be contemplated at every stage of the project. Besides completing this study for degree purposes, there were ethical responsibilities, duties and obligations which had to be considered. By participating in this study, caregivers were entrusting me with very personal information. This trust I recognised and valued and tried to respect by my genuineness with the participants when I met them and interacted with them.

6.9.1. Anonymity and confidentiality considerations.

Participants “want to know what will become of their words” (Miller & Glassner, 2004, p. 131) and so, in reporting the results, I had the responsibility of recognising that the information which the participants had shared with me, they had shared in confidence and with the expectation that I would not divulge their experiences in such a way that the findings are a misrepresentation of what they had said and also tried to ensure that the presentation of the results could not be linked to them. There was a responsibility to maintain the participants’ anonymity and that I did by allocating numbers to the participants and their interviews. The only other name mentioned in the study is the language and culture mediator, to whom I refer as P, although I have not included her surname. Participant 8 and Participant 10’s sister, who served as the interpreter for the second group, interview is only referred to as N and the teachers’ assistance is only referred to as F. However, I recognise the threats to anonymity within the small community of people who are deaf and their familial, professional, and social networks (Young & Hunt, 2011).

The name of the school from where the caregivers were invited to participate is also named for purposes of transparency but I acknowledge that this naming of the school may compromise anonymity because there is the risk that readers of the final report may identify participants based on what is revealed in the interview and the link with the school. With regard to the school, the participants were not anonymous to the occupational therapist at the school who had recruited participants from that site and she may be able to attribute the caregivers' accounts of their children with what she, and other staff members at the school, may know about the children. The occupational therapist was asked to keep this information confidential. The names of participants' places of employment were not mentioned to protect their anonymity because readers of this report may be able to link the participants with their place of employment. The one blind participant's anonymity was at risk because readers could know who she is because of her link to the school, although there may be other caregivers linked to the school who are blind and who were not interviewed for this project.

The participants' anonymity and confidentiality could not be guaranteed in the group interviews although participants were requested to respect their fellow participants' confidentiality and anonymity. Also, I had to reassure participants that the gatekeepers would not be informed of what was discussed in the interviews.

P, F, and N were all asked to maintain the confidentiality and the anonymity of the participants with whom they engaged. P, as the principal fieldworker, had a formal agreement with me and with the Health Communication Project to adhere to the requirements of the University of the Witwatersrand's Ethics Committee with regard to protection of the participants' rights. For F and for N, we came to a similar understanding, although it was less formalised than for P. I explained and reinforced the need to protect the participants' and their families' rights to anonymity and confidentiality. In his work at the school, the teachers' assistant already engages in this practice and I asked him to extend it to this study. In her involvement in the study, N assured me that she would respect the participants' and the families' rights to confidentiality and anonymity, especially as it pertained to her interpreting work during the group interview.

6.9.2. Permission from the university's ethics committee to conduct the study.

Before starting the fieldwork for this project, I first submitted an application to the University of the Witwatersrand's Human Research Ethics Committee (Non Medical) which was granted after the first submission (Protocol number: H100 520) (Appendix D).

6.10. The Research Setting

The different actors in this research project, that is, the participant caregivers, principal researcher, principal language and culture mediator, and the assistant language and culture mediators all intersected in the geographical location of the research setting, the Ehlanzeni District of Mpumalanga. For the reasons highlighted in the background chapters of this thesis, this setting was deemed suitable to for this study. The research setting is approximately 400 kilometres and about 5 hours by car from Johannesburg (Google Maps, 2014) within the Ehlanzeni District (district code DC32) as per the map in Figure 6.6 (Municipal Demarcation Board, 2011). This rural district in the far eastern corner of South Africa borders with two other districts, Nkangala and Gert Sibande, with another province, Limpopo, and with two countries, Mozambique and Swaziland (Dombo, 2014).

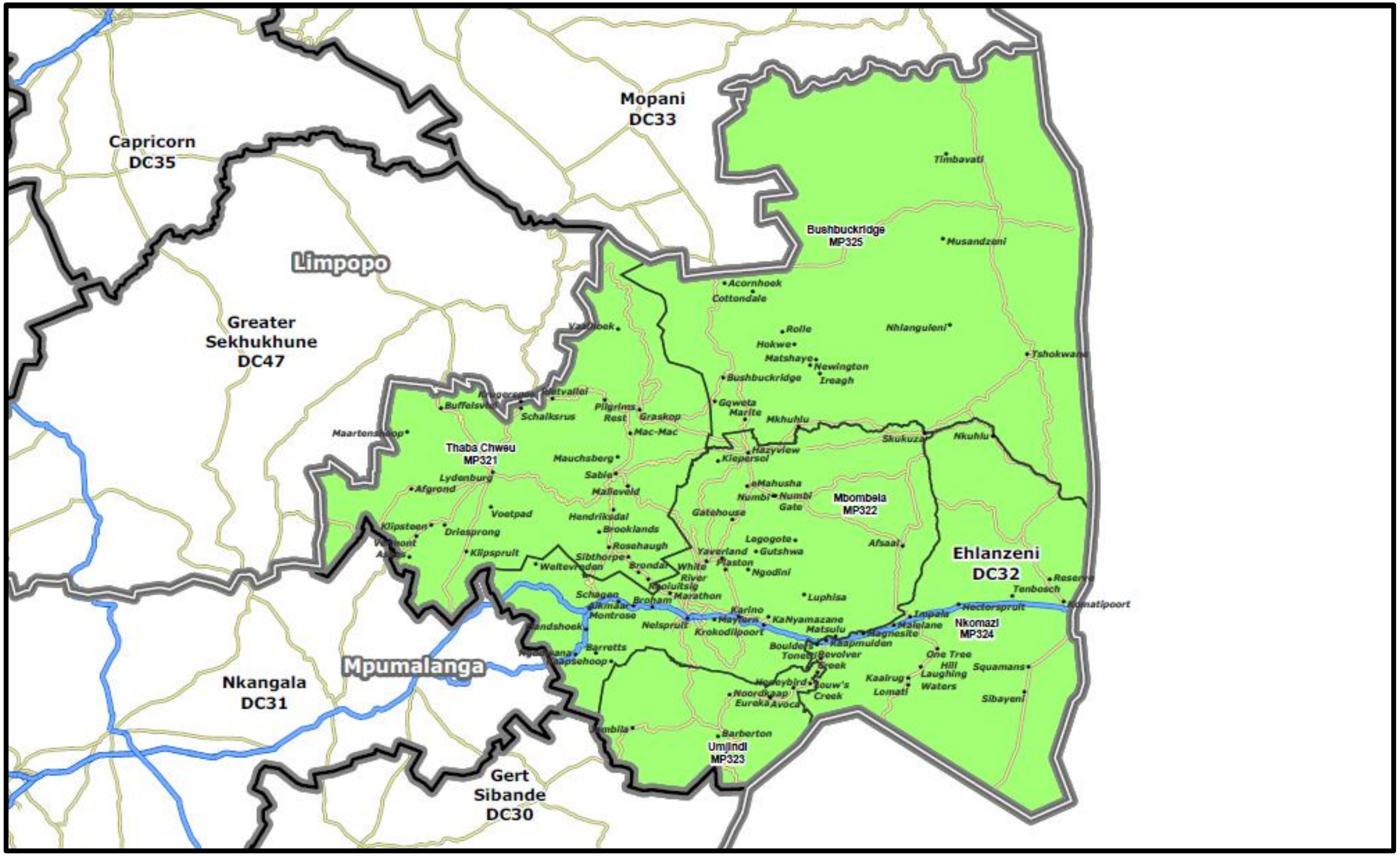


Figure 6.6. The outer and local municipal boundaries of the Ehlanzeni District Municipality (Municipal Demarcation Board, 2011, p. n.p.).

This province has a particularly rural character as it houses 7,2% of the national population in comparison with Gauteng, the most populous province, which has 22,4% of the national population and, in comparison with other provinces, is considered less densely populated since there are reportedly only 45.5 people living in a square kilometre compared with as many as 661.2 people living in a square kilometre in Gauteng (South African Institute of Race Relations, 2010). Within this rural district with few medical facilities, the maternal mortality ratio was 197.1 per 100 000 live births in the 2013/2014 period, an increase from 76.4 per 100 000 live births in 2011/12 (the national average is 133.3 per 100 000 live births) while the rate of stillbirths was recorded at 23.1 per 1 000 births and was above the national target of 19.7 per 1 000 births (Dombo, 2014).

The research was considered in preparation of the data collection phases for this study and therefore, before I formally started the interview process, I visited the research setting to prepare for the study in the Ehlanzeni District. This preparation included using satellite navigation systems to orientate the researchers to the area and obtaining paper maps of the region. However, the satellite navigation systems and maps were not necessarily always helpful because of the poor road and housing infrastructure in the villages where people lived. The examples of “Little Rose” and the “Ventures” which are included in Appendix C highlight these contextual factors. Nonetheless, these factors were considered in the preparation for the data collection although they could not always be controlled as also discussed in Appendix C in which considerations for navigating the contextual landscape while conducting this person focussed, qualitative research project in this district are discussed.

6.11. Permission to conduct the study in Mpumalanga

In order to conduct research in the province, I had to apply for permission from different government departments. I applied for and received permission from the Department of Education, Mpumalanga Province (Appendix E) and the Mpumalanga Provincial Government Department of Health (Appendix F). I conveyed this information to the school which then confirmed their earlier agreement to serve as a base from where to recruit participants and a time frame was set for the fieldwork during which the interviews would be conducted.

6.12. Research instruments

6.12.1. The ethnographic interview as the research instrument for the individual and group interviews.

I conducted individual and group ethnographic interviews with a sample of caregivers of deaf children in the Ehlanzeni District of Mpumalanga using a semi-structured interview guide as the ethnographic interviews allowed me to explore the caregivers' reflections on their dynamic and lived experience rather than observe and record one aspect of the caregivers' experience at one point in time. The ethnographic interview, rather than ethnography, enabled me to enquire about aspects of the caregivers' lived experiences, such as medical consultations and private discussions between spouses or partners, without intruding into those aspects of the caregivers' daily lives while offering participants an opportunity to meet, share experiences, and interact with each other.

Interviews are useful in "understanding motivations and decisions, or exploring impacts and outcomes" (Lewis, 2003, p. 58). Therefore, interviews were conducted with caregivers of deaf children in the Ehlanzeni District, a group of people who may be considered as a hidden population (Singer, 1999) because the focus tends to be directed at their deaf children and not at them. Therefore, through key-informant interviewing (Singer, 1999) in the form of ethnographic interviews (Davies, 2001), there was an exploration of the experience of people who may otherwise, remain a hidden population (Singer, 1999).

Additionally, the interview could offer a dedicated space and time for caregivers to talk and reflect about their experience which could be transformative (Squire, 2009) and offer a tool for coping (Vaux, 1990) for the participants because it is suggested that qualitative interviews can have therapeutic effects which come from talking about their experience. They can provide an opportunity for “validation, introspection and growth, self-acknowledgement and self-discovery, a sense of purpose, empowerment, healing, unburdening and catharsis, a sense of helping others, and means to make sense of experiences through speaking about them and refining thoughts through the interview” (Funk & Stajduhar, 2009, p. 860).

Context is crucial within qualitative studies because, “when context is ignored, the research instrumentation reflects this, the research product is likely to be flawed” (Williams et al., 2004, p. 494). The ethnographic interview takes participants’ contexts (Davies, 2001) into account and is conducted in the field and within the participants’ contexts instead of laboratories (Fontana & Frey, 2000). This interview technique is respectful of the participants’ “contextual, societal, and interpersonal elements” (Fontana & Frey, 2000, p. 647) and

> this implies not just awareness, but deliberate taking note of and problematizing the possible effects of these contexts. Thus, the data produced by an interview should include not just a record of what is said…, but full notes as to the contexts and how these various contexts are likely to affect the interactions that formally constitute the interview (Davies, 2001, p. 111).

Ethnographic interviews are considered more personally connected to the people who are being interviewed because the interviewer is permitted to have personal feelings which can influence the interview, thereby reducing the distance between the person doing the interviewing and the people being interviewed (Fontana & Frey, 2000). Because of this reduced distance between the interviewer and the participants, there was an opportunity to explore “insider understandings” (Singer, 1999, p. 172) through the active seeking of clarification of participants’ reflections. These insider understandings and co-constructions of meaning were further explored in the group interviews because the language and culture mediator was able to check the accuracy of the information which had been gathered in the individual interviews with the participants themselves. The participants were also involved in the clarification of themes and topics which had emerged in the round of individual interviews while also stimulating discussion around shared experiences by participants in the group interview (Fontana & Frey, 2000). Moreover, an ethnographic stance which is considerate of language variation and the participants’ language is very necessary and important in multilingual South Africa to avoid “a general sense of miscommunication and misunderstandings” (Van Herreweghe & Vermeerbergen, 2010, p. 141) so that the shared meaning can be explored with the language and culture mediator who can provide the necessary transfer of meaning so as to avoid this miscommunication and misunderstanding.

6.12.2. Development of the ethnographic interview semi-structured interview.

Ethnographic interviews usually assume a semi-structured format (Davies, 2001) to “ensure that relevant issues are covered systematically and with some uniformity, while still allowing flexibility to pursue the detail that is salient to each individual participant” (Arthur & Nazroo, 2003, p. 115) and to provide the necessary scaffolding to ensure a certain level of uniformity across the interviews so as to reach data saturation within the sample (Guest et al., 2006). In keeping with the qualitative orientation of this study, within the semi-structured format of the ethnographic interview, the interviewer “processes the meaning of the participant’s comments and is able to adjust questions and comments in response to unanticipated answers” (Esposito, 2001, p. 573).

The semi-structured ethnographic interview method could allow for deductive as well as inductive coding of the themes during the data analysis phase where deductive coding looks for themes and codes which “are pre-selected based on previous literature, previous theories or the specifics of the research question” while inductive coding looks for themes and codes which “are generated from the data through open coding, followed by refinement of themes” (Gale, Heath, Cameron, Rashid, & Redwood, 2013, p. 3).

A semi-structured ethnographic interview appears well suited for a combination of inductive and deductive coding. This combined approach to inductive and deductive coding is very useful to explore themes within pre-established domains while the researcher remains open to new or unexpected ways in which people experience a phenomenon (Gale et al., 2013). The semi-structured ethnographic interview is also considered more interactive and conversational than an unstructured interview which could be perceived as unrepresentative of a usual interaction because one person does all the talking and is expected to provide all the information without any interaction or response from the interviewer (Davies, 2001), again lending weight to the usefulness of the semi-structured interview for creating an opportunity for both inductive and deductive types of coding.

The development of the individual semi-structured ethnographic interview guide for this study was informed by the pertinent issues which arose from the literature review for this study and the research question. The group interview guide was formulated in relation to the themes which had been identified after the round of individual interviews, in relation to the literature review conducted for this study, and the broader research question. These interview guides are included in Appendix G. In keeping with the collaborative endeavour encouraged by the qualitative orientation to research, in the development of the guide, I sought the input of the language and culture mediator because, in this way, she continued as “a collaborator in the research process, which strengthens the rigor of language-based inquiry” (Larkin et al., 2007, p. 468).

While developing both the individual and group interview guides, they went through various iterations where the first attempts appeared too structured, closed-ended, and yielded little opportunity for caregivers to give expanded responses. It also appeared too restrictive in that the guide did not allow for any development of a segues and exploration of unanticipated responses, resulting in little room for variation (Fontana & Frey, 2000). Therefore, questions in the interview guide were kept open-ended, for example, by including ‘how’ questions and ‘tell us about’ statements and avoiding leading questions. The individual interview guide first explored demographic information and then progressed to enquire into the topic being studied (Arthur & Nazroo, 2003; Fontana & Frey, 2000), in this case, the experience of caregivers of deaf children, while the group interview began with an introduction of the participants. By starting the interview with more concrete and factual aspects, there was an attempt to reduce anxiety or reticence while all the time showing interest in what the participants said (Legard, Keegan, & Ward, 2003) while creating an opportunity at the end of the interviews for the participants to wind down after potentially emotionally laden questions (Arthur & Nazroo, 2003).

6.12.3. Piloting of the semi-structured ethnographic interview.

The semi-structured ethnographic interview underwent two piloting stages. For the first pilot stage, the manager at a community centre in Alexandra, Gauteng Province, recruited a grandmother and in the second piloting stage, nursing staff at a clinic in Mshadza, Mpumalanga, recruited a father to participate. For both pilot participants, consent for participation in the pilot and for recording of the interviews was obtained. The venue, time and date of the interviews were negotiated with the pilot participants. Both pilot interviews were not included in the final data analysis.

The pilot studies were analysed by the principal researcher and the language and culture mediator to check the duration of the interview as well as the focus, sequence and wording of questions, and the possible ambiguity of meaning underlying each question (Larkin et al., 2007). The language and culture mediator also considered the wording of the guide in relation to the translation of certain ideas into another language to see where the interview guide needed alteration in preparation for its use in the data collection phase. From the pilot studies it seemed that the interviews could last about 45 minutes. We decided that the interviews flowed better and were more conversant when the language and culture mediator performed the whole interview, rather than me asking the questions in English, waiting for them to be translated into siSwati, hearing the response in siSwati, and then having that response translated into English. Similarly, we attempted simultaneous translation but that did not work very well either because it was mechanical rather than interactional. Both pilot studies revealed that some words such as ‘disability,’ ‘hearing aids,’ ‘government,’ ‘transport,’ ‘taxi,’ and ‘bus’ were not always translated but were used in their English form, a practice which seems to occur often in the multilingual context of South Africa (Hagan et al., 2013; Kathard et al., 2011). More detail on the pilot studies is included in Appendix H.

6.12.4. Research team briefing and orientation with regard to the ethnographic interview.

Before the interviews were conducted, sessions were held with P to orientate her to the particular interview strategies for this study while “encouraging questions, discussion, and pooling ideas or worries" (Arthur & Nazroo, 2003, p. 133). Although P already had extensive training and experience in conducting interviews which came from her work with the Health Communication Project, she had not conducted interviews on childhood deafness and so I felt it important to discuss the interview techniques and considerations in relation to childhood deafness and in relation to the ethnographic interviews.

The background, aims of the study, the shift from the medical focus, and my decisions with regard to choice of setting, sample and research instrument were discussed with P and she was encouraged to take the stance that, in the ethnographic interview, "the interview is joint exploration of the topic of the research, rather than a mining of the interviewee for information … and…should…be reflected in the subsequent interactions" (Davies, 2001, p. 109). In addition, discussions were held around the ethical aspects of the project, especially with regard to anonymity and confidentiality, as well as ensuring that participants did not feel pressured to speak or obliged to respond. We also focussed on the flow of the interview guide to allow for a more conversational type of interview rather than a survey type questionnaire (Fontana & Frey, 2000). She was encouraged to engage in active listening and to be flexible in terms of the sequence of the questions during the interviews (Arthur & Nazroo, 2003; Fontana & Frey, 2000) because the caregivers could address a topic earlier on in the interview and out of sequence with the interview guide.

We discussed the sensitive nature of the interviews and the possible emotional response from the participants. She was advised to be attentive to the participants' facial expression, tone of voice and body language (Legard et al., 2003) to check for emotional discomfort. P was encouraged to express empathy with the participants without attempting to counsel them as counselling was beyond the remit of the fieldworker (Lewis, 2003). If participants cried, P was asked to check with them if they wanted to proceed with the interview and to offer them a break from the interviews (Legard et al., 2003). I reinforced the need for “listening, sensitivity, awareness, empathy, …(and)… not inhibiting the interview” (Spencer, Ritchie, Lewis, et al., 2003, p. 77) while all the time “showing interest and attention, … (and) maintaining eye contact” (Legard et al., 2003, p. 164). I advised her that she could take notes during the interview but I suggested that she not be note bound and to rather focus on the discussion since the interview was going to be recorded and so she would not have to take verbatim notes of what was said. I also reassured her that we would be reflecting on each interview and that any mental notes or inscriptions (LeCompte & Schensul, 1999) which she had made could then be written down subsequently if writing during the interviews could be perceived by the participants as an impediment to the interview. We discussed the seating arrangements for the individual interviews so that we could avoid an interrogator stance and rather to sit perpendicular to the participant rather than directly confrontationally face-to-face. These sessions were also opportunities to rehearse the interview techniques and we simulated interviews between the two of us and these were recorded and served as a way of analysing the interview technique and to allow for the fine tuning of certain strategies such as the avoidance of putting words in the participants’ mouths and interrupting their responses.

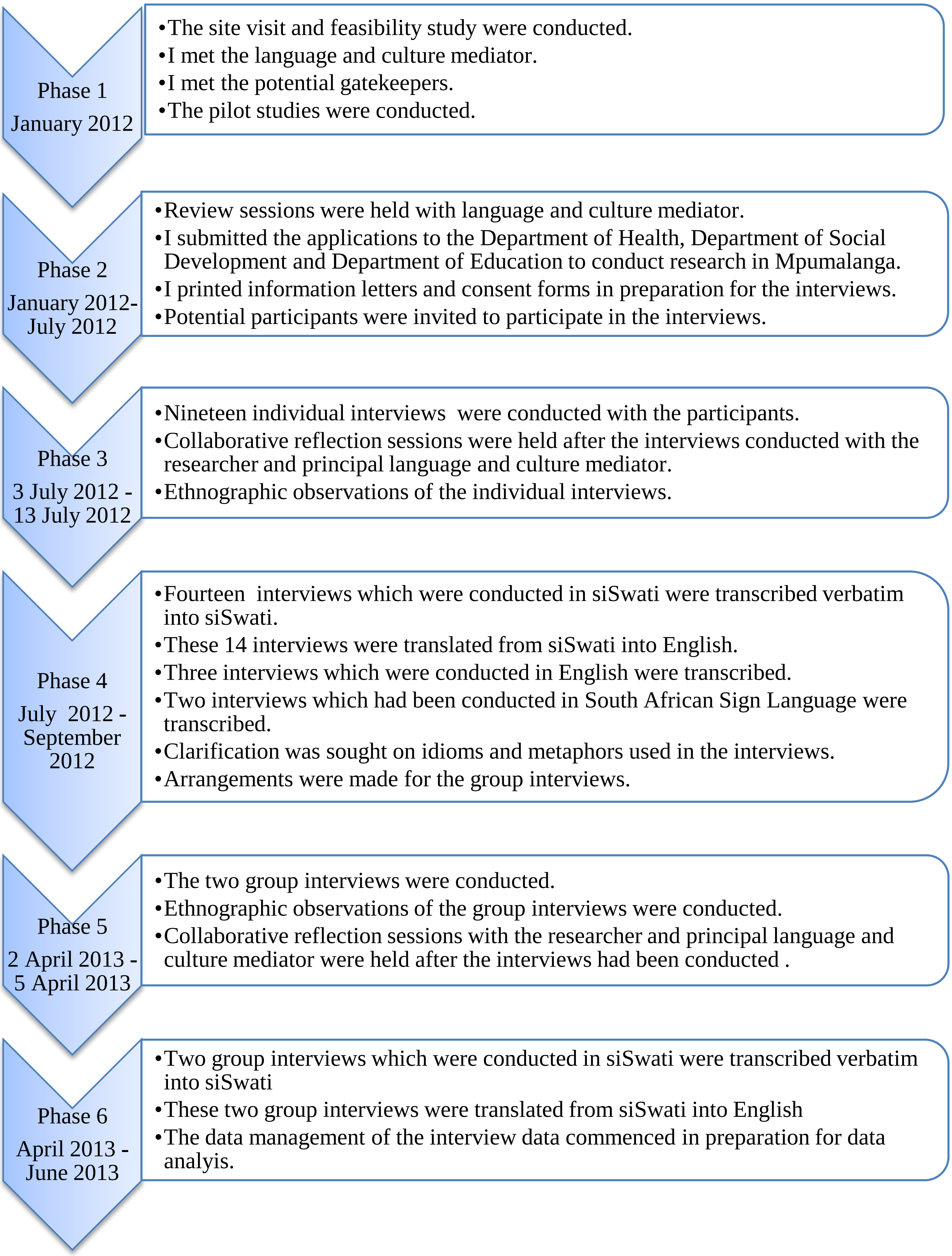
For the group interviews, similar considerations were discussed, especially with regard to avoiding dominance of the group discussion by one person in the group while trying to encourage quieter participants to engage in the discussion and getting everyone’s perspective (Fontana & Frey, 2000). Also, P was advised to gauge the dynamics of the group to keep the participants from deviating from the topic completely while still allowing the space for expansion around the topic (Fontana & Frey, 2000) and without constraining the discussion. No a priori decision was made as to what would be considered a complete deviation from the topic because of the multifaceted dynamics of the caregivers’ experience. However, the guiding principle was that, as long as the discussion was still relevant or could be brought back to the caregivers’ experience around their children’s deafness, it could explored so as to get the fuller picture of the dynamics around the deafness.

With regard to the two interviews which were conducted in SASL and the SASL interpreting conducted in the second group interview, similar orientation sessions were held with F and with N, although not to same extent because of my conversational level SASL to communicate with F while N reported that she often interprets for her deaf family members and was familiar with the requirements of interpreting, including speaking using the first person when interpreting for Participant 10, her sister.

6.13. Data Collection

6.13.1. Time Frame and Description of the Data Collection Phases.

Even though I have a prolonged interaction in this geographical area in my work in audiology, supervision of university students, and my link to the area through the Health Communication Project, the specific data collection phase for this study was spread over a year and a half across different phases as depicted in Figure 6.7.



Phase 1
January 2012

- The site visit and feasibility study were conducted.
- I met the language and culture mediator.
- I met the potential gatekeepers.
- The pilot studies were conducted.

Phase 2
January 2012- July 2012

- Review sessions were held with language and culture mediator.
- I submitted the applications to the Department of Health, Department of Social Development and Department of Education to conduct research in Mpumalanga.
- I printed information letters and consent forms in preparation for the interviews.
- Potential participants were invited to participate in the interviews.

Phase 3
3 July 2012 - 13 July 2012

- Nineteen individual interviews were conducted with the participants.
- Collaborative reflection sessions were held after the interviews conducted with the researcher and principal language and culture mediator.
- Ethnographic observations of the individual interviews.

Phase 4
July 2012 - September 2012

- Fourteen interviews which were conducted in siSwati were transcribed verbatim into siSwati.
- These 14 interviews were translated from siSwati into English.
- Three interviews which were conducted in English were transcribed.
- Two interviews which had been conducted in South African Sign Language were transcribed.
- Clarification was sought on idioms and metaphors used in the interviews.
- Arrangements were made for the group interviews.

Phase 5
2 April 2013 - 5 April 2013

- The two group interviews were conducted.
- Ethnographic observations of the group interviews were conducted.
- Collaborative reflection sessions with the researcher and principal language and culture mediator were held after the interviews had been conducted .

Phase 6
April 2013 - June 2013

- Two group interviews which were conducted in siSwati were transcribed verbatim into siSwati
- These two group interviews were translated from siSwati into English
- The data management of the interview data commenced in preparation for data analyis.

Figure 6.7. Schematic representation of the phases of data collection for this study

6.13.2. Data Collection through the Use of Ethnographic Interviews.

6.13.2.1. Date, time and venue considerations for the interviews.

Dates, times and venues for the interviews were negotiated with the caregivers because the immediate settings in which interviews are conducted may influence the interactions in the interviews (Davies, 2001; Lewis, 2003). When we met with the participants for the interviews, we met at a place (Legard et al., 2003; Lewis, 2003) and time of the participants' choosing. No imposition was made as to the setting for the interviews so as to allow participants to feel as though they were on "home turf" (Ramos, 1989, p. 59). By offering the participants this choice, they could choose a place where they potentially felt comfortable to discuss their children's deafness or a venue which would be convenient for them.

Individual interviews were conducted in people's homes (participants' courtyards, kitchens, sitting rooms, and even bedrooms), in the car (one at an avocado plantation car park and another at the car park of the hospital in Nelspruit), an office boardroom, an empty crèche playroom, a spaza (informal) shop, and a KFC. No imposition was made on the time of the interview and I asked the language and culture mediator to convey a sense of flexibility for the scheduling of the interviews to best suit the participants' schedules.

Two group interviews were held and the groups were geographically clustered (Lewis, 2003). Those participants who lived closer to each other were included in the same group so as to facilitate the logistics around getting to the group interview. The first interview was conducted in a church hall in Shabalala village. This venue was arranged by Participant 3 since she attends that church and knows the pastor there. The other two participants agreed on the venue. During this interview, we were the only people at the church. For the second interview, Participant 10 proposed the community centre in Matsulu village as she had attended at the centre various times. This venue was agreed upon by the other caregivers who had agreed to participate in this second group interview. P contacted this centre and made arrangements for the second interview to be held there. However, upon our arrival at the centre, we were informed that we could not use the centre for the group interview since this interview had no direct benefit for the centre and therefore, the interview was then moved to the garage of one of volunteers at the centre who lives in the same village. This garage was separate from the house which reduced the risk of the volunteer or her family sitting in or overhearing the interviews as they were inside the main house.

6.13.3. Obtaining informed consent.

In light of the considerations around consent, I had to consider the potential sense of obligation or coercion which participants may have felt to participate in the study. Informed consent means that participants take part in studies voluntarily (Lewis, 2003), they "have the right to know that they are being researched, the right to be informed about the nature of the research and the right to withdraw at any time" (Ryen, 2011, p. 418). Therefore, before each interview, consent was sought from each participant who had agreed to be interviewed. P gave the participants more information about the study as the first step to seeking consent and then she also sought consent to record the interviews. Caregivers were informed that participation in the study was voluntary and that they were free to withdraw from the participation at any time, although I recognise the limitations to that freedom to withdraw because of the possible power differences between some of the participants and me, the researcher.

The information letters and consent forms were typed in English to account for any language variation in the participants' preferred language. P verbally translated these letters from English into siSwati for the participants and requested their consent which they indicated by signing the consent form. For the participants who had limited literacy skills, they were asked to indicate in any way they chose to mark consent, for example, participant 13 marked her consent with an ‘X’ because she said that she could not read. The participants took the information letters away with them so that they owned a copy and participants were encouraged to contact us or the ethics committee if they had any queries or concerns.

Despite the efforts to obtain informed consent, there are many controversies with regard to the ethics around informed consent and the language and methods of securing consent, especially amongst vulnerable people, such as people who may have limited literacy skills, because the consent forms are often too long, complicated and contain too much jargon (Cressey, 2012), especially in South Africa, where apartheid denied many people the opportunity for adequate and equitable schooling. To this end, the information letter and the consent form were submitted to a readability analysis (Online-Utility.org) which revealed that these informed consent documents used in this study were at a United States of America Grade 9 level which may not equate to South Africa’s Grade 9 level but it may give an indication of the level at which the consent forms were worded. Fourteen of the participants in this study had greater than Grade 9 schooling, and although their passing of that grade does not guarantee that literacy level, it may reveal that the information and consent forms were accessible to them in English, although the forms were still translated into spoken siSwati in an attempt to make it even more accessible, especially to people who may not have completed higher levels of schooling.

6.13.4. Recording the interviews.

The interviews which were conducted in English and in siSwati were audio recorded on a Sony ICD-UX512F audio recorder while the two interviews conducted in South African Sign Language were video recorded on a Sony DCR-SX85 digital video recorder. These methods of recording the interviews were chosen as they are said to preserve the participants' accounts more completely and accurately than just taking field notes of the interviews while acknowledging that the recordings are not necessarily free of bias (Hammersley, 2010) because these recorded interviews are mediated by the researchers' orientation, background, and research intentions. The audio and the video recordings were saved onto compact discs and were transcribed so that the transcriptions could be used in the analysis of the data. These compact discs did not contain the participants' names or details on the cover or in the file names. Instead, only their interview reference numbers were used and are stored at the University of the Witwatersrand for safekeeping.

6.13.5. Conducting the individual interview sessions.

When we arrived at the designated venues for the interviews, P and I introduced ourselves and the study after which we were then invited in to where the participants had selected for the interview sessions. P and I scanned the settings to see how best to set up the Sony ICD-UX512F audio recorder to avoid contamination from other sound sources such as animals, television, radio, and other people's conversations. P then confirmed that the people whom she was interviewing were indeed the principal caregivers of deaf children because the contact person and the person who attended the interview were not always the same person. For example, Participant 6 attended the interview but her husband's contact details had been provided and when P phoned him, he referred P to speak to the child's mother. Similarly, while Participant 13, the child's grandmother, was interviewed, the appointment had been made with the child's father who sat in on the interview but did not speak or volunteer information; only the grandmother spoke. Thereafter, we explained the purpose of our visit and then sought consent for participation in the interviews and to record the interviews before proceeding with the ethnographic interview.

6.13.6. Conducting the group interview sessions.

The language and culture mediator contacted those caregivers who had participated in the individual interviews and invited them to take part in the group interviews. Seven participants took part in the group interviews as depicted in Table 6.3. The other caregivers did not take part in the group interviews because they declined participation, had moved out of the area, were not available during the period of data collection or were not contactable.

Table 6.3. Composition of the Two Group Interviews

Composition	Participant number	Participant's relationship to the child
Group 1 (n = 3)	3	Mother
	4	Aunt
	5	Aunt
Group 2 (n= 4)	9	Mother
	10	Mother
	13	Grandmother
	14	Grandmother

When we were at the interview venues, P, in siSwati, re-introduced the project and went through the information letter which accompanied the consent form. She explained how the group interview was a follow-up from the individual interviews which had been conducted in 2012 and that the confidentiality and anonymity in the group could not be ensured but she requested that the participants respect the others' confidentiality and anonymity. Both group interviews were conducted in siSwati.

For the first group interview, the one held in the church hall, I arranged the chairs in a circle with the recorder in the middle of the group to capture everyone's voices. The participants sat in the arrangement as depicted in Figure 6.8. I did not dictate where the participants ought to sit. Instead, I offered that the participants sit where they wanted and then the language and culture mediator and I sat down. Participant 5 was known to Participant 4 but did not know Participant 3 at the start of the interview. She sat between Participant 3 and Participant 4 who already knew each other.

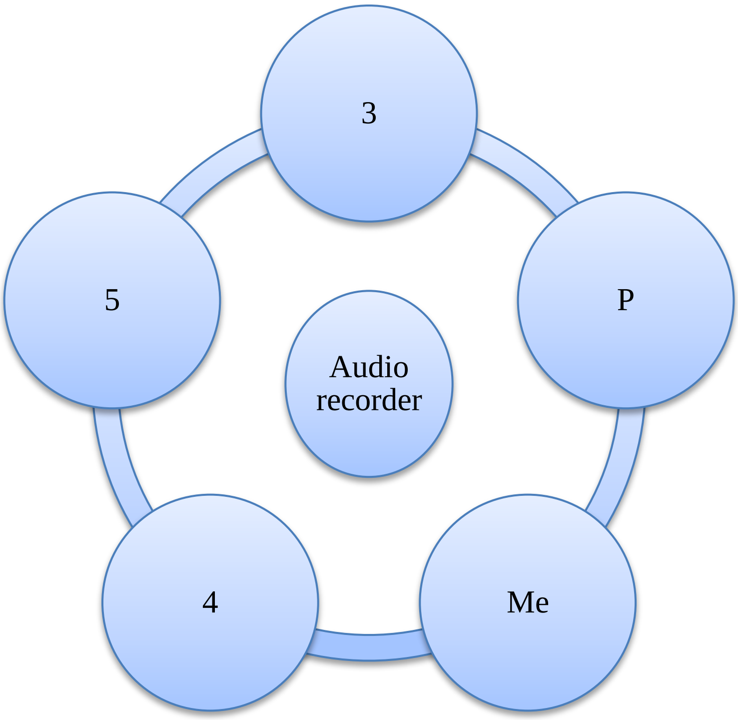


Figure 6.8. Seating arrangements for group interview 1

When we arrived at volunteer's garage for the second interview, she had arranged for four chairs and two large reed mats on which we could sit for the group interviews. P explained that N would be the interpreter for her sister and checked with the other participants whether they had reservations about her presence in the group discussion, which they said they did not. The participants' seating arrangements are depicted in Figure 6.9 which is not a concentric circle because it is an approximation of the actual seating positions of the participants. Participant 9 and N were known to each other and Participant 10 and N are siblings, but none of the other participants knew each other. It transpired that Participant 13 and Participant 14's deaf grandchildren were friends and had visited Participant 13 and Participant 14's houses respectively, although the grandmothers, their caregivers, had never met.

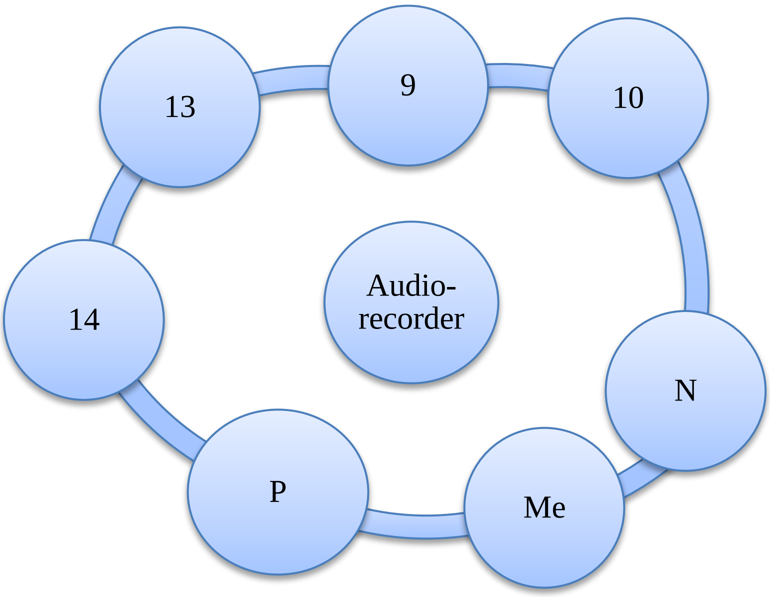


Figure 6.9. Seating arrangements for group interview 2

The first interview lasted about 50 minutes and the second interview lasted about 40 minutes, excluding the time for the refreshments. At the end of each of the group interviews, refreshments were offered to the participants in the form of biscuits and juice. For those participants who travelled via public transport to the venue for the group interviews, reimbursement for travel costs was offered when the appointment was made and then given to those participants at the group interview sessions.

6.14. The Principal Researcher's Role and Space in the Interviews

P and I decided that I ought to be present during the interviews because the "experience of being listened to and taken seriously by a researcher possessing high social status can be experienced as both empowering and reflexively enlightening" (Davies, 2001, p. 100). P said that because of my isiZulu knowledge, albeit limited, participants would feel that I was engaged with what they were saying. It was, therefore, decided that I should introduce myself to the participants in isiZulu and I should also explain, in isiZulu, that P would be doing the interviews on my behalf because I do not speak siSwati. The introduction seemed very important, because, besides it being polite and respectful, it is reported that the introduction of the researcher by the fieldworker can have an effect on the participants' engagement with the interview (Fontana & Frey, 2000). I also sought clarification from P about the transferability of certain culturally appropriate practices in which I engage in my province, Gauteng, and their appropriateness in the research setting province, Mpumalanga. For example, where I am from, when greeting people with a handshake, I hold the forearm of my right hand with my left hand as it is considered a sign of respect. I sought confirmation from P that this practice holds true in siSwati culture too, which she confirmed and encouraged its use.

Another reason for my presence in the interviews was so that I could take notes about the setting, the dynamics of the interview and to also make notes on any point of clarification which I may have wanted since I thought that I may be able to follow some parts of the interviews. By taking these notes, it also freed up the fieldworker from furtively trying to take detailed notes during the interviews.

6.15. Language Considerations for the Interviews.

Despite the demographics of the participants, in order to avoid the prescription of the language of the interview and because it is acknowledged that language and power are connected (Ahearn, 2001), at the start of each interview, P asked the participants in which language they would prefer to be interviewed. Of the 19 interviews which were conducted with 20 caregivers of deaf children, all but five were conducted in siSwati, two were conducted in South African Sign language and three were conducted in English. I wanted to respect participants’ right to choose their preferred language and to give them the freedom to do so, especially because, “although the conversation with people who use other languages is difficult, it is possible, and probably essential, if we are to move on from the objectifying gaze on difference” (Temple & Young, 2004, p. 174).

Furthermore, the participants’ use of their preferred language could encourage them to describe their experiences more freely and fully so as to get more insight into their experiences. The participants’ use of their preferred language also offered the opportunity for the inclusion of metaphors and idioms which may not have been used if participants spoke in a language which was not chosen by them. The interview guides were printed in English on sheets of paper so that the different interviewers, that is, P, F, and me could have our own copies. A new interview guide sheet was used for each interview so as to jot down any notes particular to that interview on that sheet.

6.15.1. Interviews conducted in siSwati.

P conducted 14 of the interviews in siSwati. I sat in on the interviews as an active-observer, taking notes of the interview setting and process while also making reflexive notes. I followed the advice to be cognizant of cultural decorum and the need for the appropriate level of politeness (Larkin et al., 2007). Additionally, my conversational-level isiZulu abilities were beneficial during the interview data collection phase because siSwati is a close relative to isiZulu and so there were times when I was able to greet the participants, introduce myself and thank them for agreeing to participate in the interviews. The introduction of the researcher is deemed crucial to the success of the interview (Fontana & Frey, 2000) but, besides this logistical reason, it was the correct, polite and respectful thing to do to engage with the participants. This conversational-level isiZulu offered me the opportunity to follow the conversations and, although I did not understand everything that was being said, because I knew the topic of conversation and because of the similarity between siSwati and isiZulu, I could follow some aspects of the conversation. This connection with the participants' language appeared to go a long way towards relating with participants (Davies, 2001). This engagement with the interviews seemed to have been recognised by the participants in that they would, on occasion, turn to me, thereby including me in the conversation. Even if I did not respond verbally, my engagement with what was being said and my responsive body language seemed to be noticed by the participants and they seemed to have included me in the conversation, an inclusion which I greatly appreciated and valued, not as a researcher, but as a person and felt very privileged to be listening in to people's accounts of their experiences of being caregivers to deaf children.

6.15.2. Interviews conducted in English.

I conducted three interviews in English and it appeared as though the participants' schooling and employment reflected their preference for being interviewed in English since those participants with the higher levels of schooling chose to have their interviews conducted in English. When P asked Participant 2 whether she wanted to be interviewed in English or in siSwati, she turned to me and said that she wanted to have the interview conducted in English, assuming that I should be doing the interview. The same happened in the interviews with Participant 6 and Participants 16. Even though I interviewed some participants and P others, because P and I had rehearsed the interviews during the preparatory phase, we both conducted the interviews in a similar conversational manner in order to maintain a consistency across the interviews thereby accounting for any differences in mannerisms and personalities. In the same way that I sat in on the interviews which P conducted and took notes of the interview, she sat in during the interviews which I conducted and took notes on the interview method and content which we used in our post-interview reflections, including the influence of the researcher on the interview.

6.15.3. Interviews conducted in SASL.

The particular SASL considerations and modifications for the deaf participants have been described elsewhere in this chapter. The two individual interviews with Participant 8 and Participant 10 in SASL were conducted by F who is deaf himself, lives in the Ehlanzeni District, works at Kamagugu School, and is familiar with the deafness context of this district.

N, who is hearing but comes from a family of Deaf people, was better suited to interpret for Participant 10 in the second group interview because she could hear what the other participants were saying to interpret these spoken interactions into SASL for her sister which F would not be able to do because he is deaf and would not have been able to hear the spoken interactions in order to interpret them into SASL for Participant 10.

6.16. Modifications to the Interviews

6.16.1. Participants who are deaf.

Variations came about with regard to the video recording of these interviews so as to capture the South African Sign Language interaction which audio recording would not have captured. Literacy factors also had to be considered when the information letter and consent form were conveyed in South African Sign Language to Participant 8 and Participant 10 because of the difference in the grammar of South African Sign Language and written English. With regard to the interview, the teachers' assistant arranged the interview setting so that he could be face to face with Participant 8 and then later with Participant 10. This setting was chosen so that the participants could clearly follow his signing and he asked for the door to be kept open to allow natural light into the room to make his signs and his facial expressions more visible and those of the participants. I video recorded the individual interviews on a Sony DCR-SX85 digital video recorder while P sat in on the interviews. When the interviews were finished, I thanked the participants in South African Sign Language.

The group interview in which Participant 10 took part was not video recorded because N interpreted Participant 10's SASL responses into spoken siSwati and this spoken interpretation was recorded by the Sony ICD-UX512F audio recorder together with the other participants' spoken input. N sat directly opposite her sister, Participant 10, who is deaf and communicates via SASL so as to interpret the spoken interactions between for her deaf sister. She used simultaneous interpreting in real time so that Participant 10 could be part of the ongoing discussion.

6.16.2. The participant who is blind.

When it came to interviewing Participant 9, consideration was given to her blindness. For her individual and group interviews, the audio recording and the interview itself did not appear to need any particular modifications because she appeared to have good hearing levels so there was no concern for her need to supplement her hearing with lip reading. What did require special consideration was her reading of the information letter and consent form since she is blind. Participant 9 has not always been blind and had still attended school until she was in Grade 9 so she knows how to read and write but, because of her blindness, she is not able to read by herself and so the information letter was translated for her into siSwati, just as they had been for the other participants. When it came to indicating consent, she still signed the form although P had to guide her hand to where she needed to sign, which she did. The rest of the individual interview proceeded in the same way as the other interviews.

Similarly, for the group interview, she did not need specific modifications except those with regard to obtaining consent as had been the case in the individual interview. I had offered to collect her from her home to participate in the group interview and to take her back home after the group interview but she declined. This participant travelled to the group interview venue by herself and she appeared to navigate her way despite her blindness. I walked with her to the main road for her to catch a kombi taxi back to her house.

6.17. The Interviews' Risks and Benefits to the Participants

In my interactions with the participants, I had the ethical obligation of being "committed to not disempowering them" (J. S. Jones, 2010, p. 9) and so, through the interviews, opportunities were created for participants' reflection on their own experience. These reflections are described as potentially transformative because they can allow for participants to grow from having analysed their experience within a dedicated and controlled space (Bloor, 2011; Davies, 2001; Funk & Stajduhar, 2009; Squire, 2009). However, I recognised that I ran the risk of opening up old wounds or even creating new ones by engaging participants in conversations about their children and so participants were reminded, prior to the start of the interview, that they were free to not answer any particular question or even withdraw from the study, notwithstanding that I could not account for the events after the interviews. Cognizant that interviews may arouse some emotions, the distress from the interviews is a reflection of the quotidian distress people feel (Vaux, 1990) and suggests that the interviews provide a space to reflect on that every day distress. A way of reducing that risk is to provide caregivers with a sense of control in the interview and by reflecting on the participants' value in their caregiver role (Funk & Stajduhar, 2009).

By using the semi-structured interview format within the ethnographic interview, caregiver participants had that control in the flexibility to discuss matters in the depth with which they felt comfortable and to navigate and to introduce new topics, thereby giving them some sense of control in the interview while the interviewer was able to reflect the participants' value in the interaction. I also offered participants the details of contact people at the school and the local clinics with whom the participants could speak with regard to matters which may have arisen in the interviews (Silverman, 2011) despite such support structures being poorly documented in this district. This shortcoming was a major concern for me because I knew that participants may not be able to access professional counselling services. Three participants said that they were going to make contact with the social worker to speak about some of the topics which had arisen during the interviews: one participant in relation to the feelings she harboured towards her daughter for which she had already received support, another participant in relation to her son who was displaying anti-social behaviour, and another participant for her own feelings and emotions around her life situation. But even by referring the participants to support resources proved to be ethically difficult because, by referring participants to other services, I was technically breaching their anonymity because then it would transpire that the referral came from the study sample group (Lewis, 2003). Therefore, in order to reduce this ethical difficulty, when referrals were made, I did not state that the caregivers whom I had referred to these other services had participated in this study. Instead, by referring to my role as audiologist rather than my role as researcher, the support resources to whom I referred the caregivers could assume that I had seen the caregivers of deaf children in my capacity as audiologist.

6.18. Preparation of the Data Prior To Analysis

6.18.1. Transcription of the Interviews.

6.18.1.1. Transcription of the spoken interviews.

Because P, the language and culture mediator for the siSwati interviews, had conducted the siSwati interviews, she was very close to the data set and so it was beneficial for this study that she transcribed those interviews. In this way, she was familiar with the interviews and could link the participants with their interviews, thereby reducing the distance between what the participant had said and what was conveyed in the transcription because she had conducted the interviews, transcribed them, and translated them. Because she had conducted the interviews, she had already heard people's accounts of the experience of being caregivers to deaf children and so there was a familiarity with the content when it came to transcribing the interviews. Another advantage of P conducting and transcribing the interviews was the "use of cultural knowledge and skills by the transcriber to interpret and represent what is going on" (Hammersley, 2010) and so she could contextualise what participants had said, for example, in the participants' use of metaphors, idioms, and analogies.

P was given a copy of the compact disc containing the individual interview, and then later, the group interview audio recordings from which she would transcribe the siSwati and the English interviews. She first transcribed the interviews verbatim into siSwati and she included the false starts, repetitions (Davies, 2001) and revisions. Only after she had transcribed the interview word-for-word into siSwati, did she translate the siSwati interviews into English, using the afore-mentioned suggestions too. P also transcribed the English interviews which I had conducted as she had been present during the interviews and took notes during them too, so she was closely familiar with those interviews like she was with the siSwati ones.

The transcriptions were typed up in Microsoft Word documents, one file per interview and contained the interview number as the heading rather than the participants' names. Also, to facilitate data analysis, each line of the interview transcription was numbered. Because the data would undergo thematic analysis, it was not necessary to transcribe the pauses using dialogue transcriptions (Gale et al., 2013) nor the intonation (Hammersley, 2010). Also, each interaction within the interviews was labelled according to who was speaking, for example, 'P' for P, 'V' for Victor and '09,' for example, for the participant number. For interview 16, where the child's mother and father were interviewed within the same interview, the father's responses were indicated as 16F (F for father) and the mother's responses were indicated as 16M (M for mother) so as to distinguish between their responses in the analysis of the data.

In the two group interview transcriptions, the participants' original individual interview numbers were used to indicate their responses in the group interviews and to maintain consistency between the individual and group interviews. In the second group interview, N interpreted for Participant 10 because she is deaf and in the transcriptions, because Participant 10 was using SASL and N was using spoken language, the responses are marked as having been given by Participant 10, even though it is N's voice which is recorded.

P was asked not to share these compact discs containing the interviews with anyone else or to play them to anyone else while the discs were in her possession. She was also asked to return the compact disc to me when she had finished the transcriptions so as to ensure the participants' anonymity and confidentiality by storing them at the university as required by the ethics' committee.

6.18.1.2. Transcription of South African Sign Language interviews.

Due to other commitments, F was not available to transcribe the interviews which he had conducted in SASL. Therefore, a deaf, black, female lecturer from the Department of South African Sign Language at the University of the Witwatersrand was asked and agreed to perform the transcriptions from SASL into written English. It is relevant to state her deafness, race and gender because these resemble those of the two deaf participants. She may be deaf, black, and female like the two deaf participants, but she is not from the same ethnic grouping as the participants since she has a seTswana ethnic background while the participants in the study have a siSwati ethnic background. Her ethnicity, rather than her culture, is described as seTswana because she may more closely identify with Deaf culture rather than seTswana culture (Van Herreweghe & Vermeerbergen, 2010; Young & Hunt, 2011) None the less, despite the different ethnic backgrounds between the participants and the translator of the SASL interviews, their deafness and possible Deaf identity suggest that she and the two deaf participants may share some commonalities.

She was given a copy of the compact disc on which were copied the two individual interviews which had been conducted in SASL by the teachers' assistant and the same requirements as for the spoken interviews were conveyed to the deaf lecturer such as the use of line numbering and participant numbers. She was also asked to not share the contents with anyone else, except to a colleague for corroboration of the transcriptions, and to return the DVDs to me after she had completed the transcription.

6.18.1.3. Corroboration of the Interviews.

Transcription, like all other aspects of qualitative inquiry, is mediated by context as it is “a socioculturally embedded linguistic and metalinguistic practice” (Bucholtz, 2007, p. 785). In order to enhance the consistency of the transcriptions, they underwent a process of corroboration by people who had not transcribed the interviews by comparing the audio recordings of the interviews with the typed transcriptions. The intention of this corroboration was to check the consistency of the meaning, rather than to “fix” (Bucholtz, 2007, p. 785) the transcriptions because it is accepted that there may be variability in the transcription of the audio recording which arises from orthographic and typographic variation. This corroboration was conducted so as to provide a more accurate reflection of what transpired in the interviews, rather than suggesting that the one person was checking the other’s work.

6.18.1.4. Corroboration of the verbal interviews’ transcriptions.

In corroborating the siSwati transcriptions, they were read and corroborated by a mother-tongue siSwati speaking, female, black, final year, BA (Speech and Hearing Therapy) student at the University of the Witwatersrand. This student had moved from Mpumalanga to Johannesburg four years earlier to study at the university and she regularly went home during the university holidays. Therefore, there was a sustained connection with the geographical area and research setting in which this study was based. The student borrowed the copy of the compact disc which contained the audio recordings of the interviews as well as the Microsoft Word versions of the interview transcriptions. The speech and hearing therapy student was asked to listen to all of the interviews, including the English ones, to corroborate the audio interviews with the transcriptions, and to indicate any amendments or omissions which she noticed by using the tracked changes in the Microsoft Word documents so that I could see how her version corroborated with P’s. The suggestions made by the corroborator related to spelling differences within the siSwati transcriptions rather than content differences.

6.18.1.5. Corroboration of the SASL interviews' transcriptions.

The SASL interviews were transcribed by a lecturer in the Department of South African Sign Language and she corroborated her transcriptions with a colleague in the department.

6.19. Translation of the Interviews

This study, in its qualitative orientation, recognises that "without talking to interpreters about their views on the issues being discussed the researcher will not be able to begin to allow for differences in understandings of words, concepts and worldviews across languages" (Temple & Young, 2004). Therefore, the translation of the interviews, both the spoken and signed interviews, was not limited to only the literal translation but also included the exploration of the meaning conveyed in the participants' words. This study was mindful that the "failure to accurately portray the intended meaning of the participants' words and actions renders data useless. Misinterpretation of meaning is a potential problem in any research, but the risk grows tremendously when language is a barrier" (Esposito, 2001, p. 570). More specifically, in this thesis which is context sensitive, translation refers to "the transfer of meaning from a source language to a target language" where the translator "processes the vocabulary and grammatical structure of the words while considering the individual situation and the overall cultural context of the source language" and "then conceptualises the meaning and, using vocabulary and grammatical structure appropriate for the target language, reconstructs the meaning of the statement in a new cultural context" (Esposito, 2001, p. 570). This translation and interpretation process is summarised in the adapted schematic diagram (Esposito, 2001, p. 571) in Figure 6.10 where the source and target languages have been presented in different fonts deliberately to denote the change in the language and the impact of the context on meaning.

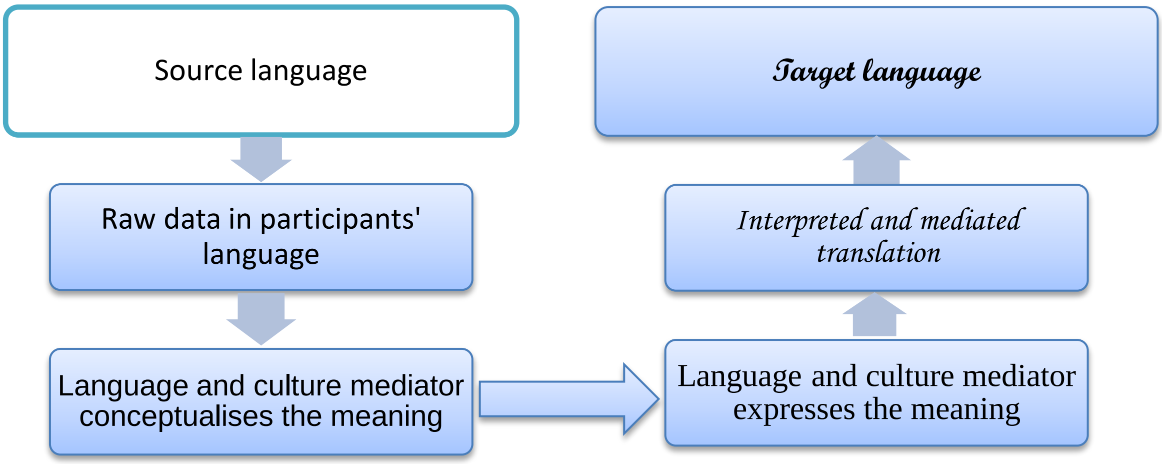


Figure 6.10. The mediation of language and culture in the interpretation of the source language into the target language: adapted from Esposito (2001).

6.19.1. Translation of the spoken interviews.

P performed the translation of the siSwati transcriptions into English transcriptions because she had been consulted during the formulation of the interviews, and because she had conducted the interviews and was, therefore, intimately familiar with the originating event. As she had performed the siSwati transcription, she was closely familiar with the information contained in those siSwati transcriptions which was helpful in her translation of the interviews into English. When the siSwati transcriptions were translated into English, P considered the differences between the two languages. Syntactically, for example, in siSwati, the adjective follows the noun whereas in English it precedes the noun and the morphology is different too since siSwati uses a compounding form of morphological markers, for example, the inclusion of the locative into the noun. Therefore, in the translation of the transcriptions, P had to consider not only the accurate translation of the content of what was said, but had to rearrange the structure of what was said in order to maintain the meaning, for example, in the one interview, a participant says that she lay her baby in the same bed as another baby. I did not understand the expression until P explained that it was a local colloquial expression which meant that the babies were of the same age. This example reinforces the idea that not all meaning is conveyed through translation and that English is limited in understanding that meaning, especially because of the power differential of English over other languages "with English often used as the yardstick for meaning" (Temple & Young, 2004, p. 167).

6.19.2. Translation of the SASL interviews.

It is acknowledged that signed language is "not grammatically structured in a linear subject – verb – object structure. Rather it is a topic – comment language in which inflection is produced through facial expression, visual orientation, movement and spatial location" (Temple & Young, 2004, p. 166). Especially with regard to signed languages (Temple & Young, 2004), "it is also worth remembering that transcription is sometimes the first stage in a process of translation between languages, where the language used by the people being studied is different from the language in which the analysis is to be carried out" (Hammersley, 2010, p. 567). Therefore, before analysing the interviews which had been conducted in SASL, it was necessary for the video-recorded SASL interviews to be transferred into text and this was performed by the Deaf university lecturer and this transcription was described earlier in this chapter. She explained that the transcription and translation occurred simultaneously because of the differences in syntax between SASL and written English which required the concurrent transcription and translation where she interpreted the SASL and wrote it down in English for me to be able to read and analyse.

6.20. Corroboration of the Interviews

6.20.1. Corroboration of the verbal interview translations.

In the same way that the siSwati transcriptions were corroborated by the siSwati-speaking, final year speech and hearing therapy student, the siSwati to English translations were also corroborated by the same student. In order for her to corroborate P's translations of the siSwati transcriptions into English, she was provided with a copy of the English translations, the siSwati transcriptions and the compact disc copy of the original interviews so that she could go back to the different sources and corroborate the transcriptions from them. It appeared as though the amendments she suggested related principally to spelling errors of terms and to the amendment of certain tenses of the verbs, for example, the original translation from the interview with Participant 5 read, "as you have came here" which the student suggested should change to "as you have come here" to preserve the English grammatical structure and from the interview with Participant 14, "when she grew up they loved playing with her" was amended to "when she was growing up they loved playing with her" in order to maintain the timing of the account .

The corroborator was also asked to give her input on the translations in terms of her personal connection with the people, customs and history of the area as she grew up in that district as well as her insights into the audiological aspects of the study in her capacity as a final year student in the degree. Her position within the field of audiology together with the familiarity of research methods, as well as her language, geographical and cultural knowledge of the context in which the study was conducted meant that she was able to comment on the transcriptions, which she did in comments along the margin of the transcriptions. These insights were useful because they corresponded with P's insights even though P's reflections had not been included in the translations which had been given to the corroborator.

6.20.2. Corroboration of the SASL interview translations.

As mentioned earlier, the SASL lecturer corroborated the transcriptions with a colleague. When she corroborated the transcriptions she also corroborated the translations because they had occurred concurrently. With regard to her reflections on the interviews themselves as a deaf person, she reflected on the participants' particular context and how that differed from hers which gave some insight into their experience.

6.21. Reflexive Notes and Field Notes

The reflexive notes and field notes which were taken during and after the interviews served as a data set too. A strength of the qualitative approach is the opportunity for reflexivity, where reflexivity "refers to the ways in which the products of research are affected by the personnel and process of doing research" (Davies, 2001, p. 4). Very importantly, it "is not whether the researcher has influenced the research process or a denial of influence, but how it is addressed" (Sin, 2010, p. 310). Part of this reflexivity entailed the inscription (LeCompte & Schensul, 1999) of what was seen, thought and observed. Therefore, I engaged in post-interview reflections with the language and culture mediators, P, F, and N and I would talk about that which we had noticed with regard to the interviews which could be related to the study. These thickly descriptive reflections accounted for the participants' contexts as well the insights gathered from the other interviews (LeCompte & Schensul, 1999). Because most of the interviews were conducted by P and because she was present during all of the interviews, even those conducted in SASL, she and I engaged most often in the post-interview reflections. Later I wrote fieldnotes which were "produced in a quiet place away from the site of observations and interaction with people in the field" and they included "reflection, preliminary analyses (and) initial interpretations" (LeCompte & Schensul, 1999, p. 18).

These reflexive notes constituted further data sets in this study, because, within ethnographic interviewing, the context and the notes pertaining to the context are firmly linked with the content of the interviews (Davies, 2001). These notes became essential because, through them, that which I observed during the interviews became usable for the data analysis. The field notes consisted of my observations related to aspects such as the run up to the interviews, the settings, the processes, and any other interactions. There were also my individual reflections, as opposed to observations, on these aspects and processes, of what had transpired during the data collection in my attempt at trying to understand the caregivers' lived experience. These individual reflections were supplemented by the joint reflections conducted with the language and culture mediators.

In addition to the individual reflexivity and the joint reflexivity on the content of the interviews, the language and culture mediators and I also conducted reflexive exercises with regard to the methodological and logistical aspects of the interviews too. In doing so, we were able to look at difficulties we encountered in the data collection and how they were "addressed, resolved, compromised, avoided" (Altheide & Johnson, 2011, p. 591), where possible. P and I reflected, for example, on the timing and duration of the interview, the flow of the conversation, and the perceived clarity of the recordings in light of background noise. However, we also reflected on what people were saying and we tried to contextualise it in order to give us an interim picture of the lived experience of caregivers of deaf children in the Ehlanzeni District. With the group interviews, the reflexivity also looked at the dynamics within the group and the flow of the conversation. Our own feelings were also considered, for example, in interviews where caregivers started crying and which may have impacted emotionally on the fieldworker and the researcher. For both the individual and the group interviews we spoke about what went according to plan and what was unexpected and spoke about how that may have impacted on the interviews. These reflexive activities were so that we could monitor within and across interviews so that the interviews were considerate to the participants' personal requirements, for example, with regard to the timing and duration of the interview on the one hand and the emotions expressed in the interview on the other hand.

Because "the nature of the social dynamic of the interview can shape the nature of the knowledge generated" (Fontana & Frey, 2000, p. 647), these reflexive activities proved very useful in my attempts at understanding caregivers' experience through the aforementioned social dynamic and knowledge generation which came from the language and culture mediator's insights and clarification. These reflexive opportunities also created an opportunity for debriefing after the interviews for her and for me where we were able to discuss matters and emotions which arose in us during the interviews.

6.22. Data Analysis

6.22.1. Thematic Analysis.

During the analysis stage, a thematic analysis was conducted on the transcriptions as it allows for a interpretative approach to the understanding of the participants' experience (Spencer, Ritchie, & O'Connor, 2003). The ethnographic interviews provided an opportunity to analyse the caregivers' expression around the phenomenon of childhood deafness. While performing the data analysis, I had to keep in mind the suggestion that I engage in an activity which "resists judgmental characterizations of the correctness of member's activities" and rather look at the "circumstantially adequate ways of interpersonally constituting the world at hand" (Holstein & Gubrium, 2011, p. 343). None the less, it is also acknowledged that within constructivist research, there is a need for reflexivity in the analysis of the data (Lincoln et al., 2011).

A thematic analysis was conducted so as to extract meaning from the participants' interviews without being bound by narrative analysis which is focussed "on the way an account or narrative is constructed" (Spencer, Ritchie, & O'Connor, 2003, p. 200). There were attempts at avoiding interference from a specific disability or medical focus but I acknowledge that it may have filtered through in terms of my etic position and my profession. Analysis of the English translations of the interviews, my field notes, personal post-interview reflections, and the joint post-interview reflections between the language and culture mediator and me were also included in the analysis. These observations and the transcriptions provided a fuller picture of the caregivers' accounts by supplementing caregivers' accounts with specific contextual information of the setting and the interview itself as well as a wider contextual setting of the interview with the insights offered by the language and culture mediator.

6.22.2. Thematic analysis using the Framework method.

In order to preserve the participants' experience in the data analysis while not diluting it (Lincoln et al., 2011), themes in relation to the experience of caregivers of deaf children were sought using the Framework (Ritchie, Spencer, et al., 2003) analysis method. Because the Framework is a context sensitive method of thematic analysis of interview transcripts (Gale et al., 2013), it met the requirements of this qualitative study and it also provided systematic stages for the analysis of the data by exploring a priori and emergent concepts (Lacey & Luff, 2009).

The Framework is not constrained by epistemology, philosophy or theoretical approach and is useful for thematic analysis within a qualitative approach (Gale et al., 2013). It analyses verbatim transcripts of interviews and observational notes and is "a matrix based method for ordering and synthesising data" (Ritchie, Spencer, et al., 2003, p. 219) using an iterative process which “allows the analyst to move back and forth between different levels of abstraction without losing sight of the ‘raw’ data” (p. 220) while recognising participants’ different perspectives (Gale et al., 2013) because all of the analysis retains the participants’ particular characteristics and by “using each participant’s own subjective frames and expressions in the first instance, before moving onto interpretation” (Gale et al., 2013, p. 5). This analysis is iterative so that themes can be refined, clarified, checked against the original data and to allow for the reflection on how the themes relate to each other and the participants’ experience (Spencer, Ritchie, & O'Connor, 2003) and thereby relate them to the domains of the areas interrogated in this study. The Framework method of analysis is cross-sectional and “is used to classify and organise data according to key themes, concepts and emergent categories … comprising of a series of main themes, subdivided by a succession of related subtopics” (Ritchie, Spencer, et al., 2003, p. 220) and is suitable for inductive and deductive approaches to qualitative analysis (Gale et al., 2013).

6.22.2.1. Familiarisation with the data.

It necessary to be familiar with the data because this familiarity is necessary for “building the foundation” (Ritchie, Spencer, et al., 2003, p. 221). Because I was present during all the interviews and because of my post-interview reflections and the post-interview reflections with the language and culture mediator, I had some familiarity with the data. However, in keeping with the method of the Framework where the analysts are called to look at the transcriptions, contextual notes and the reflective notes (Gale et al., 2013) and in order to more fully familiarise with the data, I re-read all the individual and group interviews as well as the post-interview reflections and the notes taken during the interviews when I commenced the data analysis.

6.22.2.2. Identifying initial themes and constructing an index.

After familiarising myself with the data, I set out to identify the recurring themes through a combination of inductive and deductive coding (Gale et al., 2013). The themes took various forms: behaviours or incidents, values, emotions, and impressionistic and methodological aspects (Gale et al., 2013; Ritchie, Spencer, et al., 2003). This stage of the analysis yielded a long list of recurring themes which is included in Appendix I. These recurrent themes from the long list were then grouped so as to create an initial index (Appendix J) of main themes and subthemes and this index was then refined over time so as to avoid omissions and to be all encompassing. The index was kept close to the raw data so as not to wholly impose concepts from existing literature and research onto the new data (Ritchie, Spencer, et al., 2003).

6.22.2.3. Labelling the data.

This index was then manually applied to the raw data. Each line of the translated transcriptions, interview notes, and post-interview reflections was read and assigned numbered labels derived from the main working index so as to denote the theme which was brought up in each phrase, sentence and paragraph of the transcriptions and fieldnotes (Ritchie, Spencer, et al., 2003). These index numbers were written manually in the border of the transcriptions and fieldnotes (as per the excerpt examples in Appendix K) while recognising that the same phrase, sentence or paragraph may be indexed with more than one index code because that particular phrase, sentence or paragraph may be relevant to different themes (Ritchie, Spencer, et al., 2003). Together with the fine level of analysis of the literal data, the inductive coding and global consideration of each participant's interview created the opportunity to find unexpected or otherwise invisible themes (Gale et al., 2013). Therefore, the Framework allowed for the systematic and thorough analysis of the data while also allowing for the linking of themes where index items occurred together.

6.22.2.4. Sorting the data by theme.

The grouping of index items allowed for the generation of major themes and of subtopics which were plotted within thematic charts for further analysis for each domain of this study as exemplified in Appendix L. As per the Framework method (Ritchie, Spencer, et al., 2003) of sorting and synthesising the data, thematic charts were created where each participant was allocated a row in the chart and each subtopic was allocated a column. Each column was then populated with indexed data from the transcripts which related to that subtopic for each participant so as to see how each subtopic related to each participant by "retaining the context and language in which it was expressed and placing it within the thematic matrix" (Ritchie, Spencer, et al., 2003, p. 231). Indexed information from the transcriptions and fieldnotes from the individual and from the group interviews were included in the columns. These indexes were differentiated by typing information from the individual interviews in standard font, the group interviews in bold, and information from the fieldnotes in underlined font. The review of this charted information allowed for the broader interpretation of each participant's transcription and to find linkages, meaning and relationships within the data (Ritchie, Spencer, et al., 2003).

6.22.2.5. Creating descriptive accounts from the data.

This stage of the data analysis is concerned with providing meaningful and illuminating interpretations of the data by taking the categorised data to a more abstract level (Ritchie, Spencer, et al., 2003). I followed the advice to extract the "data from the thematic charts and summarising it on a separate sheet" (Ritchie, Spencer, et al., 2003, p. 239) (as per the example in Appendix M) which allowed me to see the data with regard to the one category in its entirety. The numerous, original categories from the charted columns were refined and distilled by identifying and establishing broader categories from recurrent or similar categories in the original categories. Therefore, I followed the suggestion that the analyst engage in

> reading down the particular column across cases to understand the range of data that exist … (and) … once the analyst is familiar with the data within the chosen subtopic, he or she can then begin identifying different elements, constructs and categories that are emerging (Ritchie, Spencer, et al., 2003, p. 239).

This detailed chart analysis allowed me to recreate a more encapsulated description of participants’ experience. In other words, there was a “process of moving from synthesised or original text to descriptive categories” (Ritchie, Spencer, et al., 2003, p. 238) because data had now undergone a process whereby the original text was interpreted more conceptually and I was able to move the data analysis to a level of abstraction (Ritchie, Spencer, et al., 2003) (as per the example in Appendix N). The main themes were identified across the five domains of this study and the focus of study. By keeping the participants’ words in relation to each of the subthemes it gave me the opportunity to retain the participants’ voice and to avoid detaching the data from the participants.

6.23. Display of the results

Within a qualitative study which employs thematic analysis, the focus is on the meaning of what participants said (Ritchie, Spencer, et al., 2003) rather than the tally of those issues (White, Woodfield, & Ritchie, 2003), although these will be included to give a sense of their occurrence and recurrence. The results are presented in relation to the domains explored in this thesis, namely, communication, finances, schooling, support, and the caregiver role. The themes are presented in text and tables to display the main themes and subthemes within the different domains of the study. Participants' quotations are also be included as examples of the original material to clarify the interpretations (White et al., 2003) and are presented in italics to give prominence to the participants' words. Some literal translations are kept in the transcriptions as they are words used in South African English, for example, the word '*muthi*' which is used to refer to traditional medicine in South Africa.

6.24. Credibility and Quality of the Study

Credibility (Silverman, 2011), the believability in the study, was considered in all aspects of the study, including in the way it was conceived, conducted, analysed, and interpreted. The detailed description of the language, transcription, and translation aspects together with an explanation of the decisions and the decision making process in all aspects of the study are presented in this thesis to improve its credibility through a transparent exegesis of the method and procedure (Temple & Young, 2004) and transparency with regard to the research strategy and the theoretical aspects (Silverman, 2011) so as to ensure that this study was well-grounded (Lewis & Ritchie, 2003). Additionally, to bolster this study's quality (Spencer, Ritchie, Lewis, et al., 2003), I recognised that "the preparation, collation, and interpretation of data in a multilingual context is a cocreative process" and that "failure to acknowledge this might seriously weaken the rigor of a study" (Larkin et al., 2007, p. 474). I engaged in "an auditing process called an 'audit trail' in which the researcher documents methods and decisions, and assess the effects of research strategies" (Spencer, Ritchie, Lewis, et al., 2003, p. 40). Furthermore, I consulted with my research supervisor who has considerable local and international PhD supervision credentials and I interacted with research colleagues in the department, PhD holders and PhD candidates from my discipline and other disciplines, researchers from the South Africa Netherlands research Programme on

Alternatives in Development (SANPAD), and the language and culture mediator in order to check my work and to get “consensus on how to proceed” (Chiegil et al., 2014 p. 141). .

In qualitative studies like this one, replicability is not necessarily the goal of the methodology, but rather that the research be legitimated by the participants and that it have meaning attached to it (Yardley, 2000) and , therefore, when conducting research with people, there is a need “to acknowledge that other factors may exist which will affect its potential for replication” (Lewis & Ritchie, 2003, p. 272). More specifically, because of its context sensitivity, the Framework method of analysis “may generate theories that could be tested elsewhere, but the primary concern appears to be with the description and interpretation of what is happening in a specific setting” (Lacey & Luff, 2009, p. 17)

Triangulation in this study took the forms of method triangulation where data garnered from different methods were evaluated: firstly, triangulation of sources where data from different qualitative methods were considered, secondly, triangulation through multiple analysis where different people reflected on the data, and thirdly, theory triangulation which meant that the data were looked at from different theoretical perspectives (Lewis & Ritchie, 2003, p. 276). Notwithstanding the espoused value of triangulation, there is an argument that it is difficult to judge “with certainty that an account is true because we have no independent and completely reliable access to ‘reality’. We must therefore judge validity on the basis of the adequacy of the evidence offered in support of the phenomena being described” (Lewis & Ritchie, 2003, p. 276). Nonetheless, triangulation is “a strategy that adds rigor, breadth, complexity, richness and depth to any enquiry … (and) asserts that the central image for qualitative inquiry is the crystal – multiple lenses, not the triangle… Triangulation is the display of multiple, refracted realities simultaneously” (Denzin & Lincoln, 2011, p. 5).

In order to strengthen the credibility and quality of this study, from its inception to the presentation of the final thesis, consideration was given to the characteristics included in

Figure 6.11 adapted from Yardley (2000, p. 219) which are deemed necessary to ensure the quality of qualitative studies so as to better understand vulnerability within a specific and particular setting (Goudge et al., 2009). Additionally, “to see if the meaning or interpretation assigned is confirmed by those who contributed to it in the first place,” (Lewis & Ritchie, 2003, p. 176) the group interviews were opportunities to engage with member or respondent validation by checking the accuracy of the transcriptions and translations of the individual interviews with the participants themselves.

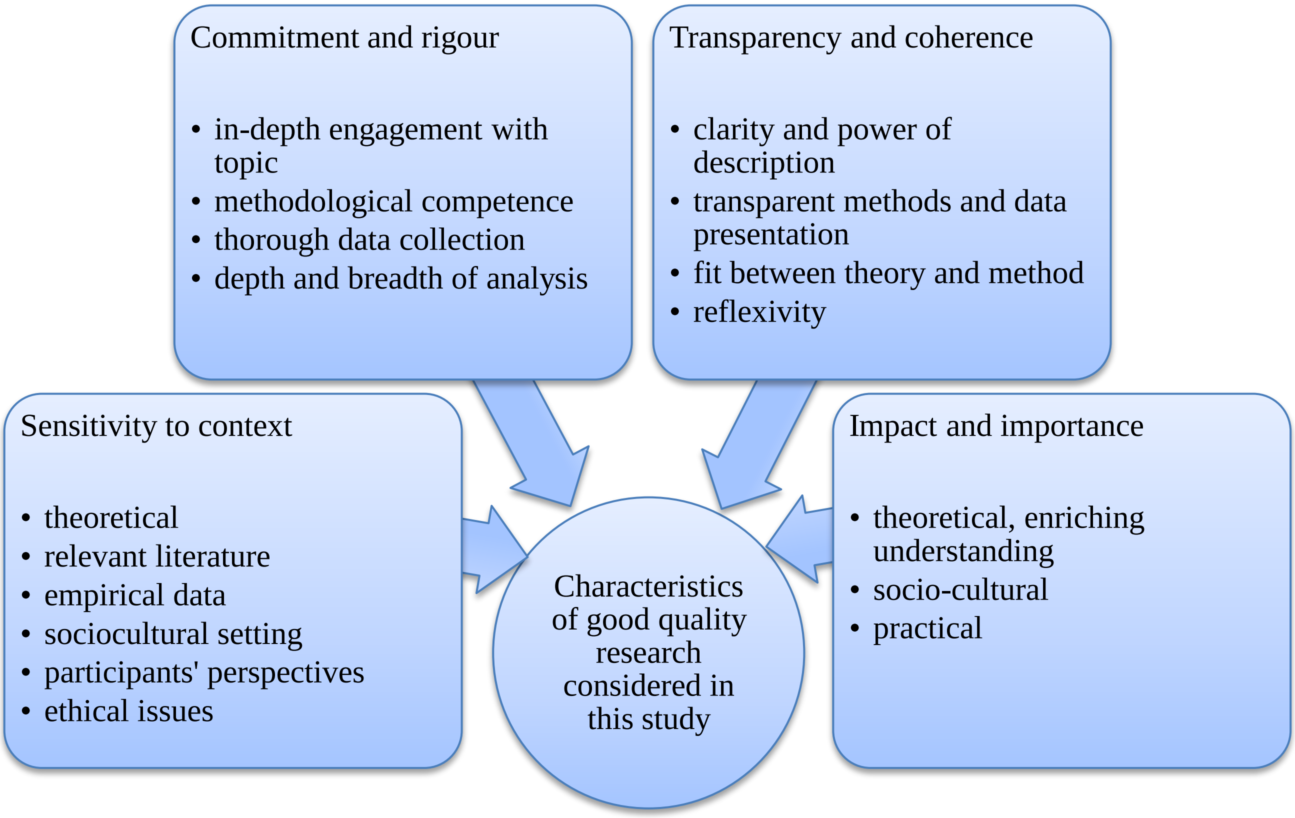


Figure 6.11. Characteristics of good quality research considered in this study as adapted from Yardley (2000, p. 219).

6.25. Chapter Summary

In this chapter I have tried to outline the decisions and decision making process as they related to the different stages and components of the study while remaining mindful of the participant caregivers', their children, their families, and the other people who were involved in this study so that the study could be respectful of them, of the theory, of the method, of the practice of research, and of the practice of audiology.

Chapter 7: Results

"It's as if those strains of music created a sort of interlude in time,

something suspended, an elsewhere that had come to us, an always within never."

(Barberry, 2010, p. 325)

Figure 7.1. This train bridge was photographed outside one the villages on the way to an interview.

The multiple pillars upon which the train track is built seems representative of the different domains of the caregivers' experience and their caregiver journey in this particular context in terms of time and place.

7.1. The Domains

The data analysis yielded themes within overarching and interconnected domains and these domains of the caregivers' experience were: communication, financial aspects, deaf children's schooling, psycho-emotional support, and the caregiver role. This chapter includes excerpts of the interviews to highlight examples of the themes which have emerged in the different domains. The excerpts which are provided are done so as to 'hear' the participants' voice while being respectful of their voice and these excerpts are followed by the line numbers from the particular interview transcriptions of their interviews.

Each domain will be discussed and illustrated with excerpt examples which are presented verbatim from the siSwati language and culture broker's English translation and transcription of the Siswati interviews without alteration while the excerpts from the SASL interviews are also presented verbatim from the transcriptions. These excerpts from the individual and group interviews are displayed in tabular form when various sub-themes are presented whereas excerpts relating to a broader theme are presented in text. In instances where multiple excerpts offer a fuller and comprehensive picture of that idea, such multiple examples around a theme are presented in individual tables. As discussed in the methodology chapter, at the level of the data analysis using the Framework, individual interview data, group interview data, and fieldnotes data were distinguished by standard font, bold font, and underlined font respectively. In this results chapter, the themes are presented in their entirety and therefore, the excerpts from the individual interviews, group interviews, and fieldnotes are generally not differentiated.

7.2. Domain 1: Communication

The communicative domain featured in the caregivers' experience because the dynamics and character of deafness seem to be aspects with which caregivers have to grapple and for which they have to find strategies with which to confront the challenges they encounter.

7.2.1. Caregivers experience challenges in communicating with their deaf children.

7.2.1.1. Communication difficulties between caregivers and their deaf children.

SASL factors appear to impact on the caregivers' communication efficacy with their children despite the caregivers desire to learn SASL which they described as difficult to learn. They also referred to the inconsistency in their opportunities for learning SASL as exemplified by Participant 3 when she said, "*You see, other things I cannot get. The thing of going once a month to school. Some you have learned and you have forgotten. Ahhh. You see, that it's not nice*" (Lines 333-334). Five expressed their attempts at communicating with their deaf children but that their attempts are not necessarily successful as exemplified by Participant 4: "*Even if we do not know how to communicate, but we try*" Line 156. Because of these SASL related limitations to communication, caregivers may give up on the use of SASL as exemplified by Participant 13 who said, "*We get each other if needs be. If no need, we do not.*" Line 216.

Caregivers said that they experience limitations in communicating with their children about deeper issues because they do not have the communicative skills and abilities to engage in this level of communication with their children. The caregivers related how they are not able to engage in complex topics such as HIV/AIDS, adolescence and puberty, poverty, family dynamics, and emotions and aspirations with their children and that their communication with their deaf children appears to be restricted to communicating about very simple topics and that their communication appears to be limited, as exemplified in Table 7.1.

Table 7.1. Caregivers' limited abilities in communicating about complex topics.

Topic	Excerpts from the participants' interviews.
The caregiver's HIV status.	Participant 1: "*Sometimes you will find that the thing she wants is important. … and also the things, the way they are now* (that the mother is ill) *they are deep, I cannot* (communicate with her)." Lines 200-204.
Adolescence and puberty.	Participant 3: "*I have a problem…talking to (Child's name). She is 10 years. She is growing. There are secrets that she has to talk to with me as a mother, so you see, then I must ask someone else to interpret. And that will hurt (Child's name).*" Lines 308-323. "*They* (the daughter and her friends) *sometimes go deep… talk many things, you see. But when I try to talk to her, I am scared, you see,… We have not been able to.*" Lines 175-183.
Family dynamics.	Participant 5: "*There are things they have not yet understood about us and you will also be stuck like that. How do I tell him?*" Lines 184-6.
The family's poverty.	Participant 12: "*You find that he wants money and you do not have it. It is then that you come down and say, 'My child, you want money and I do not have money. You see how poor we are? I am asking you to please understand that.*" Lines 307-309.
Emotions and aspirations.	Participant 18: "*He cannot talk and cannot hear. I do not know what his wishes are. I just don't know, I don't know what to say. I want to hear his voice… Because I cannot ask him 'How you doing?,' you see, and say, 'I am right'…I wish to know maybe how he feels, but because we would not know.*" Lines 256-267.

7.2.1.2. Caregivers' emotions around communication.

From the interviews, 7 caregivers made reference to different emotions such as impatience, annoyance, frustration, pain, fear, and exasperation which arise from the differences in their language modalities and the limitations of their SASL use as exemplified by Participant 6: "*But he can't say anything. He's gonna look at you. It hurt me. It hurt me a lot. It's very hurting, I'm telling you*." Line 226. There was also reference to the subsequent abandonment of communication because it is too difficult and because the caregivers feel that they are not able to communicate in SASL as per the example of Participant 1 who said, "*And I will snap and move off her way. I easily get annoyed*." Lines 187-188. "*I cannot be patient*" Line 194 and Participant 14 who said, "*With that I find that I do not know it and will shut her up and say, 'Whooa, whooa. Stop!' and say 'What are you saying? Talk well, explain well. I do not know this*.' Lines 119-121.

7.2.2. Caregivers attempt to use strategies when communicating with their deaf children.

7.2.2.1. Caregivers' communication enhancement and repair strategies.

Seven caregivers pointed out that their children are deaf and that they are not cognitively disabled which facilitates their use of these communication enhancement and repair strategies as per Participant 14's description of her child: "*in her ears she cannot hear*." Line 151 "*As she has both hands and legs. They checked her brain and it's fine*." Line 221 "*Because they* (at the hospital) *say her brain is right, is not damaged*." Line 55 "*There are those who are disabled but they do talk. Being disabled meaning their brains. But they checked (Child's name) and they said her brain is right. Just a bit of a disturbance with this* (the hearing)." Lines 270-278. Caregivers affirmed their children's cognitive ability by pointing out that their children's "*brain is right"* (Participant 14) and they are not '*crippled*' (Participant 3). Table 7.2 outlines some of the communication enhancement strategies which caregivers reportedly employ which included using variations of signs and gestures to communicate with their deaf children while others while 2 reported the use of writing but also spoke of the limitations of this strategy imposed by literacy skills.

Table 7.2. Caregivers' communication enhancement and repair strategies.

Strategies employed by caregivers	Examples from the participants' interviews.
Improvised signs	Participant 2: "*But not the* (formal) *signs. The signs we only understand as a family but not really professional and we are limited.*" Lines 147-148.
	Participant 16: *"16F: Use some, one will say, slang, if there is slang in Sign Language."* Line 212. *"16F: And if she wants to take a bath she will show you bath. Something she generated for herself. That is why I am saying, is it appropriate or is it sign language?"* Lines 218-222.
Getting the child's attention, maintaining eye contact	Participant 2: "*Certain things I was taught, like when you are calling him, don't just call him but you must take his attention…and when you talk to him, you must look him in the eyes. All those things we didn't know but now we know*." Lines 164-6.
Writing	Participant 3: "*will have to write it down first*" Line 374. "*she will only be able to* (write) *if she went to school. A better way is the sign language.*" Lines 132-133
Use of gesture and pointing	Participant 5: "*I am now able to show him or if I want something in the fridge, I show him what do I want in there. He goes and takes it and brings it to me*." Lines 194-9.

7.2.2.2. Caregivers need to ask other adults and children to communicate on their behalf.

Six participants spoke about their need to ask other adults to communicate with their deaf children on their behalf because of the limitations imposed by the language differences between them and their deaf children. This is exemplified by Participant 3 who said, "*There are secrets that she has to talk to with me as a mother. So, you see, then I must ask someone else to interpret and that will hurt (Child's name).*" Lines 320-3. Three participants said that they ask teachers from the children's school to communicate with their children when it relates to personal matters, consoling their children, and to disciplining their children.

Table 7.3. Caregivers' need to ask other adults to communicate on the caregivers' behalf.

Participant number	Examples from the participants' interviews.
2	"*Sometimes if we see that we don't have a solution, we call (Teacher's name) and she comes. She explains. She rebukes him.*" Line 282
3	"*Sometimes (Child's name) comes crying. Maybe she fell in the taxi and she will want to explain what happened. She tries. Some I do get. Some I do not and I become quiet and must start and call the teacher now. 'Hey, (Child's name) came home crying.' And she must tomorrow go and tell the teacher on what happened. The teacher must then call me. You see, that thing, that is the thing that is not nice. That me and (Child's name), we do not understand each other. It is not right and it is hurting me.*" Lines 325-331

Five participants reported that they ask other children to act as intermediaries in the communication between themselves and their deaf children (Table 7.4). There was also reference to their hearing children's proficiency at communicating in SASL.

Table 7.4. Caregivers' need to ask other children to communicate on their behalf.

Participant number	Examples from the participants' interviews.
2	*"Like my son, sometimes when I want to talk to (Child's name) I have to call my son to tell him this this, this then my son communicates very well with him. My son is 13 years."* Lines 137-9. "*The children, they communicate better with him like* (than) *us adults*." Lines 36-7
12	"*Eyi, and the kids. He talks to them. He communicates better than with the elders. And the children, some other times us elders, there are things that we do not get. You will find that the kids* (can)." Lines 263-264.
14	"*I do not know how to talk to her. I don't know. There is my child* (the deaf child's young aunt). *She learned how to sign and she did not go to school. She can communicate with her. They talk and finish a story sitting here. You will hear them by laughing. With hands. But I cannot do it. And if I do this, it means what? I don't know*." Lines 291-6. "*If I see that I do not get her* (understand the deaf child), *I call her mother* (a reference to the child's young aunt who lives in the same house, not the biological mother because she is dead). *She is from the house* (lives in the same house). *(Aunt's name) is able to talk to her. She never learned it, but she can because she is a child, you see. That when they do like this, they do like that. So it is better*." Lines 88-90.

7.2.2.3. Role reversal: deaf children as teachers of language to their caregivers.

Nine of the participants in Table 7.5 said that their children seem to take the role of teaching language to their caregivers and this role reversal appears to cut across generations because deaf children are teaching their caregivers and extended family.

Table 7.5. Role reversal: deaf children as teachers of language to their caregivers.

Participant number	Examples from the participants' interviews.
2	"*Eish, he is teaching us… sometimes he corrects us, 'But no, is not like that.' When you talk about TV you do like this, when you talk about mama you do this, when you talk gogo* (grandmother)*, is this. He is actually helping us, teaching us.*" Lines 129-133.
13	"*Now it is her that is teaching me… Ahhh, some I can, some I cannot. She will then teach me to do that and that and that.*" Lines 107-111.
14	"*She* (the deaf granddaughter) *sometimes says, 'Hah, Gogo* (grandmother). *Hah, you do not know anything.' But she can see that this one, I cannot sign. She begs me and tells me, and shows me well until I get it.*" Lines 85-7.

7.2.3. Communication difficulties pose threats to deaf children's social inclusion.

7.2.3.1. Communication differences exclude deaf children from interacting with others.

Seven caregivers described how the differences in communication and language between their deaf children and the hearing community resulted in the exclusion of their deaf children from family activities as per the example of Participant 6 when she said, "*Sometimes we laugh at home and he doesn't understand why these guys are laughing.*" Lines 11-12. "*Like when we went to, last year we went to Durban to take them, we took them to Durban. We wanted to explain it to him, 'This is Moses Madiba (sic) Stadium. This* (inability to explain to him and to include him) *is what it's not nice*." Lines 245-247. Deaf children are also excluded from societal activities as exemplified by Participant 2 who said, "*I go to church with him. Sometimes he doesn't enjoy the church because he is not hearing. He gets bored. Like now, all the new generation kids are supposed to go to a big conference in my church. They enjoy it there. They are going to sing there. Dance. Enjoy all those things. But I'm still deciding should I take him or not because after few minutes he starts to do funny things. He is bored. He doesn't hear anything.*" Lines 221-225.

Participant 1 made reference to her concern about violence against her deaf child: "*I was scared and thought she will play with the other kids and they will beat her.*" Lines 47. "*What do you want from there outside?*" "*Stay inside the house. Do not play with the other children.*" Lines 50-1 while Participant 2 referred to the perceived community insult arising from the deafness and the absence of the appropriate greeting of elders: "*When he is in the community. As he meets new people. They don't know that this child can't speak, can't hear. So, they. Like when we started staying there, another man was saying, 'You, you don't have* *manners. Every time you don't even greet me… You don't teach your child to greet elders? What's wrong with him?' So now he was giving him an attitude every day.*" Lines 214-22.

The caregivers referred to their children's purposeful withdrawal from interaction with hearing people in their community as per Participant 17: "*It is difficult outside, and when I say to him he must go visit, he does not want to. He can tell the difference. Even the sister. Where she stays he does not want to go. Even if she comes, he will get inside the house and sit there*." Lines 329-333.

7.2.3.2. Hearing aids are not facilitating communication and inclusion.

From the interviews, 7 participants expressed that their children's hearing aid amplification devices are not facilitating their communication with hearing people, thereby, excluding them from interactions with hearing people. They seem to refer to the incomplete communicative benefits of hearing aid use and 4 of these 7 caregivers seem to feel that hearing aid use is more for the children's safety and awareness of environmental sounds rather than for spoken communication. This is exemplified by Participant 4's example: "*Some say the hearing aid catches noise. Some, they say they hurt. The noise is painful. Some people cannot hear and do not see the need and will take them off… So those who have them on are the ones who can hear. But can hear from far. If she has them on, the noise will be caught.*" Lines 74-81. Three caregivers said that their children do not wear their hearing aids because their deaf children's degree of deafness does not benefit from hearing aid use, as exemplified by Participant 13: "*Hawu, she cried for them and was found that there, her doctor tried to put them on her. It makes a lot of noise. She found that niks* (nothing). *They said there that even if she can have them, she will not be able to hear. They are dead total. They* (her ears) *cannot hear a thing*." Lines 72-7. Therefore, the participants' deaf children do not always have access to the proposed benefit of hearing aid amplification devices and are not necessarily able to use such devices for spoken communication. Another three caregivers referred to the physical discomfort their children experienced from wearing the hearing aids as per Participant 12's description of her child's ear turning '*blue as the chair*,' which resulted in her child not wearing his hearing aids and subsequently losing them.

7.2.4. Domain summary: communication.

Communication limitations seem to be a major feature of caregivers of deaf children's experience. Caregivers spoke about the difficulties imposed by communicating with their children in SASL, especially because the caregivers find it difficult to learn and to use SASL and there can, therefore, be the risk that caregivers desist in trying to learn SASL or that they are unable to use it because of their own disabilities. The caregivers reported using communication enhancement and repair strategies in their efforts to more efficiently communicate with their deaf children. These efforts, although beneficial, are limited in their benefit due to factors in the caregivers' history and context such as their literacy. Because of their limited communication in SASL and because of the different communication modalities between caregivers and their children, caregivers appear to have limitations imposed on their communicating about more complex topics with their deaf children, and appear to be restricted to instructions, directions, or routines. These communicative aspects seemed to have emotional dimensions and the caregivers reported impatience, annoyance, frustration, pain, fear, and exasperation which arise from the differences in their language modalities and the limitations of their SASL use.

Due to these communication limitations, caregivers appear to need to ask other adults, such as teachers or family members, and other children to communicate with their deaf children on their behalf. Together with the caregivers' difficulty in using SASL, there was a role reversal in the teaching and learning of language where the caregivers' children were reportedly teaching their caregivers language rather than the other way around.

Caregivers expressed concern about the social exclusion of their children because of their deafness since their children are not able to engage with other children or with adults because of the communication differences. The caregivers made reference to the threats of violence and exclusion of the children who appear rude to elders when they do not greet them. They also referred to the children's conscious withdrawal from participation in society because of the communication differences between themselves and the hearing members of their community. The children's use of hearing aids was reported as not facilitating communication and inclusion of their deaf children in hearing society. Instead, caregivers said that their deaf children tend to use hearing aids only for awareness of environmental and warning sounds rather than for communication. They also said that their deaf children complained that the hearing aids were not beneficial to them as the sounds they produced were uncomfortable to them which resulted in them not wearing the hearing aids or losing them.

Therefore, it seems that the language system used by deaf children is not necessarily accessible or usable by the caregivers of deaf children which impose limitations on the communication between them. This inability to communicate between the caregivers and the deaf children results in the need to have intermediaries within the communicative interaction or transfer that communicative role to others while having to learn language from their children. They also had to utilise different strategies to address their limitations and challenges in their attempt to minimise the effects of the limitations outlined earlier. The caregivers seemed to experience unease with the different communicative challenges and limitations, as well the deafness itself. They also appeared uneasy with their inability to meet these communicative needs and appear to encounter emotional consequences of their inability.

7.3. Domain 2: Financial aspects

The second domain which emerged related to the financial aspects of being caregivers to deaf children, especially because of the context of poverty and limited resources in which the caregivers who were interviewed for this study live.

7.3.1. Caregivers' experience of deafness is influenced by their employment and unemployment.

7.3.1.1. Caregivers' unemployed status.

Of the 20 participants interviewed for this study, 15 of them were officially unemployed. Caregivers spoke about how their unemployment directly impacts on their caregiver experience and how they are constrained and limited by their unemployment as per Participant 4's example: *"If you, as a parent, you are not working, there is no other plan."* Lines 146-150. The caregivers referred to the need to survive as highlighted by Participant 1 when she said, *"I am not working. What must I live with?"* Line 407 and Participant 7's lament, *"because when we are just sitting* (not working), *we would be killed of hunger. I do not work. We are just people."* Lines 106-7.

7.3.1.2. Caregivers' employment.

The caregivers who were employed expressed that they are able to move from one place to another in their effort to sources services for their children. For example, Participant 2 moved from Zimbabwe to South Africa because of her qualification as a secretary meant that she could engage in employment seeking in South Africa which she managed to do. Similarly, Participant 6 said that, because she and her husband are employed and have higher qualifications, they have the option to move to different places to better provide for their deaf son because they have opportunities for employment in different places. For example, they first moved from Ngondwana to Nelspruit so that their son could attend school there: "*It was me and my husband to think, 'Let's just go to Nelspruit. This is not working for us.*" Line 268. When the interviews were conducted, this participant was considering moving to Pretoria: "*We were thinking about that. When he's going to Grade 4, 'cos he has to go to Pretoria. Ja, then we have to change work if we decide to take him to Pretoria.*" Lines 273-4. The father in interview 16 said that because of his qualifications, employment, employability, and subsequent mobility, he would endeavour to best provide for his daughter: "*16F: When you love your kid, you definitely have to make some mince … you need to make sure they get a better life.*" Lines 143-4. However, it seems as though the caregivers' status as employed does not remove all the financial difficulties and they still experience difficulty in accessing resources due to the costs involved as depicted in Table 7.6.

Table 7.6. Employed caregivers still experience financial and access difficulties.

Financial limitations even when caregivers are employed.	Examples from the participants' interviews.
Limited access to resources.	Participant 2: "*Ehmm, we were limited. Limited. What limited was money. That's why I said we could keep trying but the father was financially limited. Even now, if he had more resources he could keep trying, even to more professional, the specialist.*" Lines 116-8.
Transport costs are high.	Participant 3: "*I can say that the costs are too much because when you look, is only my husband who is working in the house. So it's like you must run up and down. Go there and there. It needs money."* Lines 205-210.
No financial assistance from the provincial government restricts caregivers' actions.	Participant 6: "*It's just the money thing. I could not do anything because of the money… It's just the money, and you know, Mpumalanga."* Lines 158-163
Deafness and audiological costs are high.	Participant 16F: "*But the other thing we had to pay, you must buy battery every 6 months for the hearing aid. Their cost is R600.00 every year…but now the batteries are finish. We have to go and buy them. We don't have money to buy them. They got finished last month.*" Lines 138, 141 and 167-8.

7.3.1.3. Children's deafness impacts on their employment status.

Caregivers raised concerns about their ability to find employment because of their children's deafness, notwithstanding the general unemployment concerns experienced by many people in this district of Mpumalanga. The children's deafness seems to impact on caregivers' current employment because the caregivers expressed concerns about their continued employment because of their need to perform caregiver activities related to their children's deafness which keep them away from work and also their ability to work and to find work, as exemplified by Participant 11 who had to leave her employment: "*So, when I was working, I had to leave work and stay at home to raise him* (the deaf grandson)*."* Line 24. Relatedly, participant 15 cannot go look for work: "*Even going to work is difficult because the child is the way he is* (deaf)*."* Line 133 and "*Hmmm… Even if I say I am looking for work, this child will also go during the day and go missing and go around. Where will I work?*" Line 344-5.

However, caregivers raised concerns about other factors in addition to the deafness which add to their employability such as their deaf children's HIV/AIDS treatment as per Participant 18's excerpt: "*I'm telling you that even yesterday I was not here at work. I was at Msogwaba. I used to send his sister, because sometimes, I am most at work."* Lines 103-106 "*I will try and go* (perform her caregiver activities related to her nephew) *and that is that.*" Line 125

7.3.2. Caregivers turn to various structures for financial assistance.

7.3.2.1. Government-aligned financial structures.

Fourteen caregivers reported that they rely on government aligned structures for financial assistance because, as Participant 17 said, "*a person who is like this is expensive*" Line 252. The sub-themes around the government-aligned financial assistance are presented in Table 7.7 where it can be seen that caregivers rely on government grants because they struggle financially to feed, transport and clothe their children, especially because of unemployment and single mother status of many participants.

Table 7.7. Government-aligned financial assistance.

Themes related to government-aligned financial assistance.	Examples from the participants' interviews.
Food and clothing assistance via the children's schools.	Participant 1: *"Food. She eats food at school … The white lady principal at Kamagugu, she buys shoes for her because I don't have… She* (the teacher) *said it was alright. She sees the money is little.* (The teacher said) *'I will buy the shoes.'"* Line 36-41.
Government assistance with schooling costs.	Participant 1: "*The transport* (to and from school)*, the government is the one doing it."* Line 36.
	Participant 2: "*the costs were subsidised somehow. There is never a time they paid a lot of money for school fees or anything. It was around R300, R400. There is, there was not much cost.*" Lines 11-12.
Deaf children's non-receipt of a disability grant.	Participant 1: "*She* (the child) *does not get grant.*" Line 210 "*this child is not getting grant… The government explained it cannot be able. She must turn 18 first. She cannot get paid as they are doing everything for her* (schooling and transport)." Lines 403-404.
Bureaucratic delays in the payment of the care dependency grant.	Participant 17: "*I did not buy him uniform* (school uniform) *because his money was not out yet.*" Line 130.
Caregivers' barriers in accessing government financial support.	Participant 6: "*In government complex, 'cos, I know even if I go there to ask for help, depends who you know, who are your friends. You are relative with who. All that is not gonna help so I decided I am not gonna do it* (approach government)." Lines 74-77.

Themes related to government-aligned financial assistance (continued).	Examples from the participants' interviews (continued).
Caregivers attempt to save the care dependency grant for their deaf children.	Participant 9: "*A person has his own needs. (Child name)'s one I make sure I bank it monthly. I am saving for him at the bank."* Line 235.
Caregivers use the care dependency grant for their deaf children's other needs.	Participant 11: "*This month I got grant for disabled kids so I buy him clothes with it and I also use it to buy food. It helps and also I save some so that even if the sickness starts, I can hurry him up quickly* (rush him to get medical care)." Lines 116-124.
	Participant 14: "*I got the* (grant) *money … because she needs pads, lotion to apply. She needs food and all those things*." Lines 88-92.

However, in some instances it seems as though the government's social grant is not used for its intended purposes and children do not benefit from the social grant assistance. Participant 2 said that some people receive the social grant for their deaf children but do not use it for the deaf children. She said that instead of using the money to access schooling, for example, the family uses the money: "*The ones who are disabled, the deaf ones, the disabled. The social workers give the places of schools but the parent won't agree because, if the government takes the child to study, it needs the grant money for the child* (the grant money goes toward the children's schooling costs) *and that it be them who gets it. Most of the parents, they want the grant. They just leave it* (do not take their children to school*). That is why many children who are disabled, they just stay in the community.*" Lines 686-693.

Participant 13 was a case in point because she receives a government grant which the grandmother said is used towards the child's schooling. However, when we did the individual interviews, the child was not enrolled at school and a year later, when we came back for the group interviews, the child was still not enrolled in a school despite receiving grant money, unlike Participant 14, who in the last year had managed to enrol her child in secondary school.

Similarly, Participant 18 described how her nephew in her care receives a grant but that his older sister, her niece, in whom his grant funding is registered when their biological mother passed away, uses his grant money: "*The money for the grant is not with me. I did not register it by my name. I registered with his sister. You see, so that she buys food because she is not working and is at home. I said it's going to help that she buys food, you see. But like now, she sometimes gets the grant and eat it and she knows that I am soft. ... she has a small baby and is 1 year.*" Lines 201-212.

7.3.2.2. Family financial structures.

Because the caregivers find that the government funds are insufficient, especially in situations of unemployment and single motherhood, caregivers reported that another tangible form of funding to which they have to take recourse is from family members. The family-sourced financial assistance which they receive is used for the child's care needs as exemplified by Participant 1 who said, "*a person that is helping is the son-in-law, husband of the first-born. He buys. Like Friday he bought her clothes.*" Lines 173-174. However, caregivers reported that the families are not always available to provide such financial assistance as per Participant 14's example: "*I just talk with the family, and say, 'Help me. It is like this and this and this with the child.' To say that there is somewhere, hahh, they are not helping. We are living on our own. If the child needs for or is running short of something, I must see to it on my own. There is nothing that they are going to help you with.*" Lines 406-409.

Because of their financially precarious position, caregivers appear to have to ask their families for financial assistance and to transfer these financial activities to family members. However, when they transfer these financial activities to other family members, caregivers appear to become excluded from information and processes as exemplified by Participant 13 who, because she could not afford to go to the hospital, transferred that responsibility to the child's uncle which meant that she did not have information pertaining to her granddaughter's deafness: "*I do not know that they* (hospital staff) *checked with what. She went up with her uncle* (to the hospital)." Line 110.

7.3.3. Domain summary: financial aspects.

Various themes emanated with regard to the financial domain of the caregiver experience. Caregivers spoke of the employment related factors as they pertain to their experience of being caregivers to deaf children. Unemployment appeared to be of concern to the caregivers and the resultant and associated difficulties that it poses, even just in terms of survival as highlighted by Participant 1 when she said, *"I am not working. What must I live with?"* Line 407 and *"because when we are just sitting* (not working), *we would be killed of hunger. I do not work. We are just people."* Lines 106-107. They also referred to the need to ask others to assist when they are unable to provide financially for their children. For those caregivers who were employed, it seems as though they were able to exercise some choice with regard to where they lived in order to access services for their deaf children. They also did not seem to rely on the structural financial support for survival, but they showed that being employed did not mean that they did not encounter financial difficulties and challenges. They explained how, notwithstanding their employment, they incur costs related to their child's deafness which they find stretches their finances. However, because of the deafness related activities in which caregivers have to engage with their children, participants verbalised concerns about their ability to find and continue in employment.

Caregivers spoke about the structures which could provide financial assistance but they also spoke about the limitations around that assistance. When participants spoke of the financial assistance offered by government, they referred to social grants and the funding of the children's schooling, as well as to the school meal programmes. However, they said that this funding was not necessarily sufficient or always available to them and there was reference to their children only being eligible for government funding when the children turned 18 years old. There was reference to the delays in the receipt of this assistance and to nepotism within government and how it precludes their benefit from that assistance. Moreover, there were reports of misuse of the government grants which were designated for the deaf children's use but did not necessarily get apportioned to them because the money was needed in the family to cover other costs. In order to supplement their finances, caregivers reported turning to their families to assist them financially but they said that, as with government, families are not always available to provide this assistance. Because of these financial aspects, it appears as though caregivers have to transfer some of the financial activity to their families.

Therefore, it seems as though financial and employment aspects of the caregivers' context impact directly on the caregivers and on their children where those caregivers who are employed seem to be able to exercise some choice in their deafness related activities. Deafness related activities require additional funding which may require caregivers to seek financial assistance and may also impact on the caregivers' ability to find and continue in work.

7.4. Domain 3: Schooling

Schooling and school related aspects featured in the caregivers' relating of their experience and various themes emerged with regard to this domain which are outlined in the following section.

7.4.1. Caregivers experience challenges in accessing schooling for their deaf children.

7.4.1.1. Shortage of schools which cater specifically for deaf children.

Caregivers expressed particular concerns with regard to the provision of schooling for their deaf children with the particular sub-themes as highlighted in Table 7.8.

Table 7.8. Shortage of schools which cater specifically for deaf children.

Sub-theme	Examples from the participants' interviews.
There are insufficient schools for children who are deaf where people live.	Participant 4: "*The deaf schools are available, but far. For them to be in Mpumalanga, there are none. They are in Gauteng and Limpopo.*" Lines 535-539. "*It is difficult because there are no schools this side of people who talk, talk using signs. And the children who are deaf, they are young. If your child is deaf and you make him/her to stay at home, he/she will feel ashamed.*" Lines 116-123.
Children who are deaf have specific educational needs.	Participant 3: "*It* (Kamagugu School) *is a mix. The deaf ones and there are slow learners there. The ones who cannot see, they are there. And now, when you look at Gauteng, there is a school of the deaf only. They are not mixed."* Lines 563-8.
Caregivers disagree with the provincial government's schooling policy.	Participant 6: "*but our government is neglecting us as parents that we have these kids with disability. 'Cos I hear now that they want to take the kids to a normal school. How can you take a child to a normal stream if he can't hear?" How is he going to communicate with the kids? Our government, especially Mpumalanga, I, I don't know. They don't do anything for us.*" Lines 72-75.
Caregivers, who can relocate, have to do so to access schooling.	Participant 2: "*The reason I'm staying with him is there was no other school where they are staying so I happen to stay here where we can happen to get the school. We moved all over looking for a good school for the deaf and it was difficult. Actually, it caused me to come work here for me to have (Child's name) here.*" Lines 7-9.
Caregivers have to transfer the school-sourcing role to others.	Participant 19: "*She got there* (Kamagugu School) *because my father was looking for schools nearby and there were none.*" Line 70 "*We could not find schools.*" Line 90.

7.4.1.2. Child-specific considerations and access to schools.

Two caregivers whose children have health, behavioural, or developmental concerns appeared to have more difficulty in accessing schools for their deaf children. Participants revealed that their children were not attending school because the schools are unable to accommodate their child-specific considerations such as epilepsy, developmental delay, and behavioural concerns. For example, in the case of Participant 15, she was still looking for a school for her 12 year old son because schools will not accept her son due to his developmental delays, epilepsy, and behavioural concerns: "*He is not schooling. As I was saying, when I apply this side, they took him out. They don't. They say they want a person that can be able to bath himself and he still is in the waiting list from 2008.*" Lines 19-20. When she tried to get him at another school for children with special educational needs, he could not stay because: "*He got there and he took all his clothes off and was naked.*" Line 310. Therefore, it seems as though the challenges which caregivers of deaf children experience in sourcing schools for their children are amplified when their deaf children have health, behavioural, or developmental concerns.

7.4.2. Caregivers engage in various endeavours in accessing schooling for their deaf children.

7.4.2.1. Caregivers' recourse to structures to assist in accessing schools.

Participants referred to the structures to which they turned in trying to access schools for their deaf children as outlined in Table 7.9. Despite the caregivers' reservations about the government's provision of schools for deaf children, 6 caregivers referred to the government's assistance with regard to schooling. However, Participant 4 said that the government provides schools but that the caregivers have to utilise the schooling opportunities offered by government: "*There are people who are blind and there are deaf and what what what. Ehh, and all of them. The government has opened schools for them but it is up to us parents, the children's parents, that they* (the deaf children) *go* (to school) *or not*." Lines 458-460.

Four caregivers mentioned that they approach social workers to assist them in getting their children to school because they did not know how to find schools for their deaf children. Besides the assistance provided by government and social workers, it seems as though community structures may also assist in caregivers' endeavours to access schooling for their children when caregivers do not have information about schools for deaf children. Three caregivers who did not know how to get their children to attend school turned to people in their communities who may have already engaged in similar activities and people with whom they share common characteristics to assist them, including a person with a disability, another mother of a deaf child, and the caregiver's church congregation.

Three caregivers whose children were not at school seemed to express that, through the researchers' interest in their children's schooling, that the researchers would be able to facilitate the caregivers' access to schooling for their deaf children and they asked about how the researchers could assist in them finding schools for their deaf children.

Table 7.9. Structures utilised by caregivers in accessing schools for their children.

The structures	Examples from the participants' interviews.
Social workers	Participant 4: "*It is okay that you take your child to the social workers and ask them. They will transfer you to the schools where you will take your child.*" Lines 118-123. "*They say, 'Take him/her to school.' It is then he/she* (social worker) *gives the names of the schools and says that this one is like this and like this.*" Lines 682-4.
Government	Participant 14: "*When her mother died, I was left and I carried on. So, at Kamagugu they helped us because they said she must not pay school fees and should not buy a ticket* (for the bus). *They* (the school) *ask for help from the government and they paid for their school fees."* Lines 206-208.
Community	Participant 5: "*and then came time for him to go to school. Other things* (about schooling) *I do not know what to put together.*" Line 45. "*I also go to the* (disability) *centre there, the other side and talk to them. There was this guy, his name is (Man's name). He also does not talk. He used to come here* (and he advised her about schooling)." Lines 41-3.
	Participant 9: "*There was a lady who stayed this side and her child also goes to Kamagugu and said I must not have a problem. Just go to Kamagugu and look for a space for your child. I said okay. I went very early. ... They took him at Kamagugu.*" Lines 32-46.
Researchers	Participant 15: "*Do you have a way of helping that he finds a school? They turned me away.*" Lines 290-2.

7.4.3. Caregivers experience psycho-emotional and somatic effects of their endeavours to access schooling for their deaf children.

7.4.3.1. The psycho-emotional and physical impact on caregivers.

From the interviews, and as displayed in Table 7.10, 4 caregivers seem to have experienced a psycho-emotional and physical impact from their endeavours at sourcing schools for their deaf children including pain, anxiety, and even physical illness. Participant 15 went as far as to say the difficulties associated with finding a school for her son are "*killing*" her.

Table 7.10. The psycho-emotional impact.

Participant number	Examples from the participants' interviews.
11	"*It's not going well sister… Still looking for a school. It's school. That is what is on my mind.*" Lines 225-233.
12	*"I was stressed. I threw myself down and I was crying"* Lines 151-2.
14	"*it's painful for me because I cannot find a school for he*r" Lines 216.
15	"*is what is beating me. The stress is killing me. I got up at the hospital. They said my heart has a hole.*" Lines 309-12.

7.4.4. Caregivers are concerned about their children's attendance at school.

7.4.4.1. Concerns about the appropriateness of their children's schooling.

Despite caregivers' difficulty in finding schools close to their homes for their deaf children as outlined elsewhere, 4 caregivers expressed an additional anxiety about the appropriateness of education that is not specifically for deaf children. They want schools which cater specifically for deaf children while distinguishing their children from children with cognitive disability as exemplified by Participant 2's child who had previously attended a school which catered for children with cognitive disabilities: "(The school was) *mixing the deaf and those who are mentally retarded.*" Lines 96-97. Besides the caregivers' concerns about the appropriateness of their children's current school placement, they also expressed dissatisfaction with the progress that their children are making at school as per the example from Participant 3: "*I must take her out* (of Kamagugu School) *and take her to school of the deaf only…here* (Kamagugu School) *the children are mixed* (variety of disabilities). *And when I take a look, now she just left standard 2 and there at standard 2 there are kids who are in standard 3. They are mixed. The kids in one class. You will get one teacher having many standards* (grades)." Lines 217-225. "*When I go to that school, I still find her in the very same class with the very same teacher, but she has passed. The child is not going to another class. You must go with the grades… She is delayed again… You learn and you pass until you are 18 years and when you are 18 years, you come back and stay at home.*" Lines 583-8.

7.4.4.2. Concerns about their children travelling to school.

Another source of caregivers' unease in relation to their children's schooling relates to their children's travelling to schools which are far from home as exemplified by Participant

14 who said, "*Now she is in Pietersburg… where she is studying. Even if it's far. I never wanted her to be far from me…I do not want her to travel a long road and not seeing her. But because of education, I wish her to study, and school she loves, and she also wishes too.*" Lines 155-159. The 3 caregivers who had chosen to send their children to schools far from home said that, despite this choice, they felt uneasy about their children travelling long distances to get to and from school. For example, Participant 10 expressed the discomfort she felt which comes from her daughter walking home after dark and the need to use public transport, especially when having to change buses in order to get home "*They have transport group by kombi… Sometimes she comes home after sunset so it is dark. That is not safe at the road. I want her transport to drop her off at home, not the road.*" Lines 109-111.

7.4.4.3. Concerns about their deaf children boarding at schools away from home.

Three caregivers said that they preferred that their children attend day schools nearer to home, despite the limited choice in schooling options for deaf children in their district. For example, Participant 3 said that it hurt her to be separated from her daughter and that she chose to enrol her daughter in a school for children with different disabilities, even though she would have preferred her daughter to attend a school which caters specifically for deaf children in another province. She said, *"When she started school, I took her to Silindokuhle at Nkomazi… The thing that caused me to take her out from there, I was always hurting when I stayed long time without seeing her… I ended up getting her and taking her to Kamagugu… the transport is always there. She comes home."* Lines 227-233.

Participant 19 said that there was concern about the removal of the family's influence in the child's life if the daughter boarded at a school away from home and so the mother and the grandfather chose a school nearer to home rather than one which required boarding: *"It* *was that she must go to Letaba* (to school) *and my father said Letaba is far. He wants to always see her near. He does not want her to go. He wants to see what kind of child is she."* Lines 72-3.

The boarding school arrangements were highlighted by Participant 14 who expressed concerns about the risk of her granddaughter falling pregnant because she is boarding away from home while she attends a school far from home: "*She is now studying. I am now praying for that it helps her at school and that the boys do not fool her and impregnate her there. They say they kick you out if you are pregnant. She must study until she finishes.*" Lines 169-171.

7.4.5. Caregivers are concerned about their children not attending school.

7.4.5.1. Concerns about their deaf children's future if their children do not attend school.

Seven caregivers stressed the importance of their children's attendance at school to facilitate their future participation in society, future employment, and development of knowledge as presented in Table 7.11. The references to being '*open*' and not being '*lost*' reinforce the idea that they want their children to learn more than just vocational skills while Participant 14's reference to her own experience of poor schooling opportunities seems to have reinforced her concern that her child may experience the same limitations which she has encountered.

Table 7.11. Caregivers' concern about their deaf children's future if their children do not attend school.

Sub-themes of the concerns.	Examples from the participants' interviews.
Children's future independence.	Participant 3: "*She was supposed to get right education that she can stand on her own tomorrow*." Line 257.
	Participant 16F: "*We want to see her like us now, grown up like other people. Not to say she is not living. She is living, ja*." Lines 281-282.
Children's future ability to communicate.	Participant 4: "*If the child, the child is not studying and staying in the house, you will not be able to talk to him/her.*" Lines 114-5.
	Participant 12: "*I said, my child, I do not want him to be a fool and stay like this. I want him to have education and read at least. It must not be for his situation* (deafness) *that he is the one who is lost.*" Lines 85-88.
Children's future emotional risk.	Participant 4: "*And the children who are deaf, they are young. If your child is deaf and you make her stay at home, she will feel ashamed*." Lines 118-120.
	Participant 9: "*If he would stay with me, it won't benefit him anything, you see. It is better that he goes and finds a school for the deaf.*" Lines 134-137.
Children's need for knowledge and insight.	Participant 5: "*I pray that he carries on with learning ... That his things become open* (understands) *and learns for himself.*" Lines 138-140
Children's responsibility to look after their elders.	Participant 14: "*In these times we must help those who are young so they can study as we did not study and we must not just leave them because tomorrow they can help us. They will help us.*" Lines 231-234.

7.4.6. Schooling can be an opportunity for reducing caregivers' unease.

7.4.6.1. Deaf children's socialisation and deaf awareness through schooling.

Three caregivers said that, in addition to serving an educational role for their children, schools offer an opportunity to learn socialisation skills as well as a deeper awareness of their deafness, as exemplified by Participant 2 who said of her nephew, "*When he was growing up…he was so emotional…so the people, they did not like him. But by growing, I think when he was 5, 6 years, he started to change. Maybe it was going to school. And maybe understand that he is deaf. All of that. He has started to be liked by people so much*." Lines 31-34. There was reference to the children's identification with other deaf children and their children's psycho-emotional growth as per the example of Participant 15 who felt that it would be better for her son's development if he were able to attend school because it could offer him an opportunity to identify and socialise with other deaf children: "*If he can find a school he can be better in his brain, … that he gets another mind set of thinking and other kids, he can be right.*" Lines 277-279.

7.4.6.2. Hearing society's socialisation and deaf awareness through schooling.

Besides the socialisation and deaf awareness amongst deaf children, three participants felt that schooling and the learning of SASL in particular is a potential tool for encouraging the increased interaction between deaf and hearing people. This is exemplified by Participant 2 who said, "*It can also be a subject, also in* (hearing) *schools, even for those people who are hearing, because we are having a lot of this people* (deaf people). *Sometimes maybe in the buses, people, we don't understand and we don't even know how to talk to deaf. Sign Language. At least to know the basic things, ja.*" Lines 219-227. Participant 4 made reference to schools which cater for deaf children as vehicles for the fostering of deaf awareness in society so as to foster acceptance of deaf children when she said, "*Many people do not know it* (know about deafness). *If there are schools here, people in the community can be used to the children. They will be used to that. This thing, it is natural*." Lines 539-541. "*The Sign Language could be there in schools. I think that the community would know it by now and they would be happy if they can communicate with the children because you know you will be knowing few things*." Lines 623-625.

7.4.7. Domain summary: Schooling

Caregivers expressed various challenges when they were trying to access schooling for their deaf children. They referred to the shortage of schools in their area which cater specifically for the needs of deaf children in light of their specific communication needs and SASL considerations and there were instances of the transfer of the school-seeking activity to other people. Caregivers were not in favour of mixed schools because they did not feel that their children were cognitively disabled and did not have to attend school with children with developmental delay; they referred to their children's unique communication needs. For caregivers whose deaf children presented with health, behavioural, or developmental concerns, the difficult school-finding activity was even more complicated because of a particular shortage of schools which cater for their children's needs in addition to the children's deafness considerations.

Caregivers referred to four main structures which they could approach for assistance with regard to their children's schooling: social workers, government, community, and the researchers. They referred to the assistance provided by social workers in advising them and directing them to schools which cater for deaf children. The caregivers referred to the government's provision of schools for deaf children, albeit that they felt that the schools were not necessarily always near to their homes. There was also reference to the government's financial assistance to facilitate their children's attendance at school, not to mention the government's provision of food for children who, due to extreme poverty, may not have other sources of meals. When they spoke of the community assistance in their endeavours to access schooling for their children, they referred to their linking in with other members of the community who may have gone through the process themselves or with other people with whom they strongly identify. Caregivers enquired about what input the researchers could provide with regard to assisting them in finding schools for their children.

The caregivers' endeavours to find schools for their deaf children appeared to have a psycho-emotional impact on them and caregivers reported pain, anxiety, and even physical illness as a consequence of trying to get and keep their children in school. When the children were in school, caregivers expressed unease about their attendance at school. Firstly, they referred to their concerns about the appropriateness of education that is not specifically for deaf children and which does not account for their language needs and does not encourage adequate scholastic development and progress. Caregivers also expressed unease about the long distances that their children have to travel to and from school, not to mention concern over their children's use of public transport and the need to walk far in rough terrain from the main road to get home after they have disembarked from their transport at the main road. They seemed to prefer that their children did not have to board at schools far from home and would have liked their children to attend schools near their homes so that they would not have to be away from home.

Nonetheless, despite their unease about their children attending school, they expressed unease about the consequences of their children not attending school. Caregivers expressed unease about their deaf children's future if their children did not attend school, especially with regard to the possibility of finding future employment and the requirement to fulfil family and social responsibilities. Reference was made to the caregivers' desire for their children to have access to learning and knowledge, not only vocational skills and it seems as though one caregiver's own experience of not having attended school was reflected in her desire for her child to attend school.

It seems as though deaf children's schooling could serve as a tool for reducing caregivers' unease because they felt that their deaf children's socialisation, identity, and deaf awareness could be enhanced by attending school. Also, caregivers felt that schools could serve as vehicles to transmit deaf awareness in society, especially through the teaching and learning of SASL by hearing people at the schools for children who are deaf but also at schools for hearing children.

Therefore, it appears as though the domain of schooling poses particular challenges to caregivers of deaf children but they also referred to the role schools and schooling plays in addressing some of their challenges with regard to their experience of being caregivers to deaf children. There was reference to the need for assistance from other people with whom they share common traits but also from the structural systems put in place by government.

7.5. Domain 4: Psycho-emotional support

Caregivers reported various experiences and challenges which may suggest the need to support them. Themes around their psycho-emotional support emerged during the interviews with the caregivers and this domain seemed to feature with regard to their experience as caregivers of deaf children and the results in this regard are presented in the following section.

7.5.1. Caregivers' experience of governmental structures offering psycho-emotional support.

7.5.1.1. Social work services as a governmental structure provide psycho-emotional support.

Five caregivers spoke about the psycho-emotional support they received from social workers and it seems as though the psycho-emotional support they received was not necessarily always direct counselling, but, instead, the social workers' presence and input appears to have had a supportive element. Participant 1 referred to the benefit of the social workers' presence when she had thoughts of killing her child and how their monitoring of the child's well-being was necessary and beneficial when she said, "(I) *thought of strangling her* (the deaf child). *Kill her and dump her.*" Line 89. "*They sent me a social worker and they would come here in the house… coming to check if the child is still here.*" Lines 96-100. "*It helped a lot. It helped a lot because the counsellors, they came here. All came here to tell me that they want to see the child here at home. 'We do not want to hear that you took the child to another place, or maybe you mistreat the child. Or we find that the child is dead. If the child dies, we will arrest you.*" Lines 144-155.

Their support was described as valuable because they are considered to be educated people who can keep secrets as referred to by Participant 3 "*Because sometimes you would want the thing to be confidential. The social worker will be able to keep my secret." Lines 648-650. "The social worker is able to do that. If there is something you do not understand or maybe, you, as a parent, you see it as a problem, not understanding that when you are here, how do you get out of it? The social workers are people who are educated. He/she will take you out of your mind-set and make you to be able to face the situation. ... He/she will tell you in a way that opens your eyes.*" Lines 695-703.

There was also reference to the professional stance from which they are able to offer advice from the perspective of people who are not strangers' to the caregivers' situation and context as referred to by Participant 4 when she said that the social workers are not strangers: "*I won't say it* (social work) *is a stranger. The stranger does not know anything about children but I do go to the social worker. ... The social worker will be able to say, 'How do we help you?*'" Lines 644-678.

It seems as though the caregivers benefit from the social workers' presence with regard to their psycho-emotional support to caregivers about their deaf children but that they also seem to appreciate the practical advice with regard to dealing with the general family dynamics and family wellbeing as revealed by Participant 18 when the deaf child's aunt was experiencing difficulties when the deaf child's sister who was too embarrassed to collect the deaf child's HIV/AIDS medication: "*I used to send his sister ... I said she must collect his tablets at the clinic and to find that the sister was not going ... I went to the social worker. I got there and explained and the social worker said maybe the lady, the sister, is embarrassed ... we must try to change* (the procedure of collecting the deaf child's AIDS medication)." Lines 105-125.

7.5.1.2. Government as a structural entity does not provide psycho-emotional support.

Though the caregivers acknowledged the psycho-emotional support which caregivers received from the governmental social workers, caregivers did not feel supported by government as a structural entity which is exemplified by Participant 3 when she said, "*the government says it helps those who are disabled.*" Line 243. "*So, if the government does have help, I do not see it ... I won't say the government is supporting me.*" Lines 728-729.

Caregivers displayed a great deal of mistrust in the government as expressed in the concerns with regard to immigration matters, disability classification, nepotism, and government's dis-identification with the caregivers as per Participant 6: "*Government complex. I don't like going there. People there, they know themselves too much* (they are conceited). *Government people, you can't speak to them. If you do not know them, they can't help you. If you don't have a friend or, or, or maybe a relative that is working there, no-one is gonna help, ja.*" Lines 5-7. Although Participant 2 did not verbalise her mistrust of government during the interview, her concerns about confidentiality and government access to the interview data reflect her mistrust. When we met with this caregiver who is a Zimbabwean national living in South Africa and explained the purpose of the interview and sought consent from her, she seemed wary of how the information gleaned from the interview would be used and she asked if government would see this information and use this information. I assured her that the information was confidential, anonymous, and would be used for research purposes. The aunt agreed to participate in the individual interview but then declined to participate in the group interviews which may reflect her wariness, despite our efforts to allay her concerns, and also reflect issues of being an immigrant to South Africa and how other caregivers may react to her and to her nephew.

Therefore, when caregivers spoke of government support, they only described support with regard to financial and schooling aspects as outlined elsewhere, and not to their own psycho-emotional support. However, this government sourced support in terms of schooling and finances could indirectly provide psycho-emotional support to caregivers because it addresses those concerns which caregivers may have although they seem to require specific psycho-emotional support from the structural entity that they equate to 'government.'

7.5.2. Caregivers have different experiences of community-level psycho-emotional support.

7.5.2.1. The presence of community support.

As part of the ethnographic interview, throughout the results section, it can be seen that participants used family terms even when the people to whom they were referring are not biological family. For example, it can be seen that terms such as sister and grandmother are used to refer to people who are not such but rather as terms of intimacy and of respect and the sense that the community is an extension of the family and, in the same way that the participants seemed to be supported by their families' and spouses' acceptance of the deaf children, they also seem to value that acceptance from the community.

This community-level acceptance and support is demonstrated by Participant 3, for example, when she describes the concern the community shows for her child and the community's acknowledgement of her child: "*It* (support) *is there. Maybe, like, here in the community, you see. Because in the community, you see that they are not the same* (not all people are as supportive as others)*. ... I am just making an example of my sister* (a term of respect for another woman, not biological sister). *She calls me, 'Where is (Child's name)? Greet her.' What, what, what. And also granny* (a term of respect for an older woman, not her biological grandmother)*, 'Hey, where is the child? Is she well?' What, what, what. You see, I can say in the family, the support is there and the neighbours. But it depends on the people you are surrounded with* (community/neighbours)*. ... That time when others are giving love to the child, they make you feel something and say* (to herself)*, 'Woooo, it means that the child is special.*' Lines 714-724. "*You come to church* (and other people ask), *'Hey, where is she? Did you call her? When did you last see her?' So, you see, it is another way of supporting that person* (caregiver)." Lines 724-726. When she said, "*So, you see, it is* *another way of supporting that person*" reinforces this idea that the acknowledgement of the child is considered supportive by the caregiver. She suggests that she has community support in terms of them understanding her child's needs: "*The neighbours, they understand (Child's name)'s situation.*" Line 20.

Participant 6 recounted the value of the greeting and acknowledging the child as a validation of the child as a person and the support she garners from that acknowledgement when she said, "*Yesterday I was with this other guy. He greeted him* (the child). *He* (the child) *did not respond and he* (the man) *asked me why he doesn't talk. ... Then I told him he's* (the child) *got a problem, that he is deaf. Hauw, he was good with him. He went to him and hugged him.*" Lines 209-212.

7.5.2.2. The absence of community support.

There was also a reported absence of community support where, for example, Participant 14 said that the community members do not get involved*:* "*Ahh, they just look.*" Line 153. Because they just look and are not involved, she feels that she has no recourse or resource in the community: "*There is nowhere that I can go to. And even an outside person, there is nothing they can help me with. They do not help. They just laugh at you and say, 'Wooa, she has started again.' So you, yourself, you must see it yourself and do not disgrace yourself and your house going around telling to people. You must see to it yourself. It is facing you. You must see it yourself.*" Lines 452-456. Her comments suggest that she does not get support from the community and feels disgraced at being turned away when she asks for support.

7.5.3. Faith system structures offer positive and negative psycho-emotional support opportunities.

7.5.3.1. Faith systems and faith communities offer psycho-emotional support.

Five caregivers mentioned that their faith systems and faith communities offer them psycho-emotional support as per Participant 9's acknowledgement: "*Ah, but it does come and I say the Lord will help me.*" Line 217. Faith systems and faith communities were described as structures to assist in the caregivers' attempts at addressing their challenges as explained by Participant 10: "*I have many barriers, but I only go to church.*" Line 172. Three participants said that they get support from their churches where one referred specifically to her sense of being let down by a person and so turned to her faith instead for support: "*In the beginning I was talking to this other lady. But now we do not talk to each other. Now I choose to go to church.*" Lines 202-203. One of these 3 caregivers, Participant 6, referred to how her church pastor had supported her when she had questioned her belief in God after her son was diagnosed with deafness and how his counselling was supportive, especially with regard to being assured that God will assist and strengthen her: "*Everyday* (I was) *asking God, 'Why? Why me?*" Lines 48-49. "*My pastor came to my house tried to convince me but I was convinced 'cos I went back to church explaining it's God, God knows why. He can't give you something that you can't handle.*" Lines 214-217. Participant 15 referred to the value of the sympathy and support from her church community and from her fellow church-goers: "*Sometimes I have stress and not be well, you see. If you give yourself to prayer. You sometimes, you tell others and they feel sorry* (sympathise)" Lines 79-80. "*I got hurt. The Lord kept me and the stress is killing me.*" Line 311.

7.5.3.2. Faith systems do not offer psycho-emotional support.

Despite some of the caregivers finding support within their faith systems, there were also references to where the faith systems are not supportive and the 5 participants who had earlier said that their faith systems are supportive, also referred to aspects of faith systems which were not supportive. For example, Participant 6 had stopped attending church because she questioned her belief in God when her son was diagnosed with deafness: "*Because, at first when they told me that his not going to talk or walk I neglect to go to church almost for 6 months*" Lines 214-215 although she later found support from her pastor at church as described earlier while Participant 14 said, "*It is from God that something like this happens in this house. It would be known by God. But it was not my wish.*" Lines 236-240.

Eleven participants referred to traditional faith systems and they reported not feeling supported by that particular faith system as per the sub-themes presented in Table 7.12. Caregivers reported that, in their desperation to address their children's deafness, they had engaged in these faith based practices even when they do not believe in traditional faith systems as per the example of Participant 4: "*Some tell me she has been bewitched… At the end, where will I trust? I will trust that she has been bewitched or will trust the tongue. And if there are other people who cannot be patient and not be able to accept. A person says, 'Better you take her to the traditional healer' and you go.*" Lines 418-426 *"The problem, when you are taking her* (to traditional healers), *you are telling yourself that you are trying. You stay not believing in traditional healers, but if someone is like that, you will take her."* Lines 496-501. "*I will say, I want to try because I want my child to talk and to be like other children.*" Lines 467-468. Caregivers expressed concerns about certain faith system practices and their effects on their children and these concerns seemed to motivate them to not engage in such faith system practices or to discontinue such faith based practices as presented in Table 7.13.

Table 7.12. Traditional faith system practices which caregivers did not feel offered psycho-emotional support.

Example of traditional faith system practice.	Examples from the participants' interviews.
Cutting the children's tongues.	Participant 3: "*So they tell themselves it is a small thing. If we cut, she will talk. And when you are cutting the tongue, you are also hurting* (the child) *again*." Lines 396-398. "*As a parent you will try that the child talks. I took her to have the tongue cut and give her muthi to drink. Though there was no difference*." Lines 481-485.
	Participant 4: "*They took her to this granny, a traditional healer. She then cut her a bit here* (the tongue). *They thought that maybe it was glued. It was not glued. There was no difference… She did not help us because she was born like that. We thought the tongue was glued together, so she did not help us with anything.*" Lines 192-203.
Smoking and inhaling muthi (traditional medicinal herbs).	Participant 13: "*I went and went. Went with her and got there. They prepared smoke then they said, 'Bring her. She will be opened. You will hear her saying, AHHH. If she says AHHH she will be open.' Ehi, they closed us* (she and the granddaughter were covered with a blanket while they were made to inhale the smoke from burning herbs), *the two of us. Heeh, me, I was saying, 'Take us out. We will die in here with the smoke. The child is not doing anything.' They opened. I signed* (vowed) *from there* (not to go back to traditional healers). Lines 351-355. "*Haaai, I would kill my child* (in the smoke). *I do not take her anymore. I do not take her.*" Lines 381-385.

Example of traditional faith system practice (continued).	Examples from the participants' interviews (continued).
Drinking muthi.	Participant 17: "*They* (the child's uncles) *took him and went with him to sangomas* (traditional healers). *They made him drink their traditional medication. And when they started working on him and making him vomit, having diarrhoea, I spilt those things* (threw them out)." Lines 185-190.
Dispensing snake fat into the children's ears.	Participant 16M and Participant 16F: "16M: *You know elders. They just say it's witchcraft when I was pregnant. But I don't believe that. Something like magic.*" Lines 98-99. "*16F: Ja, you know. We have tried mamba fat. 16M: Lots of things I don't know. Ja, they told us to go buy this other oil. They sell it in town. They say it's python oil. We tried that. ... We tried, but still nothing.*" Lines 148-155.
Mistrust of traditional faith systems.	Participant 9: "*If I take him to a traditional healer, he/she will not say, 'I don't know how to heal this one.' He/she will say, 'Come, let me help you' and you will end up not being helped and you will regret ever doing that. After some time and you go to another one and find the same thing.*" Lines 373-375.
Futility of traditional faith systems.	Participant 1: "*To the traditional healers, you took her 3 times and it does not work. Next the money that you are taking out to those people, is a lot of money.*" Lines 324-325.

Table 7.13. Caregivers' choice not to engage in expected faith system practices.

Participant number	Excerpts from the participants' interviews.
5	"*There was this other lady in a taxi who was playing with him, you see. Ahh, when she was playing with the child, he does not turn and it was then she said, 'Why is he not talking?' And I said, 'He was born like this.' And it was then she said, I do heal that what what what. I will come and make him smoke and also cut the tongue.' But because at home we do not believe on those things, you see, I ended up not going to the lady.*" Lines 486-492. "*Some they come check the tongue. Take it up and cut it under. And they make you smoke. But really, can a child be able to smoke and cough and it come out?*" Lines 365-368. "*And when you have cut the tongue, what then? The ears, they cannot hear.*" Lines 400-401.
12	"*People, they love talking many things…One day his grandmother said they must cut his tongue and I said, 'He must to cut his tongue?' and I was going on looking at the tongue and I did not see how the tongue is glued. Can a person's tongue be glued? … 'Hayi, the tongue is right and the string is not glued' and I said maybe those ones they believed in traditional medication a lot and I do not believe in that and that of sangomas* (traditional healers)." Line 43.
14	"*People tell me lies that are not there, make me do unnecessary things. That one, traditional healers, I do not go. I do not even take child there to traditional healers.*" Lines 364-368.
17	"*I saw they came with a 2 litre of medication. They said he must drink it.*" Line 289. "*the traditional medication is giving him diarrhoea … and from there they say the child is being bewitched. I was quiet. I threw out the traditional medication. … They* (the child's uncles) *are fools.*" Lines 311-327.

7.5.4. Caregivers' experience of research as a structural form of psycho-emotional support.

7.5.4.1. Qualitative research offers a model of caregiver support provision.

It appears as though caregivers feel that the qualitative interview method offers an example or model of how support can be offered. For example, Participant 3 said that she feels overlooked by government structures and that they could do as the researchers did in looking for caregivers of deaf children and approach them directly as was done during the purposive sampling of the participants: "*If you* (the researchers) *were coming from government, I would say the government is doing a great job because you went straight to Kamagugu and then went to look for us. If government was to play its role, it was to be going door-to-door, sending people to look for people who are deaf in the community.*" Lines 735-740. She feels that the snow-ball sampling was useful because caregivers can direct structural entities to other caregivers: "*And you come to me and I will direct you and show you, 'That one, the child is deaf. They* (the caregivers) *cannot take him/her to school.' The government must go and look. There is nothing that it is helping.*" Lines 740-2.

It became apparent that the interview in itself was seen as supportive for the caregivers who participated in the research process. Five participants referred to the benefit of the interviews where in interview 16, it was said that by talking about the caregiver experience, the interview helped them by talking about their child's deafness: *"16F ... sort of lowers the pressure, ja. ... Cos even if you don't talk about it, if you keep it to yourself, it becomes like a burden*" Lines 314-317. "*16F For instance, now you guys came, you're also relieving some of the burdens that we have… Get it out, ja*." Line 317 and Line 322. Relatedly, Participant 1 encouraged us to conduct more such interviews when she said, "*I thank you. Shame. You must not stop doing it* (interviewing) *at my house. Don't stop doing* *it* (interviewing) *here.*" Lines 440-442. During the group interviews, participants spoke of the change which came about after their participation in the individual interviews as exemplified by Participant 14: *"Do you remember when you first came to my house? I was crying that she finds a school. From then I never relaxed and just sat down. I went with her town, to her doctor. He/she did all the papers, the doctor. All the papers were right. The child is in school now*." Lines 159-162."

7.5.4.2. The research interviews as opportunities for creating networks of support.

The individual and group interviews created the opportunity for the network to be established through the snowball sampling strategy and enabled caregivers to interact and to talk to each other about their experiences. From the interview transcripts, it can be seen that some caregivers were familiar to each other while others met for the first time through the research project. When the group interviews were conducted a year after the individual interviews, it was observed that participants exchanged telephone numbers after the group interview and were arranging to meet up with each other.

Here follows an excerpt from the first group interview, although the same interaction was observed in the other group interview, which exemplifies the opportunity offered by the participation in the group interviews for the participants to establish links with each other. In this interview, Participant 3 and Participant 5 did not know each other but Participant 4 was the link between them as she knew them both separately.

P: *"How do you know each other?"*

Participant 3: *"Me and sesi* (sister – a term of respect) *(Participant 5), we do not know each other."*

Participant 4: *"Do not know each other."*

Participant 3: *"It is my first time seeing her (Participant 5). I do not know her. I am sure she does not know me, meaning we all know (Participant 4's name)."*

Participant 4: *"To me, she (Participant 5) is my auntie* (a term of respect). *This (Participant 3) is my sister, my mom's bigger sister."*

Participant 3: *"So it is my first time to see auntie (Participant 5)."*

P: *"You are all related?"*

Participant 4: *"Not that we are relatives, just that I am used to saying auntie* (a sign of respect)*."*

Participant 4: *"Ja, we (Participant 3 and Participant 4) are relatives." Lines 5-22.*

7.5.5. Psycho-emotional support from other caregivers of deaf children.

7.5.5.1. Support from other caregivers of deaf children.

Caregivers' psycho-emotional support for their peers seems necessary as Participant 4 pointed out when she said, "*And that is why I am saying support because support means everything, you see?*" Lines 590-591. "*Ahh, it is right to give each other support as people*." Line 544. "*Caring, love, patience. Things like that. ... . Because if you love each other, you care about* (each other)*, ... and support them and listen to her or him.*" Lines 446-561. Four participants referred to the ideal type of peer support because they can identify with the other caregivers' needs and Participant 15 even referred to knowing how "*painful*" it is to be the caregiver to a deaf child when she said, "*If I see another mother having a child who is disabled or deaf, I would take him/her and stay with him as I know how painful is it ... now I can take someone's child and stay with them. I would prefer to nurture the child because the pain of children, I know it.*" Lines 198-203.

Five participants referred to the supportive role they could play in advising each other and Participant 3 referred to how caregivers must accept other deaf children as theirs too and to recognise that they are not alone in their experience: "*As mothers* (of deaf children), *there is someone that you maybe know who has a child like that, or a granny. Do not look at you're one only. Just like me. I am (Child's name)'s mother. In my world it is (Child's name) only. You must think of all the deaf children as yours.*" Lines 828-542.

Five caregivers spoke of the value of other caregivers and the support and the information they shared with each other. Participant 10 highlighted: "*What can I support with? If I would ask, 'Is your child studying?' If she is not, I would help by giving out information about schools and tell her to do so so so so that your child can study. I would help with that.*" Lines 515-517. Caregivers can create a network to support each other as exemplified by Participant 9 who spoke about how she can introduce caregivers to other caregivers, especially after being "*here*" at the group interview: "*Like now, we see each other here. You are able to go to a friend. 'Hey, my friend, I have this problem. Can you help me?' If I have it, then I would help. When I do not have, I will say to my friend, 'I do not have, go ahead* (to someone who is better positioned to assist and thereby move ahead)." Lines 519-521. There was reference to the support which caregivers can give each other through this informal structural network as exemplified by Participant 12: "*Some* (caregivers) *I do not know where they stay. You will find them calling me. You will hear them saying, 'Ehh, this side, we see your child he is studying. How did you do it so that we can also find our kids studying?' ... I do not know them and their phone numbers I do not know.*" Lines 401-404.

Furthermore, there was reference to the potential creation of a support group for caregivers of deaf children, especially because they identify with other caregivers of deaf children as per Participant 6's suggestion: "*Maybe to build a group, like maybe, ehh,* *monthly. Maybe in two weeks' time, all the parents that they have problems with their kids that are deaf, to get together, like giving us tips on, 'OK, if something like this happens, you must treat your child like this.' Something like that, just to give us support 'cos it's so difficult.*" Lines 12-15.

7.5.5.2. Absence of support from other caregivers of deaf children.

However, not all the caregivers said that they feel the support or the potential for support from other caregivers. Participants said that they cannot support other caregivers and they used analogies to explain their limited ability to support other caregivers, or as Participant 14 said, "*We are just sitting as we are sitting.*" Line 508. The analogies, as exemplified in Table 7.14, were used to explain that caregivers cannot share from their limited resources and that they have to survive their vulnerable livelihoods with their limited resources. P, the language and culture broker who conducted the interviews, explained that these food analogies were used to refer to the food itself but also with regard to other forms of support too because the food was a metaphor for the ability to sustain other caregivers in other ways besides food.

Table 7.14. Food analogies to represent caregivers' inability to support each other.

Participant number	Excerpts from the participants' interviews.
13	"*Ja, even if you have it, a cabbage, here, do you think I will cut the cabbage for you to eat? ... Hahh, I am trying to grow with it till they* (children) *grow*." Lines 523-6.
14	"*Hahh, there is nothing. We are not supporting each other. ... You can open your eyes about how do we support each other. We do not know anything. We are just sitting as we are sitting.*" Lines 505-508. "*So, for me, if I have bread, can I carry a plastic* (bag with bread) *and go give it to sesi* (sister) *or granny? No ways. Heh ehh. There is nothing. Even if I get a cabbage, it is mine and my family's and my children's. Nothing to support each other with.*" Lines 508-512.

7.5.6. Psycho-emotional support from families to caregivers.

7.5.6.1. Psycho-emotional support from families is present.

Six caregivers referred to the value of psycho-emotional support from their families and that it has a particularly intimate character as exemplified by Participant 9, who is blind, when reflected that she preferred the family as a source of psycho-emotional support over other forms of such support: "*I talk to my family. It is them that help me. I do not tell anyone from outside. We sit down and talk alone. And we advise and talk about how do we go about it.*" Lines 426-428.

There was reference to the reassurance that the caregivers get from their nuclear family and their extended family's acceptance of the deaf child as exemplified by Participant 12's grandfather's statement: "*I am relying on family a lot.*" Lines 362. "*In the house* (family), *he is in right hands.*" Line 218. "*If he* (the child) *is not going to talk, he is not lost.*

He belongs to this family." Lines 70-71. *"(Child's name) is deaf. We do not care about that and we accept him as our child and in the family, there is someone who is deaf. You must just accept it too*." Lines 75-76.

Similarly, Participants 16 referred to the collective action and effort required to raise their deaf child and that the family and family elders can offer that collective support when they said: "*16F: They support us 'cos of what we got. What I told the elders is that we cannot raise this child alone. I mean that we are not strong enough so we need their support in whatever they can support with.*" Lines 264-267 "*16F: what we've concluded is that we need to raise the child, all of us support.*" Lines 276-277.

7.5.6.2. Psycho-emotional support from families is absent.

Despite participants' reports that they value family support, they said that they still feel alone and uncared for as per the example of Participant 1 when she said, "*There is no-one that cares for me.*" Lines 240-256. Moreover, their families misunderstand the children's needs, are suspicious of the deaf children, distance themselves from the deaf children, and, therefore, do not always support the caregivers' actions exemplified by Participant 17's shunning by the family: "*His* (the child's) *family, the uncles, they're the ones who have a problem because they ended up not knowing what is he sick of. They thought I was bewitching him. There was no understanding with the brothers* (uncles)." Lines 176-180. "*I am being disturbed by the uncles and the mother's brothers.*" Lines 160-161 "*When the child is sick, they think… that, wooo, you are bewitching the child.*" Lines 184-185. "*even if I meet up with them, they do not talk to me. Even him, when they meet up with him, they do not greet him. They keep quiet.*" Lines 210-212.

Three caregivers felt that their families do not accept their deaf children and, therefore, they as caregivers do not get that family support. The families do not seem to acknowledge the deaf children, especially as that acceptance pertains to traditional and cultural practices surrounding the deaf children and the deafness as explained by Participant 6: "*My family, some of the family, they don't understand why, 'cos there is no- one in my family, no-one in my husband's family who is deaf. They don't understand.*" Lines 52-53. "*And some family, they don't understand. You know, us blacks, we have the witch. They* (family) *think something like that.*" Lines 53-54.

Moreover, Participant 18 described how she does not feel that she gets support from her family because they do not see the child as their responsibility or their concern when she said, "*Sometimes I go to the relatives. You see, if a burden is not yours, not everyone feels it the same as you. I can come and tell you is like this this but because the thing is not yours, you will not take it to the head. It must burn you that here is my child.*" Lines 193-199 "*I am talking to the families but they are not helping.*" Line 215.

7.5.7. Psycho-emotional support from spouses.

7.5.7.1. Caregivers' sense that spousal support is present.

Five participants referred to the value of the psycho-emotional support from their spouses and they spoke of the benefit of the cooperation between spouses, the opportunity to discuss matters and advise each other, and the value of mutual decision making between the spouses, although, as per the demographic information presented earlier, this sample was characterised by single, female caregivers. Those caregivers who were with spouses or partners and those who had support from the children's fathers felt an alleviation in their psycho-emotional stress as demonstrated by Participant 3 when she said, "*We sit down and we advise each other. We agree in one word because I do not do anything apart from him and he won't do anything apart from me.*" Lines 272-274. "*I do not think I had that much* *stress because her father was here.*" Lines 302-304. "*I think it's a gift…because her father was here so I think it's a gift.*" Lines 298-304.

It seems as though the spousal support does not need to come in the form of support from married spouses or the children's biological fathers as demonstrated by Participant 12's account: "*His* (the child's) *father died when he* (the child) *was 3 years. He fell sick and died while we were separated.*" Lines 315-318 but at the time of the interviews, this participant had another partner with whom she had a hearing child and she said that he is supportive of her and of her deaf child: "*He* (her partner) *is the one who took responsibility and said, '(Mother's name), I love you and if I love you, I cannot love you and not your child. What I do to my child … I do for your son. I want him to also have something. I want them to be equal.' He is not a person who is separating them.*" Lines 322-330. The new partner even said that if the mother were to leave him, he would be prepared to stay with the children, including the deaf child who is not his biological child: "*he will say, 'Sisi, if you want to go marry and leave me, go and leave me with the kids … And I will say, '(Child's name) is not your child, remember.' And he will say, 'Why are you telling me that? Problem (Child's name) is mine.*" Lines 334-338.

Women caregivers seem to be especially vulnerable to family criticism, especially when considering faith systems' apportion of blame on mothers. Therefore, male spousal support appears necessary to mediate the support of women caregivers as exemplified by Participant 17: "*I work hand in hand with the father* (her husband, the deaf child's uncle). *He is his* (deaf child's) *father now.*" Line 98. "*I talk to my man and will say I know his family is sick because they have no right. He is the oldest. The do not have the right to say these things on their sister's children.*" Lines 223-226. As mentioned elsewhere in her interview, the child's other uncles took the child to traditional healers against the caregiver's wishes and her husband supported her in preventing the child from going to traditional healers: "*They* *talked alone and ended up speaking to my husband. And they did not understand him too saying if the baby died, he is going to eat him.*" Lines 198-200 which means that the uncles were critical and suspicious of the aunt and spoke to the husband expecting him to side with them. Instead, he agreed with his wife (the primary caregiver) and the uncles said that if something happened to the child, that is, if the child died, the husband would have to take responsibility for the death of the child. The expression "*he is going to eat him*" is a local expression which could equate to the English expression, the blood would be on the husband's hands or the blame would be laid at the husband's door.

7.5.7.2. Caregivers' sense that spousal support is absent.

Ten of the participants in this sample are single caregivers and 3 referred to the absence of spousal support in their interviews. Participant 1, who had earlier said that she felt alone because she does not have family support, also said that she does not have a spouse from whom she can get support and she expressed the need to fulfil dual roles, her own role and the one which would have been the man's role when she said, "*In the house, I am the man.*" Line 403. Caregivers referred to the absent psycho-emotional support from their spouses because those spouses do not accept their children's deafness as exemplified by Participant 15's history: "*When I tell his father, he does not take that* (accept it)." Line 75. "*We broke off and he told me he does not have children like this. He abused me a lot, the father of the child. He was a person that paid lobola* (dowry) *and* (I) *stayed with him for 10 years, us staying together. It ended up not going well.*" Lines 187-192.

As mentioned earlier, caregivers value spousal support even if the children are not their spouses' biological children. However, caregivers experience an absence of psycho-emotional support when their spouses do not accept the deaf children in their care when these deaf children are not their biological children and, consequently, may only offer logistical support but not psycho-emotional support as relayed by Participant 18: "*Ah, you see, I do not talk to him* (husband). *Just that there is nothing… He does help with the children. We do talk about that. But if things happen, he does not have a say because they are not his. … He won't take it seriously because they are not his*." Lines 230-235.

7.5.8. Psycho-emotional effects from the absence and presence of opportunities to talk.

7.5.8.1. The potential psycho-emotional benefit.

There was a benefit to four caregivers of the opportunity for them to talk about their experience as reported by Participant 4: "*it does help … I will say that I am having a problem like this this. When I explain it, if I can solve it, I solve it*" Line 183. Caregivers seemed to express that by talking about their difficulties, they have an opportunity to reflect on their experience from a different perspective as exemplified by Participant 3 who explained, "*Or maybe, you as a parent, you see it as a problem, not understand that when you are here, how do you get out of it, the social workers, as people who are educated, he/she will tell you in a way that she opens your eyes"* Lines 695-704 and Participant 4 when they said that they are able to look at their challenges from different perspectives when they talk about these challenges.

Participants referred to the physiological benefit of being able to talk about their experience when they referred to the removal of pain and to the psychological alleviation that came from such an opportunity to talk as per the examples of Participant 1 who said, "*When I talk, is like I am letting my frustration out. Taking the hurt.*" Lines 392-395 and Participant 14 who explained: "*it does help here* (said while tapping the side of her head)" Line 435.

7.5.8.2. The potential psycho-physical-emotional consequence.

Caregivers spoke of psycho-physical-emotional consequences of the absent opportunities to talk about their experience. Four caregivers referred to the consequence of not being able to talk about their experience and all of them used words referring to pain and hurting as exemplified by Participant 1 who said, "*I want it to pass out my heart… I do not like that I stay with it in my chest. It will hurt me* (if she does not talk about it)" Lines 371-381. "*It will cause me to be ill.*" Line 395. Participant 15 even said that "*sometimes my brain is destroyed.*" Line 80. Participant 11 seems to contradict herself when she says, *"I do not talk to anyone. I talk to my kids in the house. That is where I talk my things"* Lines 160-163 *"It is painful when I am alone"* Line 173 which implies that the children in the house to whom she could speak do understand her particular situation as a caregiver to a deaf child because they are children.

7.5.8.3. Caregivers' unawareness of their emotional load and of the potential value of talking about their experiences of being caregivers to deaf children.

While interviewing participants, it seemed as though some were unaware of the potential value of talking about the emotional aspects of being caregivers of deaf children. When participants were asked about to whom do they talk to about their psycho-emotional needs, five were unsure to what we were referring which suggests that talking about their psycho-emotional state was not an area of attention or focus for them. The example of from Participant 19's interview demonstrates this unawareness together with the language and culture broker's attempts at trying to explain the concept of talking about their experience. The mother had been crying during the interview and was visibly upset, yet she seemed unaware of that psycho-emotional need and the offloading that could be of benefit to her:

P: *"So, if you are stressed like this, who do you talk to?"*

Participant 19: *"Meaning? Speaking about?"*

P: *"Like now, the thing you are staying with is not right. Who do you talk to?"*

Participant 19: "As in now?"

P: *"Mmm."*

Participant 19: *"Ah, there is no-one."* Lines 123-128.

P: *"Mama, you must get someone you must talk to."*

Participant 19: *"Talk to someone because of what?"*

P: *"So, how does it come down with you?"*

Participant 19: *"But now I am talking, isn't it?"* Lines 190-198.

7.5.9. Community perceptions around deaf children and deafness.

7.5.9.1. The community's suspicions.

From the interviews it appears as though there are suspicions within participants' communities which results in caregivers experiencing the need to hide their children as per Participant 4's explanation: "*They* (the caregivers) *will look at themselves. ' What are my friends going to say?' or 'What is my family going to say? They will gossip about me or laugh at the child,' you see?*" Lines 336-341. "*Some will tell you that the tongue is glued. Some will say that and that it will take time…you will lock him/her in until he/she is grown.*" Lines 342-345. Five caregivers spoke about this unease and four participants reported how they were aware of people who locked their deaf children inside their houses so that their neighbours would not know that they have deaf children because of the stigma surrounding deafness and being caregivers of deaf children as detailed by Participant 6: "'C*os I remember, there was one lady that I know in Ngondwana … she had a baby. A baby boy also … I didn't know that the baby can't speak* (is deaf) *but she was hiding that baby for people* *not to see*." Lines 36-39. "*It was like, we never knew about it. She was hiding the child. I don't know why. She has got her reasons, but it was bad.*" Lines 65-66. Participant 14 referred to caregivers who abandon their children due to this absence of support arising from suspicion when she said, *"Some, Sesi* (sister), *they dump them* (children) *in dustbins."* Lines 482-483.

Caregivers explained how deaf children are at risk of being ostracised by communities because they are considered unacceptable. Participant 3 said "*It was not accepted in the community… They used to hide those kind of things* (deaf children)*... Because at my house, at next door, there was a child like that, will call her 'pewu', a not an acceptable child.*" Lines 192-200. The children were at risk of not being accepted because of the supernatural attributions of their deafness as Participant 6 went on to explain the benefit of a support group to dispel those ideas amongst caregivers: "*Some parents hide their kids. If we have that group, talk about kids … that parents can get used to the idea* (of the deafness). *No, it's not because the child is bewitched.*" Lines 56-58.

7.5.10. Domain summary: psycho-emotional support.

Caregivers spoke about different opportunities for psycho-emotional support. They referred to the benefit of the social workers' support, especially because the participants described the social workers as educated yet contextually sensitive and that they are able to maintain the caregivers' confidence and secrets. Although these social workers are government employees, the participants seemed to mistrust the government and said that they find it difficult to approach government for support. The participants said that government could employ similar techniques as those employed by the researchers in conducting this qualitative study, especially with regard to government finding caregivers of deaf children in the way the researchers had done through snow ball sampling. Over and above the sourcing of caregivers of deaf children, the research process itself was described as beneficial because caregivers expressed the benefit of being able to discuss their experience and the psycho-emotional effects and benefits of being able to talk about their experience. It was also reported that the interviews had created transformative opportunities where caregivers had been able to garner insight into their challenges or make connections with other caregivers in similar situations so as to address these challenges.

At a community level, caregivers stressed the value of their communities’ acceptance and acknowledgement of their deaf children and the benefit of that acknowledgement to the caregivers. However, it was established that that community support of the caregiver is not necessarily guaranteed and there was reference to the disgrace that comes from the communities’ rejection of caregivers’ attempts at getting community support.

Caregivers’ faith systems provided support through prayer to God and through the support from the caregivers’ churches and church members. However, faith systems were not always reported as supportive in that caregivers also spoke about the challenges and difficulties they had encountered with regard to certain faith based practices which they felt were harmful or not beneficial to their children. Caregivers recounted how desperate they were to attend to their children’s deafness needs that they engaged in some of these practices in the hope that it would be of benefit to their children, even if they did not believe in bewitchment or in the power of traditional healing.

Participants spoke of the value of the support from other caregivers of deaf children, especially because of their identification with other caregivers of deaf children. They referred to the psycho-emotional and physical benefits of that support and there was the suggestion of starting a support group for caregivers of deaf children in that district. Besides logistical support, it was identified that caregivers need “c*aring, love, patience*” which could be offered by other caregivers who are in similar situations and who face similar challenges.

However, caregivers referred to their contextual limitations in their ability to offer support to other caregivers. Participants in this study highlighted the research interviews and the connections they made through the research process as beneficial in caregivers supporting each other. Both the individual and the group interviews created opportunities for the caregivers to establish links with and between each other.

When caregivers spoke about their families' psycho-emotional support, it appeared as though caregivers found their families' acceptance of their deaf children as an act of support to the caregivers and there was reference to the benefit of their families' support, especially because of the intimacy of the family. However, some caregivers did not feel that they had their families' support and that their families did not acknowledge their deaf children and that their families questioned their caregiver abilities. They also referred to their families' distancing of themselves from the deaf children because they do not accept responsibility for the deaf children.

Spousal support seemed very important to caregivers and when it was available, caregivers said that it made the caregiver experience easier because they were able to discuss and share with their spouses, even if their spouses were not the deaf children's biological parents. However, for the caregivers who did not receive spousal support, they felt that they had to carry the role of two caregivers in one person. They described how their spouses did not accept that they could be parents to deaf children and therefore withdrew from the deaf children's lives and they also referred to differences between logistical support and psycho-emotional support and how they longed for this psycho-emotional component too.

Some participants spoke of the psycho-emotional effect on caregivers of the absence and presence of opportunities to talk about their experience. They referred to the potential psycho-emotional benefit of talking about their experience which included the opportunity to look at their challenges from different perspectives to the physiological benefit, such as the removal of pain and psychological alleviation that came from being able to talk about their experience. However, for those participants who did not get such an opportunity, they spoke of psycho-emotional consequences of not being able to talk about their experience. Some participants did not seem to be aware of the psycho-emotional benefit of being able to talk about the emotional aspects of being caregivers to deaf children. They seemed to focus on the responsibilities, practicalities, and logistics of being caregivers to deaf children and did not consider their psycho-emotional well-being.

With regard to the caregivers' psycho-emotional support, they seemed to not receive such support when people around them were suspicious of them and of their children's deafness. Participants reported that there are still caregivers who hide or abandon their deaf children because of the stigma around deafness which is often linked to bewitchment and the belief that deaf children are unacceptable as people.

Therefore, in their experience as caregivers of deaf children, it appears as though caregivers require not only practical and logistical support but also psycho-emotional support. The acceptance and well-being of the child appears to be, by extension, supportive of the caregiver too and caregivers referred to their psycho-emotional well-being as being linked to that of their deaf children and they referred to the ways in which that support can become manifest in them while also talking about the consequences of its absence.

7.6. Domain 5: Caregiver role

The experience of caregivers of deaf children in rural Mpumalanga is influenced by the domains of communication, financial aspects, schooling, and the psycho-emotional aspects of their caregiver experience. Another domain which emerged from the interviews was the expected roles which caregivers have to fulfil and the associated responsibilities as well as the way the role is internalised and enacted, especially in light of the other domains which mediate the caregivers' experience.

7.6.1. Caregivers' responsibility towards deaf children.

7.6.1.1. Grandmothers have been given the role and responsibility.

Four of the participants in this study were grandmothers who assumed this role after their own children had died and left their children in the care of the grandmothers. Three of the grandmothers said that their deaf children had been abandoned at some stage and they ascribed that abandonment to the children's deafness. For example, Participant 11 described how she took on the caregiver role when the child's parents died and he had been abandoned by the new caregiver because of his deafness. She said: "*His parents left* (died) *when he was young. He came when his father died first and then his mother was sick.*" Lines 16-18. "*He was brought by his grandmother and* (she) *left* (abandoned) *him here.* (He) *was around 3 years or so.*" Lines 20-22. "*I got back from work and found that the grandmother left* (abandoned) *him here at the house with my kids.*" Lines 40-7. Nonetheless, although she was given this responsibility, she said, "*I accepted because I knew the child*" Line 54. "*…he's ours*" Line 187. "*I also told myself that he loves me like his mother.*" Line 220.

Of the children who are in the care of their grandmothers, the deaf children's fathers only feature in two of the children's lives. One of these fathers who is involved lives near the grandmother and his child but the caregiver role has been taken on by his mother, Participant 13, the child's grandmother. The other of the involved fathers had assumed the role of primary caregiver before he died but when he died, his mother, the child's grandmother, Participant 7, took on the caregiver role.

7.6.1.2. Aunts have been given the role and responsibility.

Five of the participants in this study were the deaf children's aunts where two became caregivers because the children's mother's had died, one because the biological mother could secure employment, one because the child's mother moved to another province, and one because the child's mother separated from the father and abandoned the child.

Employment factors seem to have played a role in deceased mothers' transfer of the caregiver role to the aunts. For example, in the case of Participant 17, the dying mother specifically wanted this aunt and uncle to take on the caregiver role because this uncle, unlike the other uncles, was employed: "*He* (the deaf child) *came to me when he was not talking already. When his mother was sick, she asked her bother to take her kids because they are going to suffer* (without a caregiver). *She said if she dies, we must take them… When she was in hospital, I and her brother went to visit and she said, 'Brother, did you take my kids?' And the brother said, 'Yes, I took them.' She said 'OK' and when we left* (the hospital) *we heard that she is dead."* Lines 43-56. However, the uncles disagreed with the arrangement that the mother's brother took the child, even though it was supposedly on the dying mother's request: "*And the children, he* (her husband, the deaf child's uncle) *did not steal. He was given by his sister. They* (the other uncles) *are like that. They were not working. They do not work.*" Lines 228-230. Similarly, Participant 18, who had been unemployed at the time of her sister's death, filled her deceased sister's position at work which enabled her to provide for her dead sister's deaf child: "*His mother is my sister. See, his mother died in 2009… It is better for him to be with me.*" Lines 57-64. "*I was not working, and when she died I came to work here*." Line 95.

Two of the children in the care of the aunts have contact with their biological fathers whereas the other children in the care of their aunts do not have such contact. However, despite the contact, the aunts carry the primary caregiver responsibility as exemplified by

Participant 5's nephew who only gets financial support from his father. "*I saw him when he was born. The mother brought him and separated with the father of the child. Brought him when he was still a new-born.*" Lines 15-16 "*So I stayed with him.*" Line 20 "*Isn't it that I am the one bringing him up? I do not have a child. I took him while he was very young. His mother broke up with his father when he was very young. … I took him and stayed with him.*" Lines 145-148. "*He is supported* (financially) *by his father*." Line 107.

7.6.1.3. The responsibility and role are supernaturally given.

Eight caregivers said that the caregiver role is a blessing and that their deaf children are gifts from God as highlighted by Participant 6: "*You just tell yourself that, 'OK, it's a blessing from God.'*" Lines 244-245. Participant 4 pointed out that because the deaf children are considered supernatural gifts that they ought not be considered disabled when she said: "*Because they are a gift from God, as children. I said before they are not disabled. Even a disabled child is a gift*." Lines 546-547 and, therefore, as Participant 5 pointed out, deaf children ought to be accepted, notwithstanding the suspicion with which some people consider deafness: "*I accepted it as a gift from God. We say it is well, God gave us it.*" Line 157.

7.6.2. Caregivers of deaf children face particular challenges in fulfilling their caregiver role.

7.6.2.1. Caregivers feel their challenges are insurmountable.

Because of the challenges which the caregivers recounted with regard to the communication, financial, schooling, and psycho-emotional support domains, six caregivers expressed that they feel as though they are not able to carry on or that they seem to be limited in how they can proceed in their ability to adequately and fully fulfil their expected caregiver role. Table 7.15 illustrates the caregivers' sense that they cannot overcome their challenges with regard to the domains described earlier.

Table 7.15. Caregivers' sense that their challenges are insurmountable.

Inability to overcome challenges.	Examples from the participants' interviews.
Legal and bureaucratic constraints to fulfilling the caregiver role.	Participant 6: "*Our government, especially Mpumalanga. I, I don't know. They don't do anything for us. I don't see them. That is why I, I do not even know which department I must go. In government complex, 'cos, I know even if I go there to ask for help, depends who you know, who are your friends. You are relative with who. All that is not gonna help so I decided I am not gonna do it* (approach government)" Lines 74-77.
Caregivers' inability to read.	Participant 14: "*I sometimes say if her mother was still alive, as she was educated, she was going to look where she* (the child) *can study. Where it is written that I can get help. But, because I did not study, even if they write that she can be helped I cannot go there. I do not see anything* (cannot read anything)." Lines 78-81. "*And also, in school, I never went. I do not even know how to write. I do not know anything, and for me to learn that, I won't be able to.*" Lines 114-117.
Caregivers' sense of having given up.	Participant 7: "*What can I help him with? Nothing.*" Line 84 "*When I think of it, there is nothing I can do.*" Line 98.

7.6.2.2. Caregivers have to mediate between their deaf and their hearing children.

Caregivers expressed concerns about their efforts at trying to treat all their children equitably and that they experienced challenges with regard to mediating between their deaf and their hearing children. Table 7.16 presents examples of the five caregivers who spoke about the mediation between their deaf and hearing children.

Table 7.16. Caregivers' mediation between their deaf and their hearing children in their caregiver role.

Caregivers' mediation role.	Examples from the participants' interviews.
Acceptance and understanding of their deaf children by their hearing children.	Participant 6: This caregiver described how her older, hearing child struggled to accept his younger brother's deafness and how she had to attend to his needs while addressing the deaf son's needs too: "*It was difficult for (Child's brother). One day at school, he was in Grade 5, they asked him to write an essay about his family. Yo, I was shocked 'cos the teacher called me. I must read the essay he was writing about his baby brother. That he's not happy with God. Why God made his brother to not communicate with us. He's not happy about that. Even in school, with his grade and test, not doing well at school…It started to hit him a lot. They say sometimes at school you will find him crying alone. Then we tried to explain to him that, ja, 'There is nothing you can do. It was God's plan.*'" Lines 67-74.

Caregivers' mediation role (continued).	Examples from the participants' interviews (continued).
Caregivers respond to each child differently due to the deafness.	Participant 3: "*I have two children. There is (Deaf child's name) and her brother. I do not have a problem with her brother. The child that I end up having a problem with is (Deaf child's name) because, like now, if I want to go to Hazyview, her brother, I do not have a problem with … I must ask my neighbour, 'Will you be here? OK, now I want to go out. Can you stay and guard (Deaf child's name)?'*" Lines 238- 245.
Caregivers strive for equality between their children.	Participant 5: "*Once he sees you having money, he knows that you want to send the one who is talking* (to the shops). *He will see it as if you are segregating him… Now when I want to buy something, I call him and tell him… He wants to mix with the others* (to be like the other children in the house)." Lines 564-574.
Caregivers' difficult role when the children are not their biological children.	Participant 18: "*Now I just keep quiet. Sometimes when I talk to her* (the deaf child's older sister) *she just goes the other way. There is nothing that I end up doing. I just keep quiet.*" Lines 217-219.

7.6.2.3. Caregivers have to mediate the family's suspicions around deaf children and deafness.

Four caregivers spoke about the need to allay their families' suspicions around the children's deafness so as to reduce the family's suspicion about bewitchment. It appears necessary for families to understand how deafness and deaf children fit in the family context so as to be able to explain the occurrence of the deafness. Two participants were able to show that there had been a history of deafness in the family in the past and that seemed to reduce their families' suspicions as exemplified by Participant 3: "*So, I found that* (deafness) *in her father's family. Her father said his uncles was not hearing and talking.*" Lines 35-37. "*The family that we have, they understand, we do not see it as a curse.*" Lines 278-279 whereas 2 participants were not able to prove that familial link and Participant 6 referred to her family's suspicions around bewitchment: "*My family, some of the family, they don't understand why, 'cos there is no- one in my family, no-one in my husband family who is deaf. They don't understand. And some family they don't understand. You know, us blacks, we have the witch. They* (family) *think something like that.*" Lines 52-54.

7.6.3. Caregivers' sense of inadequacy in fulfilling their caregiver role.

7.6.3.1. Caregivers were not the first to notice their children's deafness.

Five caregivers spoke about how they were not the first to notice that their children are deaf and that other people had to point it out to them because their work commitments, and their multiple responsibilities resulted in not noticing their children's deafness as per the example of Participant 6: "*'Cos during the day, they're* (the crèche) *with him. I'm only there at 5 o'clock taking him home. Just bathing him. I'm tired. Go to bed. I don't go through that. They are the one that knew there is something wrong and they called me in and told me that there is something wrong"* Lines 83-84.

In the case of non-biological parents who are caregivers, participants pointed out that they did not know the children and so did not notice the children's deafness, especially because of their work commitments, as per the example of Participant 11: "*Because I took time to see that he is this way. Isn't it if he was mine, I would have seen this when he was* *still young or what? ... And I couldn't see it. Getting up every morning and going to work and leave them. I didn't take notice.*" Lines 64-73.

Table 7.17. Caregivers were not the first to notice their children's deafness.

Person who first alerted the caregiver to the child's possible deafness.	Examples from the caregivers' interviews.
Crèche staff.	Participant 6: "*I was lucky. When he was still a baby at Ngondwana, there was a nursery there. There the one that saw him, the problem with him. ... They called me in then I made an appointment with my doctor.*" Lines 85-89.
The deaf child's grandmother.	Participant 3: "*Granny said, 'Go to the clinic to be checked. Maybe she has a problem with the ears. Or maybe the tongue is glued. So I went to the clinic.*" Lines 124-127.
The deaf child's uncle.	Participant 11: "*I only saw it when my son* (the child's uncle) *said, 'Mom, this child does not seem right.' I said, 'How do you mean?' and said still he cannot talk. Looks like he is crippled.*" Lines 65-70.

7.6.3.2. Caregivers overlooked their children's deafness.

During the interviews, when caregivers were asked to describe their children, they tended to refer to other aspects of their deaf children first and not their deafness as exemplified by this interaction between P and Participant 4: "*P: What made you notice that the child cannot hear? Participant 4: That she started talking at a later stage*." Lines 25-26.

Eleven participants referred to their children's motor aspects such as walking, talking, and sitting rather than hearing even when they were asked about their children's hearing specifically. It seems as though they refer to the more visibly noticeable aspects of their children's difference as these may be more noticeable as per the example of Participant 3: "*It took time for (Child's name) to walk. She walked when she was 3 years.*" Lines 30-34. "*I started taking her to the clinic… I took her full time when she was 3 years…. I did not then see that she has a problem of not hearing with the ears. I was taking her because of this problem that she was not walking. That she is not talking I discovered when she was 3 years. Isn't when a child grows, she starts calling names and differentiate? But she had no word that she was calling out."* Lines 101-115. Six participants first referred to their children's delayed walking, six first referred to delayed talking, two first referred to delays in standing, and one first referred to a delay in the sitting.

7.6.3.3. Caregivers' sense that they caused their children's deafness.

Caregivers expressed a sense of responsibility for their children's deafness as exemplified in Table 7.18 which impacts on their caregiver experience with regard to their perceived guilt in the cause of their children's deafness although these attributions were not confirmed as the cause of the children's deafness.

Table 7.18. Caregivers' sense that they caused their children's deafness.

Causes of deafness.	Examples from the participants' interviews.
Punishment for caregivers' sins.	Participant 3: "*Lord, what have I done?"* Line 282. "*Is it because the parent sinned that the person is born blind*?" Line 287.
Caregivers did not perform the necessary cultural rituals.	Participant 6: *"… some people, 'cos, you can see, my colour of skin. My dad is white, but, ja, that's a long story. Some of my elders says it happened 'cos I never met my dad* (he is deceased). *His spirit now, where he is now, wants to meet me now. So now his ancestors got to my child so that I don't know if it's true. But they say it's because of that. I had to meet my* (father)*, the white man. Take my child to him. Then he will* (would) *be fine.*" Lines 57-60.
Caregivers' error.	Participant 10: "*I think she was fine when she was born. But the problem that I mistakenly drop her down the floor and she became deaf.*" Lines 26-27.
Caregivers' actions during pregnancy.	Participant 12: "*I would not know, really, really. I can say maybe he was affected by my crying when I was 8 months pregnant because my father passed away when I was 8 months and he was in my stomach. It was on the fourth of August and I delivered on September. I can say that because I cried when my father passed away. I even fainted and got up in hospital.*" Lines 28-33.

7.6.4. Caregivers' responsibility in relation to their deaf children's health, safety, and well-being.

7.6.4.1. Health responsibilities.

Table 7.19 suggests another layer of caregiver responsibilities to which they have to attend, over and above the deafness related responsibilities and activities. There were reports of health concerns around injuries arising from violence, epilepsy, and two children were reported to be receiving treatment for HIV/AIDS.

Table 7.19. Caregivers' concerns about their deaf children's health.

Health concern.	Excerpts from the participants' interviews.
Consequence of violence against the child.	Participant 5: "*They shot him when they were coming from Moriya. He was carried on the back by this other lady, and the wife had an argument with the husband and had him on her back. And the husband shot the wife. The bullet shot the lady and went out to the child.*" Lines 76-83. "*He was shot. When he was shot, I went to the clinic at Themba and stayed at Themba and ... they discharged him and removed the cement* (plaster of Paris). *And his leg was always* (and has always been) *painful where they shot him.*" Lines 58-61.
Neurological health concerns.	15 "*He has epilepsy.*" Line 3 "*He takes his treatment for epilepsy there at the clinic.*" Lines 152-154. "*He just does meaningless things that he should not be doing.*" Line 111. "*This person* (her son) *is sick. They told me that he is sick.*" *If you make him angry, he will go, take a cup or a glass and break it. Or sometimes he will bite. Bite himself for that you made him angry.*" Lines 147-150. '*his brain is damaged*' Line 135. "*But when the illness* (epilepsy) *comes, it seems like it takes something. If you teach him to bath himself, after three, two. Three days after he doesn't know how to bath. He will enter the basin and just sit, quiet. And you will give him a cloth and soap and will apply. Will just be quiet or apply soap on one place… His brain is damaged.*" Lines 295-301.
Consequences of traditional medicines.	Participant 17: "*…those things* (traditional medicine) *could have killed him because you see this disease does not want traditional medication."* Lines 206-208.
HIV/AIDS concerns.	Participant 17: "*But now he is getting treatment. HIV positive. He takes ARVs.*" Lines 7-12. "*He used to have sores on the body. ... he had sores a lot and even in his ear and pus was coming out. And he had sores inside his ears.*" Lines 117-122.

7.6.4.2. HIV/AIDS considerations and the caregiver role.

HIV/AIDS was mentioned as a dimension of the caregivers' general health responsibilities towards their children. However, it seems to add another dimension to the caregiver role and contributes to the caregivers' multiple responsibilities with regard to their deaf children in a very particular way with its related stigma. This stigma is highlighted by Participant 18 who said that the child's deafness is a buffer to protect him from the stigma associated with HIV/AIDS: "*The neighbours … they tease him that he is drinking ARVs. Them. Ah, I tell myself that it's better* (that he is deaf) *because he cannot hear them tease him. It happens sometimes but not too much.*" Lines 33-39.

Caregivers whose children have HIV/AIDS may face additional responsibilities in their caregiver role than the caregivers who do not have to account for HIV/AIDS. Participant 17 spoke about the difficulty in attending to her child's HIV/AIDS needs and his deafness needs simultaneously: "(He) *has not put them* (hearing aids) *on. I took him to Robs. They said the machine* (hearing aid), *they cannot find it and it was when he started being sick* (from the HIV/AIDS) *and have been attending his* (HIV/AIDS) *treatment.*" Lines 282-286.

It is also very apparent that the stigma around HIV/AIDS requires a great deal of manoeuvring by the caregivers and the family as demonstrated in the account by Participant 18 when she said that she had to juggle her work responsibilities while attending to the child's HIV/AIDS treatment so she had asked the child's older sister to collect the child's HIV/AIDS medication. However, the older sister stopped collecting his ARV medication because she was embarrassed to be seen at the clinic collecting HIV/AIDS medication and was, instead, giving her brother some other medication to cover up the fact that she had not collected his antiretroviral medication. She said: "*I used to send his sister, because sometimes, I am most at work. I said she must go and collect his tablets at the clinic and to find that the sister was not going … she comes with this other tablets … I went to the social* *worker. I got there and explained and the social worker said maybe the lady, the sister, is embarrassed because there, you see, she is 21 years. She thinks that maybe, she sees that her friends, they think that she is sick.*" Lines 105-125. Because the older sister was embarrassed and did not go collect the antiretroviral medication, in order to avoid censure from her aunt, she gave her deaf brother some other tablets. Therefore, the deaf child had not been consistently taking his antiretroviral medication and the caregiver had to forego work so that he could catch up on his treatment regimen: "*There were those* (antiretroviral medications) *that he was drinking. When did he finish? When was it? It's like February, March. Around there* (and this interview was conducted in June which shows a long interruption in his treatment). *And when they give him* (ARVs), *they gave him extras. Then it was that. And now I'm trying that. They said I must come back on Tuesday so that we will fix that.*" Lines 127-132.

7.6.4.3. Caregivers' responsibility and role with regard to their children's safety related to the children's deafness.

Five participants recounted their concerns about their children's safety, especially in relation to their deafness and the hearing aids' inability to sufficiently amplify danger and warning sounds as exemplified by Participant 2's account: "*Something terrible that happened to* (Child's name). *Like they were playing football with other children and there came a kombi from nowhere....when he saw this* (sic) *children on the road he hooted. All the other kids ran away from the road. (Child's name) kneeled down to take his ball as he kneeled down…and he was hit by the kombi…he stayed 21 days in hospital… so it was caused by the deafness. And the other children, they were running for their lives. Nobody could come and say, 'Come off the road!'*'" Lines 189-200. Caregivers spoke of their hypervigilance when their children play outside of the house, as per the example from the father in interview 16: "*16F: But the most difficult thing is that, is to keep her by your side because, if you like, mmmm, lose sight of her. She might be, let's say, for instance, you are here and maybe if you, she will go and cars would bump her because she will just cross the street.*" Lines 228-233. This hypervigilance is amplified because of their children's deafness as per the example from Participant 9: "*Even when a car will come, he will not turn and look. No matter how noisy the sound is, he does not turn.*" Lines 14-17 "*because even if he has it* (hearing aid) *on and a car comes, if he hasn't turned first and look back, he won't move out of the way.*" Lines 95-96.

7.6.5. Caregivers' communication impacts on their caregiver role.

7.6.5.1. Challenges in communicating information about their children's deafness.

Over and above the communication differences between the hearing caregivers and their deaf children, caregivers also experienced communication challenges in their interactions with hearing care personnel such as doctors and audiologists and they subsequently had difficulty communicating information about their children's deafness. They did not seem to have the audiological, medical, diagnostic, and hearing aid amplification terminology associated with their deaf children and tended to use vague descriptions or analogies to refer to the deafness aspects.

These challenges in the use of the terminology are highlighted in Participant 13's account where it is unclear whether the use of the word '*machines*' refers to the assessment equipment or the hearing aids: "*They got there and gave them days on when to come so that they can try to treat her ears. Then they came with machines. The ones to put here* (ears) *and tried to talk to her but, hawu, no. She could not hear. Ah, nothing.*" Lines 112-117.

Examples of these challenges are provided in Table 7.20 where 10 caregivers used vague terms: four participants referred to '*things,*' four referred to '*machines,*' one referred to '*something,*' one referred to '*some test,*' one referred to her child being '*dead*' (referring to sedation for the sedation used during electrophysiological assessment of hearing), and one referred to the deafness as a '*cloud.*'

Table 7.20. Caregivers' challenges in communicating with hearing care personnel.

Non-specific descriptors	Excerpts from the participants' interviews.
'*things*'	*Participant 4: "They gave her the, what do they call the things to put on the ears? P: "Hearing aids." Participant 4: "So that she can hear*." Line 44.
'*machines*' for diagnosis.	Participant 3: "*There is a machine that they used. I do not know. They put inside the ears. They looked wherever they look. They can see. I do not know what is happening. The machine they put on the ears. Then they look on the sonar or what. I do not know what it is.*" Lines 155-163.
'*machines*' for hearing amplification.	Participant 9: "*They sent me to Witbank…that was when we got the machine* (hearing aid) *that he uses.*" Lines 88-91. "(Child's name) *had them. If he has them on, even when there is noise, he does not turn. The time when we applied for Pretoria to the physio* (referring to the audiologist)*, they put, they put these machines.*" Lines 67-70.
'*something*'	Participant 19: "*They just gave her something to put in* (her ear)*, that she hears noise of a car when she is walking*." Lines 94-99.
'*some test'* *'dead'*	Participant 6: "*They have done some test. Took him to, um, he was dead for the test … that test about two hours*." Lines 127-129.
'*cloud*'	Participant 14: "*The doctor said that this child has a cloud when she is talking. If she wants to say 'mama,' she wants to say it but then it blocks her.*" Lines 273-275.

7.6.5.2. Caregivers' use of English terminology facilitates their communication about their children's deafness.

The four caregivers who chose to be interviewed in English seemed to be able to more precisely detail the audiological and medical aspects of their children's deafness, including the diagnoses and the aetiologies of the deafness. They were able to use the specific terminology to describe their children's hearing amplification devices as illustrated in Table 7.21, unlike the other participants whose interviews were conducted in siSwati. The mother who was interviewed in interview 16 was the only participant in the whole sample who was referred to an audiologist whereas other participants had referred to doctors and one had referred to a physiotherapist.

Table 7.21. The use of terminology to communicate about their children's deafness.

Terminology used during the interviews.	Examples from the participants' interviews.
Aetiology	Participant 2: "*When he was a child he was affected by meningitis. I think he was 6 month or so. The doctor told us he gonna lose one of his senses. Either sight or hearing or his mind or his back bone and he lost his hearing.*" Lines 42-44.
	Participant 6: "*It was jaundice. Yes he had severe jaundice so it damaged his brain. Ja, so the doctor said he won't talk, he won't walk. … . He was in I.C.U for 11 days they had to do the exchange of blood and all that.*" Lines 36-46.
	Participant 16M: "*He* (the doctor) *said that he thinks it's the thyroid, 'cos when she was born, she had jaundice. It was a different one. They said it's hyperbilrubin* (hypobilirubaemia). *Yes, she had that one. So it ruined the thyroid with the hearing and also had a liver problem.*" Lines 82-85.
Personnel	Participant 16M: "*'Cos we took her to the, what do you call, this, it's the paediatrician. That doctor that helped when I was giving birth. And he took care of the baby … We took her to another Indian doctor and he said we must at least try to get a therapist and that's when he directed us to Dr (Doctor's name) of which he took us to the audiologist.*" Lines 61-70.
Hearing amplification devices	Participant 6: "*He* (the doctor*) said to us, 'Something that can help, it's called cochlear implant.*'" Line 77. "*Then he start using the hearing aid when he was 5 years.*" Lines 103-104.

7.6.5.3. The demands on caregivers' literacy impact on their caregiver role.

The participants who had not attended school and who had very limited schooling referred to their challenges with literacy as impacting on the caregiver role. Although other participants had said that they experience difficulties in communicating with their deaf children, for the caregivers who do not know how to read, these communication difficulties appear to be multiplied across different modalities. Participant 14 provides such an example.

She said that it was because she had not been to school that she could not read: "*Also, in school I never went. I do not even know how to write. I do not know anything.*" Lines 115-116 and she felt that her literacy limitations impacted on her caregiver role because she had not been able to read a letter she had received which contained information about schooling options: "*…where it is written that I can get help. But because I did not study, even if they write that she can be helped, I cannot go there. I do not see* (read) *anything.*" Lines 79-81. Because she cannot read, she had to ask someone else to take this letter in order find out about schooling options for her granddaughter but the person whom she had asked never returned to her with the necessary schooling information: "*So they gave me that letter. I came with it and when I came with it I gave it to this other man, we attend church together … only to find that they said they were going to call. Till now they have not called.*" Lines 17-25.

The demands on Participant 14's literacy became more pronounced when the granddaughter moved to a school in another province because the deaf granddaughter writes text messages which the grandmother cannot read: "*And she will sms me and you find that also the sms I cannot see* (read). *I just hear a phone ringing. I take it and give it to her mother* (term of respect for the child's aunt, the mother's sister). *Then she* (the child's aunt) *will say, 'It's (Child's name). Granny, she is greeting you. She is saying you must not cry. She is in school now. She has found a school.'*" Lines 164-166.

7.6.6. The caregiver role and responsibility has an impact on the caregivers.

7.6.6.1. The emotional and physical impact.

Notwithstanding the impact the different domains of their experience with regard to communication, finances, schooling, and psycho-emotional support have on the caregivers, nine participants referred to how the overall caregiver role in itself has an emotional and physical impact on them as caregivers. Eight of those nine participants referred to the physical pain or hurt which they felt in their attempts at fulfilling the caregiver role. This physical pain was described as so great that Participant 15 had contemplated suicide and she referred to the high blood pressure she had as a result of the challenges she encountered in her caregiver role.

Also, through their role as caregivers of deaf children, the insulting terminology used for deaf children and other people's negativity towards their children appears to be felt by the caregivers too as exemplified by Participant 5's pain at hearing her child being called '*imbhebebe*,' a derogatory term for deaf people which means 'dumb.'

Table 7.22. The caregiver role and its emotional and physical impact on the caregivers.

Impact on the caregivers.	Examples from the participants' interviews.
Painful	Participant 1: "*It is not well in my heart*" Line 182 and it is "*painful*" Line 85. "*It was very hurting. Was hurting too much, because when I looked at the child."* Lines 118-119.
	Participant 14: "*God came and took her mother. And I stayed with her. But it hurts me."* Line 73.
Negativity directed to the children is felt by the caregivers.	Participant 5: "*… some they usually say, 'That one is imbhebebe* (derogatory term meaning dumb)*.' And you, as the parent, you feel hurt."* Lines 31-32.
	Participant 15: "*With me, when another lady is cheeky with him, it hurts*" Line 214 and "*If there is someone who is not treating him well and I see, I feel hurt and say, 'Shame, you must treat him well'*". Lines 227-228.
Difficult	Participant 6: "*… so difficult, I'm not lying to you, to have a kid with deaf* (sic)." Lines 10-11. "*I'm telling you, it's not nice to have a disable* (sic) *child. It's hurting … it's difficult*" Lines 238-240.
Insomnia	Participant 5: "*I slept heartbroken. That the child does not have parents* (the parents died) *and the things they* (children) *want are many. I did not really sleep.*" Lines 205-208.
Suicidal thoughts	Participant 15: "*Eish. I am struggling, struggling badly*" Line 22. "*I am not right about this child. It comes to that I may take a rope and hang myself and pass this problem.*" Lines 314-315.

Due to the distances and long travelling times, caregivers who do not have their own personal transport are forced to take extraordinary measures to get to their hospital appointments which has an impact on the caregivers as exemplified by Participant 1 when she said that she had to travel from her village out of town to be at the hospital in Nelspruit by 4am to then catch hospital transport for an appointment in Pretoria, notwithstanding that this mother has other children and has HIV/AIDS: "*Go to Pretoria. Come back on this date. I got there and slept there. At about 4, the ambulance took me to Pretoria and when they explained and checked* (performed the hearing assessment)." Lines 106-111. This participant lives in Tekwane South and had to travel approximately 20km (one-way) to Nelspruit and then from Nelspruit approximately 320km (one-way) to Pretoria during her child's diagnostic process. This example reflects the considerable distance, time, and exertion demanded from the caregivers in their caregiver role. Additionally, these distances are approximations to the hospitals and do not take into account the distance and time required for the caregivers to get from their homes to a main, tarred road where they can access transportation to hospitals. During the data collection phase, P, who lives in that district, and I often got lost on the way to the participants' homes as many of the houses in the townships in this rural area have no street markers or house numbers and may, therefore, also reflect the difficulty hospital transport services have in accessing people in this area too. However, it seems as though the caregivers' access to their own personal transport facilitated their transport as exemplified by Participant 6's comment when she spoke about travelling the 320km from Nelspruit to Pretoria: "*It was easy because I've got a car.*" Lines 133 unlike the other participants in this study who relied on public and hospital transport such as kombis and buses which means that the travelling time would be even greater which can impact on the caregivers' fulfilment of their caregiver role to their deaf children but also impact on their multiple responsibilities to their other children and families.

7.6.6.2. Caregivers' concern about the impact of their death on their children.

Caregivers expressed concern about their death and what impact that would have on their children. Participant 3, referred to her concerns about the person who her widower would marry were she to die and the impact her death would have on the child. She said, "*Because sometimes when you are a woman, you think and say, 'Hey, one day I will die.' Yo, that thing. I really think about that. When I'm dead, who will (Child's name) be left with? Whoa, my child. Where is she going to stay when she is grown up? Who will she stay with? Will the person give her the same love I was giving her? Maybe when I am dead and her father takes another wife…The brain thinks. I do not get peace. ...I wish to know what will happen when she grows up. What will happen? I wish God can keep me till (Child's name) works and is able to stand on her own. Then I die maybe*." Lines 762-774.

Similarly, Participant 12 was concerned about where her child would live should she die, especially because the shack where she lives is registered in her name: "*I registered the place, doing it for life … Let's take, maybe death has arrived and I leave my child with a place for him and not squeezing in my mom's home as we are many*." Lines 363-366. She expressed concern about her son's independence if she were to die when she said, "*I just wanted that tomorrow he will stand for himself, even if I die*." Line 94.

7.6.6.3. Caregivers' disability.

Three caregivers who participated in the interviews have disabilities: two are deaf and one is blind and the impact of their disabilities is exemplified in Table 7.23. The two deaf caregivers who are sisters, Participant 8 and Participant 10, said that their family is very involved in the caregiver role and they explained how their family members have to perform some of the caregiver roles on their behalf because of they use SASL in contexts where people use spoken language.

Participant 9 referred to how she encountered barriers when people were dismissive of her caregiver role in finding a school for her son and she detailed the barriers to communication due to her inability to see her son use SASL and his inability to hear her speak to him for which she has to call on her sister to communicate to her son on her behalf.

Table 7.23. Caregivers' disability impacting on their caregiver roles.

Participant number	Excerpts from the participants' interviews.
8	This caregiver is deaf: "*My world is silent*" Line 5 and has deaf family members: "*Yes, they* (family members) *know us well and can communicate* (with) *us.*" Line 25. "*My hearing family help me.*" Line 89. "*Yes, my mother takes my child to hospital for hearing test and get hearing aid. It was her idea.*" Lines 138-139.
9	Participant 9 is blind: "*This thing* (blindness) *started when I was very young. I was just telling myself that my eye is just closed, you see. And found that also the other one is also giving me a problem too and it was then when I started attending the doctors and it was late because the other one was not coming all right totally.*" Lines 208-214 "*and they ended up not taking my matter up seriously.*" Line 28. Her blindness combined with his deafness may impact on her being able to completely fulfil her caregiver role: "*…just that when he speaks* (signs), *I do not see…*" Lines 104-105.
10	"*I want them* (other people) *to speak to me by face to face, not other side so I can't understand what they say. Yes, I can lip-read. If person is speaking outside while I am inside, I can't hear.*" Lines 198-201.

7.6.6.4. Caregivers' sense of the potential for personal growth arising from their caregiver role.

Five caregivers expressed a sense of personal growth in their caregiver journey and they revealed that they had developed certain attributes as a result of being caregivers to deaf children and had also grown in their acceptance of their children's deafness. Excerpts of this personal growth are presented in Table 7.24 in which it can be seen that caregivers grew in their insight into deafness and have learnt a great deal from being caregivers to deaf children despite the challenges mentioned in their interviews.

Table 7.24. Caregivers' sense of personal growth arising from their caregiver role.

Growth area	Examples from the participants' interviews.
Enabled to engage more successfully with people who have a disability.	Participant 3: "*Because of* (Child's name) *being here and that she is deaf, it has given me wisdom. I can now see a child who is not right and it does happen that I talk to other parents about their kids.*" Lines 297-299. "*I have learnt to care for people who are disabled.*" Line 264.
	Participant 15: "*If I see another mother having a child who is disabled or deaf … I know it. There is a lot that I have gained.*" Lines 198-205.
Growth in assertiveness.	Participant 13: "*The one saying she is imbhebebe* (dumb)*, ehhh, I do not like it, that one. Hhayi, I do not like it. Some, when they want to say it, I stop them saying, 'Hey, do not start. It is crime. Don't start with that one.' They quickly leave it at that.*" Lines 302-311.
Social recognition they receive.	Participant 17: "*Ahh. In the community they said, 'You did good. God is going to bless you.'*" Lines 160. "*Some say I am being strong. Some,* (say) *we could not have done it*" Line 246.
Good role models.	Participant 3: *"You can be a good example in the community…And when they are teaching others, they will teach about you saying, 'You see that lady? She cares for her child and loves her.'"* Lines 819-812.
Child's appreciation of the caregiver.	Participant 14: "*My learning comes from me looking at the way she is growing.*" Line 195. "*I wish for her to finish studies and when she is grown, she* (the granddaughter) *can say, 'Granny, my mom died but my granny would stand for me so that I study and I was staying with her. … they* (the community) *say, 'Her mother died but there was her grandmother who stayed with her.'*" Lines 249-255.

7.6.7. Domain summary: caregiver role.

In exploring the caregiver role in particular as it encompassed various individual domains, it was established that grandmothers and aunts of deaf children often had to assume or were given the caregiver role over the deaf children. The death of the children's biological parents, especially the death of their mothers, meant that their grandmothers were ascribed the caregiver role, even if the children's fathers were still alive and lived nearby, although abandonment was also a reason for the grandmothers' assumption of the caregiver role. The deaf children's aunts became caregivers to the deaf children due to the death of the children's mother, migration, secure employment, and due to abandonment. There was some contact with the children's fathers but the aunts assumed the primary caregiver role, as did the grandmothers. The deaf children were described as supernatural gifts and it was explained that God had blessed them with a special child and they considered their children gifts from God, despite the challenges and difficulties they reported with regard to communication, finances, schooling, and psycho-emotional aspects.

After their assumption of the caregiver role, caregivers said that they encountered particular challenges to their caregiver role which they seemed to feel were insurmountable and they spoke of their limited ability to adequately and fully fulfil their expected caregiver role. They spoke of having to mediate between their deaf and their hearing children and between their deaf children and their families while trying to foster acceptance and understanding of their deaf children.

Moreover, caregivers expressed a sense of inadequacy in fulfilling the caregiver role because they had not first noticed that their children were deaf and, instead, other people had to make them aware of their concerns about the children's hearing. They said that because of their limited resources, work commitments, and their multiple responsibilities, they had not noticed their children's deafness and that other people had to fulfil this role. Caregivers also seemed to have overlooked the deafness and focussed on their children's speech development and motor and other development and not the hearing per se. Along with their responsibility for their children, caregivers, in their interviews, expressed a sense of responsibility for the cause of the deafness itself due to their action, inaction, or punishment.

The caregivers expressed concerns about their children's health and physical wellbeing. Over and above their children's general health, caregivers gave examples of their concern for their children's wellbeing as a result of their deafness and the dangers of being hit by oncoming traffic because their children cannot hear the vehicles or the warnings to avert accidents. HIV/AIDS considerations were mentioned as impacting on the caregiver role because there was reference to the stigma surrounding it where one participant even mentioned that the child's deafness protects him from people's negative response to his illness. Additionally, caregivers spoke about the extra dimension the HIV/AIDS brought to their caregiver role because of the additional medical appointments in the treatment of the HIV/AIDS as well as the need for the caregivers to shift focus from the deafness aspects to the HIV/AIDS.

Caregivers seemed to experience challenges in communicating about their children's deafness and they did not seem to possess the audiological, medical, diagnostic, and hearing aid amplification terminology associated with their deaf children and tended to use vague descriptions or analogies to refer to the deafness aspects, for example, referring to '*things*' and '*machines.*' The caregivers' proficiency in English appears to facilitate caregivers' communication about their children's deafness, as those caregivers who were interviewed in English were more able to detail the audiological and medical aspects of their children's deafness, including the diagnoses and the aetiology of the deafness and they were able to use the specific terminology to describe the hearing amplification devices which the other caregivers were not able to do. Moreover, caregivers spoke about the limitations imposed on their caregiver role by their inability to read. The oldest participants referred specifically to this challenge as it related to their inability to communicate with their children via text and that they were not able to read the information or letters given to them which were necessary to fulfil their caregiver role.

It seems as though the caregiver role may have emotional and physical impacts on the caregivers as they described the pain and the health consequences they experience due to their attempts and challenges at fulfilling their caregiver role.

In getting their children's deafness diagnosed and in their attempts to get hearing aids for their children, it seems as though caregivers have had to travel great distances to get to the hospitals which they accessed using hospital or public transport which, within this particularly rural context, means that the journey is not necessarily easy or straight-forward. With regard to the caregivers' concern about health and wellbeing aspects, they also expressed concern about their death and its effect on their deaf children because they were worried about who would look after their children, if the children would be well cared for, and if the deaf children would be able to be independent if their mothers were to die. The deaf participants and the blind participant referred to their own disability in their ability to fulfil their caregiver role and how they have to ask other people to perform certain tasks which they are not able to in their caregiver role. Nonetheless, besides their challenges and limited ability, some caregivers expressed that they experienced a sense of personal growth and social recognition as a result of their caregiver role.

Therefore, it seems as though the caregivers experienced numerous challenges to their caregiver role which resulted in their need to engage other people to fulfil some of those roles. However, they also referred to the potential growth which could come from their fulfilment of their caregiver role while navigating the challenges in different domains.

7.7. Overall Summary of the Results

This chapter reflects the domains identified as characterising the caregivers' experience as well as the interconnectedness of these different domains within the caregivers' experience as depicted in Figure 7.2.

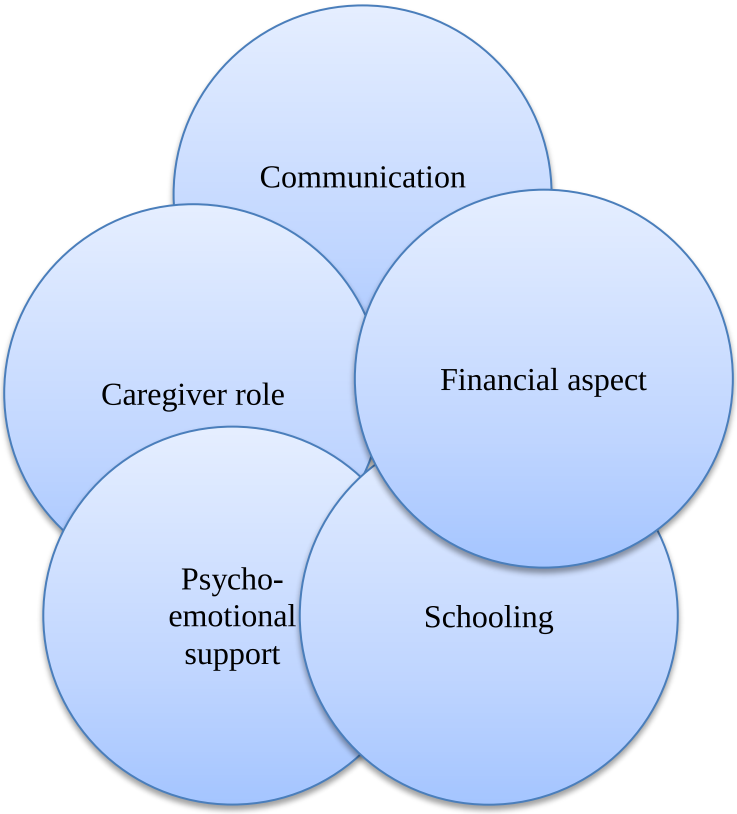


Figure 7.2. The different domains of the caregivers' experience are interconnected.

The different domains which are most salient and the themes within those domains reflect the complexity of the caregivers' experience as mediated by their context in rural Mpumalanga and it is seen that this context appears to offer few opportunities for caregivers to satisfactorily achieve their desired outcomes for their children while also not being able to provide for themselves within their caregiver experience.

The caregivers highlighted present and historical infrastructural deficiencies which have left them feeling alone and unsupported in their experience. Moreover, over and above the established and researched aspects of the caregiver experience as presented in the foundation chapters of this thesis, they spoke about the contextual infrastructural constraints on their full expression of their caregiver-selves related to their particular rural context within the turbulent historical context of apartheid and poverty and the current experience of governmental failure to meet their needs. In light of the historical and current insufficiencies, they highlighted the aspects relating to language, literacy, cultural practices, faith-based practices, spousal relations, familial expectations and relations, community level interactions, amongst others, as impacting on their caregiver experience.

Therefore, the results confirm that the experience of caregivers of deaf children in the Ehlanzeni District of Mpumalanga cannot be and is not compartmentalised and lived in discrete units but that the domains of their experience are formed, informed, influenced, and shaped by the other domains.

Chapter 8: Discussion

"Rise, tranquil sun, once more all pure and shining,

Clear purple morn with new-born light be clad"

(de Camões)

Figure 8.1. This photo of the sun over the water which I took in the province where this study was conducted, Mpumalanga, 'the place where the sun rises' or 'where the day begins,' reflects the need to consider the context in which deafness is experienced as this incorporation of context in the understanding of deafness sheds light on the caregivers' experience and on deafness itself.

8.1. The Fuller Picture

The translated quotation at the start of this chapter from the Portuguese poet de Camões, reflects the context where this study was conducted, Mpumalanga. It illustrates the shining of new light on the caregivers' experience within this province named for its location in the east of the country, the land where the sun rises and where the day begins. This study, situated within a qualitative paradigm, recognises that the experience of deafness is not devoid of context and that this contextual consideration in the experience of deafness extends to caregivers too. Deafness is not only experienced by the children who are deaf but by those who care for them too, extending the experience of deafness which calls for an appreciation of the fuller picture of that experience and landscape. In the earlier chapters of this thesis I proposed different ideas to facilitate the understanding of deafness while highlighting the caregivers' experience and the way in which to explore more deeply deafness and the experience of caregivers of deaf children. The findings of my study have enabled an elaboration and expansion of these concepts and, therefore, in this chapter I will elucidate on these.

In art, the visual arts specifically, painting in particular, Seurat's pointillist technique is an example of how perspective shapes the experience and appreciation of the painting because these are dependent on the angle from which his paintings are perceived. It is a reminder that the small and discrete points, when observed up-close, may appear not to form part of a coherent picture, but, by stepping back and viewing them from farther away, they blend at the edges and come together to create a bigger and more defined image which is brought to life by these tiny components. There is the opportunity to see how the smaller parts constitute the whole, and to appreciate the whole more fully, rather than being limited to seeing them as discrete points on a canvas.

Similarly, in this thesis, the perspective from which the caregivers' experience is viewed, as well as the appreciation of the overlap and interconnectedness of apparently discrete domains, is necessary so as to internalise caregivers' experience more fully as it pertains to deafness and their deaf children. This study showed that deafness is not only a phenomenon confined to ears and that there is a backstory to the experience of deafness while confirming that it is insufficient and inappropriate to compartmentalise the domains of the caregivers' experience into unrelated and disconnected aspects.

When caregivers arrive at audiological or deafness-related appointments, they may arrive with a priori conceptions, previous experiences, concurrent emotions and experiences, parallel anxieties unrelated to the deafness, and multiple responsibilities in their homes, workplaces, and communities. A contextual sensitivity calls for, and is revealed by, an ethnographic method in that people's interpretation of their experience is also part of the context and because, in talking about their experience, meaning is made. Meaning is not unidirectional but bidirectional where caregivers and hearing care personnel, including audiologists, are collaborative partners in the meaning making and this partnership is cooperative. Therefore, the results of this study suggest the need for a simultaneously respectful, contextual, bidirectional, interactively ethnographic, multi-domain attuned sensitivity and partnership with the caregivers of deaf children so as to engage more fully and personally with caregivers of deaf children.

8.2. Towards a Contextual Understanding of Deafness

I contend that deafness is more than just about hearing: it is a complex, multi-personal, and multi-dimensional experience for caregivers resulting in an embodied third-party disability within a rural context. Reference to the physiological and audiological aspects of deafness alone is insufficient to describe deafness because, as the analysis has demonstrated, there are interrelated variables which constitute the landscape of deafness. I argue that deafness has an experiential dimension in the third-party too in the person of the caregiver and this experience is mediated by available structures and whether or not they facilitate agency. More specifically, this thesis has shown that five domains predominate within the caregivers' experience of their children's deafness. These domains emanated from the themes which were extracted from the interviews and reveal the interrelated experience across the domains of communication, finance, schooling, psycho-emotional support, and the caregiver role.

Although the literature on deafness is replete with the arguments about the distinction between deafness and Deafness as discussed in Chapter 2, this thesis has demonstrated that, within the South African context of poverty and rurality with the associated structural constraints, deafness is embodied and experienced as disabling for deaf children, and then by extension, also disabling for caregivers of deaf children. Over and above the embodiment of context, this study affirms that poverty is disabling for caregivers of deaf children as well as deaf children and that poverty is not a straight-forward concept with a unidirectional trajectory and impact. Poverty is multidimensional and this study confirms that the "long-standing assumptions by economists, which consider those individuals as poor whose income falls below a reference subsistence level called the poverty line, have given way to poverty increasingly being considered a multidimensional issue beyond insufficiency of income or consumption levels" (Groce et al., 2011, p. 1496).

The results of this study suggests additional contextual factors to those which were identified as structural considerations in the caregivers' experience in Chapter 3 in Figure 3.4 (Andrews et al., 2010; Denzin & Lincoln, 2011; Kleinman & Benson, 2006; Penn, 2002). It appears as though the factors which have been added in bold and in italics in Figure 8.2 hereafter also need to be considered. These factors appear very powerful contextual influences on the caregivers' agency and include: language dominance, language proficiency and confidence, literacy and health literacy, employability, participation and the consequent sense of contribution, disability, and stigma and suspicion.

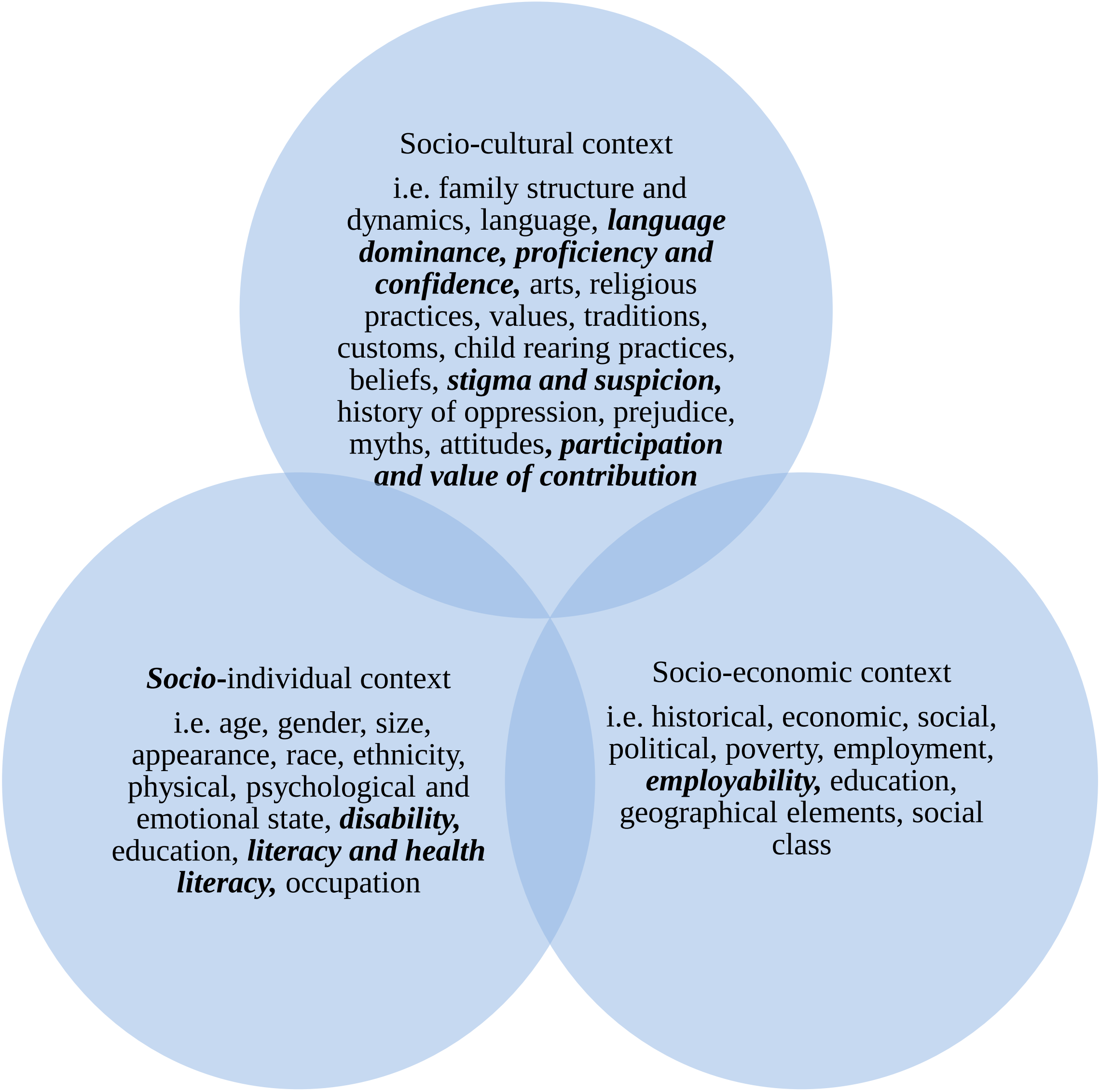


Figure 8.2. A revised representation of the contextual considerations in the caregivers' experience.

These aforementioned factors impact on the caregivers' experience and demonstrate the need for a contextually attuned understanding of the caregivers' experience rather than a reductionist one which reduces experience to discrete, unrelated, and disconnected domains.

Moreover, I suggest that the caregivers' individual context be reconceptualised to reflect a socio-individual context because this study confirmed that people's experience is not only contained in the individual but is also a product of the individual's interaction with society, especially in a setting where these socio-individual interactions are highly valued, although not always implemented or actioned.

Due to caregivers' reported sense of isolation and abandonment, the results of this thesis specifically highlighted the potential value of support from other caregivers, that is, from similar others (Thoits, 2011) to mitigate their sense of inadequacy in fulfilment of their caregiver role through their shared experience of children's deafness through a community of practice (Moodie et al., 2011), a potential structural support mechanism. However, it became evident in this thesis that this support is not available from these different structures and this absence of support from their social networks challenges the notion of ubuntu and its application within a context of vulnerability, suspicion, limited agency, and poverty. Caregivers revealed that they did not receive this utopian notion of ubuntu-support and that they felt alone in their experience and reduced their sense of self-efficacy and thereby constrained their agency when they did not receive the support they needed while they also described the physical effects of this absent support. It seems that, as a consequence, their ability to fulfil their caregiver role became then further constrained when they experienced the disabling effects of these psycho-physical-emotional manifestations of the absence of support in the form of third-party disability. Also, the exclusion of caregivers of deaf children by those who do not accept their children's deafness may result in third-party disability through the caregivers' association with their deaf children.

These structures appear limited in their support of caregivers and in the facilitation of their self-efficacy and agency, and seem to weaken caregivers and destabilise their self-efficacy which impacts on their agency in fulfilling their caregiver role and forces them to devolve their agency. This study has demonstrated the particular need to consider self-efficacy in the different domains of the deafness experience as these have not been described in detail before. The low levels of parental self-efficacy which the caregivers seem to display impinges on their agency to act and it results in what was previously referred to as proxy control (Bandura, 1982). In this thesis, it became apparent that caregivers have to devolve their agency to others in five domains because they "feel overwhelmed by their parental responsibilities, often actually becoming immobilised by the emotional and physical tasks of parenthood" (Coleman & Karraker, 1997, p. 78) especially related to their unfamiliarity (Bandura, 1982) with deafness. Caregivers are in a very vulnerable position and they seem to experience psycho-physical-emotional embodiments of that absence of structure and, as a result, potentially a third-party disability. Embodiment is a recognised phenomenon, but this study showed how children's deafness becomes embodied in their caregivers, an aspect which has been insufficiently described in the literature.

Figure 8.3 is a graphical model of the different components of the caregivers' experience that, when stepping back and observing the bigger picture, offers a description of the caregivers' experience. In this model, it can be seen that context is a variable which is present and influential in different spheres of the experience. This recognition of the caregivers' broader and interconnected contextual landscape heeds the call to make the position and experience of caregivers more "visible" (Munford, 1994, p. 268) with respect to their human rights by recognising their value as people and the qualitative approach in exploring the caregivers' experience seemed particularly valuable in this endeavour.

Very importantly, this study has confirmed that deafness ought not be reduced to calculations and descriptors of deafness but that a more humanist and qualitative approach is needed so as to fully understand the interconnected nature of the different domains of the caregivers' experience. This broader awareness of the interconnection of the different domains avoids a narrow and constrained appreciation of the caregivers' experience. The results of this study point to the caregivers' multiplicity of roles which they have to perform simultaneously with limited self-efficacy and agency which are mediated by their contexts and resources. This thesis has shown that the experience of deafness by caregivers of children who are deaf is mediated by time and space and that deafness is not only experienced by the children who are deaf but by those who care for them too, their caregivers. Therefore, this thesis identified the weak structures in the caregivers' context and showed their need for support in the different domains especially because of their weakened agency and subsequent devolution of agency and the embodiment of third-party disability.

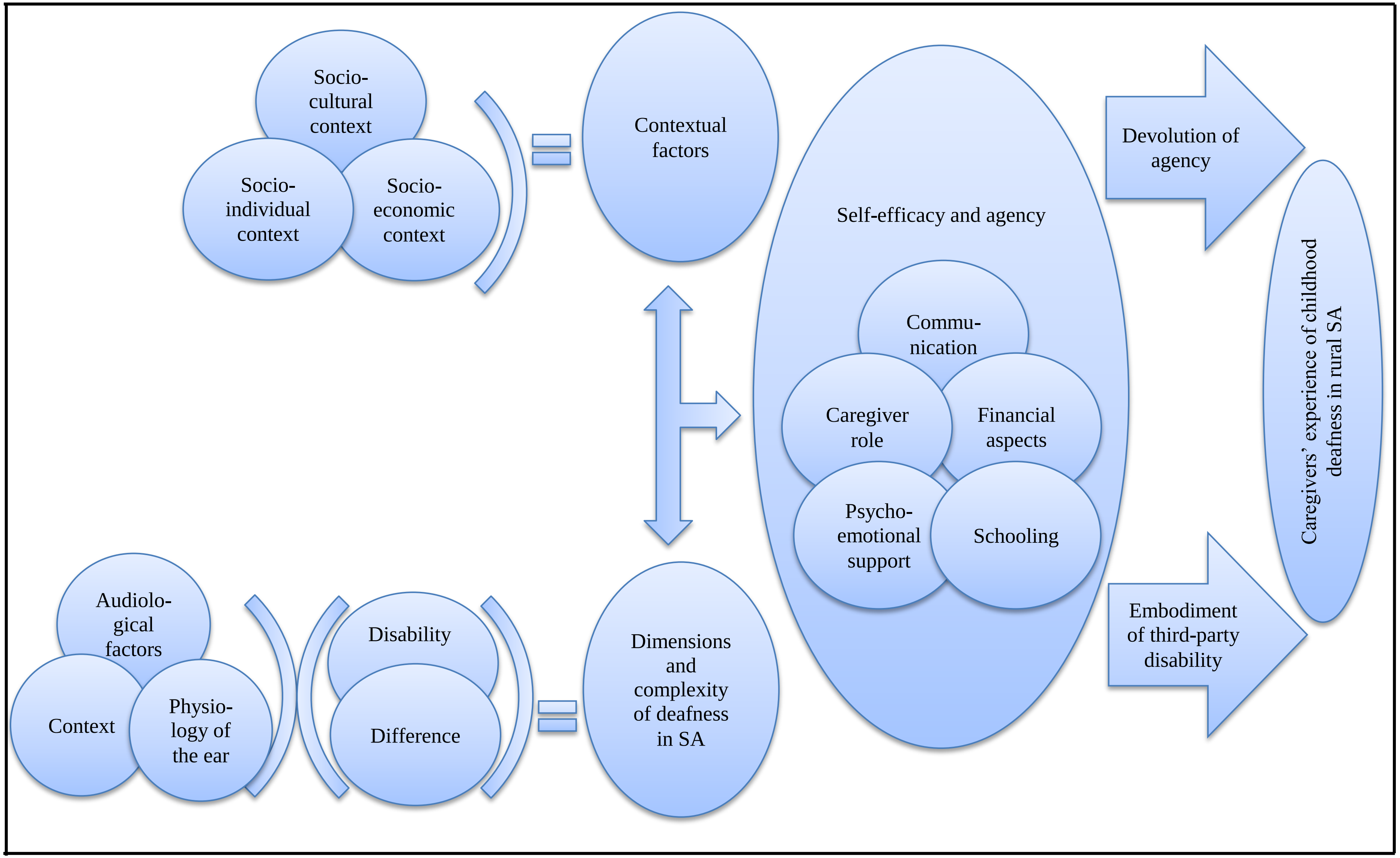


Figure 8.3. A proposed model of the challenges in structure to caregivers' self-efficacy and agency in five domains which influences caregivers' experience

8.3. Caregivers of Deaf Children Experience Structural Barriers to Self-Efficacy and Agency

This study revealed that caregivers of deaf children in the Ehlanzeni District of Mpumalanga encounter structural challenges to their self-efficacy and subsequently their agency as caregivers of deaf children and that their rural and poor context impacts on their experience. It highlighted the structural components that perpetuate the "social marginalisation, and lack of access to basic resources such as education, employment, health care and social support systems that link disability and poverty at the household level" (Groce et al., 2011, pp. 1503-1504). It is recognised that

> what people can positively achieve is influenced by economic opportunities, political liberties, social powers, and the enabling conditions of good health, basic education, and the encouragement and cultivation of initiatives. The institutional arrangements for these opportunities are also influenced by the exercise of people's freedoms, through the liberty to participate (Sen, 1999, p. 5 cited in Graham et al., 2013, p. 325).

However, specifically within this study, it became apparent that caregivers of deaf children, in a context of limited resources, seem to encounter structural obstructions to their ability to attain self-efficacy and therefore enact agency. "Social environments may place constraints on what people do or may aid them to behave optimally" (Bandura, 1982, p. 131) which in this study included such structures as government, family, community, language, unemployment, and faith systems, amongst others. It appeared as though the availability of resources to which caregivers have access appears to impact on their agency while the absence of a stable and supportive structure in government, schools, communities, families, language, finance and spouses appears to make it difficult for them to exercise agency within that weakened structure within the five domains which emanated from the data analysis, despite the identified need for support for caregivers of deaf children (Hintermair, 2006).

8.3.1. Poverty contributes to structural constraints.

This study has demonstrated that the caregivers’ experience is characterised by poverty. However, although financial constraints and economic vulnerability are dominant themes within the caregivers’ interviews, they also reveal that the poverty which they face is more than economic and extends to their difficulty escaping poverty. Their caregiver difficulties and challenges are compounded by their financial limitations. Structures such as government grants and funding are not necessarily always forthcoming or available and in this study there were repeated references to the provincial government’s poor financial support to caregivers of deaf children, especially in the light of nepotism in government.

Participants described government structures as unapproachable and out of touch with caregivers and they spoke of their children’s ineligibility for the disability grant. The disability grant to which they referred is for people 18 years and older who have disabilities and the people with disabilities then receive the grant money directly. However, caregivers of children with disabilities are eligible for a care dependency grant for their children (South Africa Government Services, 2014). It points to the inaccessibility of the structural support to which they are entitled due to the caregivers’ lack of accurate information which could result from the government’s inaccessibility as highlighted by the wariness displayed in approaching government while also pointing to the caregivers’ illiteracy as contributing to this inaccessibility because they cannot check this information.

Caregivers reported how their resource constrained context in their poor and rural setting posed challenges in accessing schooling for their deaf children. They reported a shortage of schools which cater specifically for deaf children and their children’s particular communication needs. Caregivers of children with developmental delay or with health concerns in addition to the deafness appear to face even greater structural challenges because they struggle even more to find schools for their children.

This study revealed that due to caregivers' contextual vulnerability related to poverty, gender, historical oppression, and association with disabled children together with their limited access to money, transport, and literacy, amongst others, caregivers may not be able to overcome barriers to accessing education for their children. These findings confirm that, in terms of structure:

> With few exceptions, people with disabilities face not only the consequences of poverty in accessing quality education – that is lack of resources at schools, inadequate teaching staff, teacher strikes and lack of school safety – they also face the challenge of being physically excluded from the educational environment. With too few schools operating to deal with the specialised needs of children with disabilities, and available resources being directed to enhancing the general education level, many children with disabilities are forgotten and are unlikely to be able to access the resources to enhance their own capabilities (Graham et al., 2013, p. 330).

8.3.1.1. Ubuntu is challenged.

Because of possible stigma associated with deafness and its possible conflation with cognitive disability, caregivers appear uneasy about their children's possible exclusion from society because their children are deaf and cannot communicate with hearing members of their society. The deaf children, therefore, miss opportunities for socialisation with other hearing children when families and community members are engaged in activities from which their deaf children are excluded. Therefore, it seems as though the structures which are supposed to encourage the interaction of people are not providing those opportunities because of their children’s deafness and the caregivers’ concern about others’ response to their deaf children. This possible exclusion is not congruent with the notion of ubuntu.

8.3.1.2. Caregivers of deaf children do not receive the desired community support.

Support to caregivers from their community is available but is limited within a shared context of limited resources and in a setting where deafness is not always accepted. The caregivers appear to have the need to validate the presence of the children as community members and for the child to feel part of the community in order for them to, by extension, feel supported because it seems as though the acceptance of the child is a form of support to the caregiver where the community’s non-acceptance or non-recognition of the deaf children is, by extension and secondarily, a non-acceptance of the caregivers of deaf children. This need for acceptance by the community is necessary for the caregivers because they can only enact agency on real objects, their children, and if the community do not acknowledge their children, their endeavours to enact agency may be considered non-directed and fruitless by the community if the deaf children’s presence is not acknowledged.

Community support and acceptance are very valued in this context because the community is considered an extension of the family. In this setting, community members, even if they are not biological relatives, are referred to by the caregivers in family terms through the use of terms such as sister and grandmother to refer to people who are not such but rather as terms of familiarity and of respect. However, although this support is valued and present, it is neither a certainty nor universal. Caregivers’ experience of the absence of community support may challenge their agency because they may not have that community resource upon which to structure their action and they cannot build on their own limited agency.

8.3.1.3. Family-level support is not a guarantee for caregivers of deaf children.

Even at the level of families, it appears as though, within a context of constrained resources where many people find themselves in the same financially difficult position, financial support, even from families, cannot be guaranteed or expected. Moreover, it seems as though, in the case of caregivers who have very limited resources, family structures which could potentially augment those resources become, instead, structures to which agency is devolved and this devolution removes the caregivers' influence over child care decisions because the power is held with the family members who have the financial means.

Despite the value of family support and the its potential for "cohesion, hardiness, problem solving skills, creativity" (Hintermair, 2006, p. 495), some caregivers felt that their families do not accept their deaf children. The caregivers referred to how their families' exert a sense of social control over caregivers (Thoits, 2011) when they challenge their decisions pertaining to their children. They appear to expend energy on justifying their actions and decisions to the family, particularly when the family is suspicious about where the deafness came from and the family's feeling that there may be a possible supernatural cause of the deafness when there is no family deafness. There is the sense that caregivers who may try to show agency, have that agency curtailed because they cannot expand on their limited agency due to their families' challenges to their agency and their families' misunderstanding about their children's needs, especially as it pertains to traditional and cultural practices surrounding the deaf children and the deafness. Families appear to have suspicions about the children and therefore distance themselves from the deaf children. An example of this acknowledgement comes from the siSwati greeting '*sawubona*' which literally translates into English as "I see you." So, the act of not greeting people as detailed in the results section of this study suggests that deaf children are not seen or do not exist which can remove the caregivers’ agency because they cannot be seen to be enacting agency on people whom the family do not acknowledge as existing. Therefore, if the children are not acknowledged, it suggests that the caregiver may also not be fully acknowledged which also challenges the notion of ubuntu.

The absence of family support also means that people are having to try enact agency individually and these individual attempts may mean that they cannot achieve the same effects they could have achieved if the caregivers had the family’s support thereby limiting caregivers’ agency. Therefore, the caregivers may show agency in approaching the family for support but if the support is not forthcoming, that agency may be blocked and cannot proceed into action. Even though some family members may provide logistical or financial support, those kinds of support, although useful, are not all the caregivers need. In this study, caregivers referred to the particular need for psycho-emotional support too. Although there may be a preference for support from within the family because they may be seen as more closely attuned to the caregivers’ situation (Hintermair, 2006), that may not necessarily be the case for all caregivers which suggests the need to consider that not all families interact in the same way and that family resources are not necessarily automatic, congruent, or empathic.

The composition of caregivers in this study confirmed findings from other research which explains how, within the South African context, the caregiver role is not reserved to biological parents and there is often the involvement of the extended family (Bock & Johnson, 2008; Makoni, 2008). It also reflected other findings that men and fathers may be less involved (de Villiers & Giese, 2008) as caregivers of deaf children than women (Meadow-Orlans & Sass-Lehrer, 1995). Women, especially single and unemployed women, appear to have particularly low access to agency (Zhao & Cao, 2010).

This study demonstrated how, caregivers value the support of their extended families, not only their nuclear families and it also revealed that there appears to be a preference for support from the family rather than the support from external and artificial resources. This preference may arise due to the perception of families as natural networks of social resources (Hintermair, 2006). It appears as though, for those caregivers who received psycho-emotional support from their families, they preferred the availability of that natural network resource support from the family, without having to turn to artificial networks (Hintermair, 2006) and formal structures. This preference for the family as a support resource may be derived from the intimacy and trust which is associated with families as well as the suggestion that the family members have an insight into the caregivers, the deaf child, the context, and history and that they can identify with the caregivers thereby offering support that is congruent to the caregivers' context. Caregivers seem to appreciate their family's efforts to encourage the caregivers' acceptance of their children's deafness and this family encouragement offers them agency in fulfilling their role as caregivers of deaf children because the caregivers can proceed unhindered with the task at hand of being caregivers to deaf children without expending their energy and attention on trying to foster their families' acceptance of their children.

8.3.2. Faith as a mediator of self-efficacy and agency.

Faith-related factors has previously been identified as assisting in the adaptation to deafness (Ahlert & Greeff, 2012). Similarly, this study showed that, in addition to the caregivers' faith in itself, there is reference to the support offered by the grouping of people within their faith systems and that particular system's social network support. Caregivers described how faith based social networks offer the support the caregivers require when they cannot access it in other ways, when other support systems fail them, or when other support systems are insufficient. The psycho-emotional support offered by the caregivers' belief systems does not necessarily remove their hardships or the barriers they encounter. Instead, faith-based support seems to offer caregivers hope, especially through a sense of identification and shared belief systems which may create a sense of shared understanding and empathy. The support garnered from people's faith and from their faith groupings can be useful to augment their agency in that they may feel strengthened to take action (Ahlert & Greeff, 2012).

Faith systems also offer another opportunity for agency: the opportunity to believe in their faith or not. Participants made reference to faith based practices including: cutting the children, cutting the frenulum of children's tongues, smoking and inhaling *muthi* (traditional medicinal herbs), prayer, drinking traditional medicine, and dispensing snake fat into the ears. Many of the caregivers in this study challenged the prevailing notions within their contexts by choosing not to engage in such practices or to discontinue such faith based practices, even if they had initially tried them in their efforts to best address their children's deafness. As has been highlighted in this thesis, caregivers of deaf children in rural Mpumalanga may not have many opportunities to enact agency with regard to their and their deaf children's lives, but it seems as though they have some agency in choosing not to engage in expected faith based practices. It seems as though caregivers call upon very personal resources in their decision to not engage in certain practices and it seems as though it could be an opportunity for them to engage in a psychological agency in their decisions, regardless of the social pressure to engage in such practices. They may experience some opposition to their choice of not adhering to faith systems, but decisions around faith are attempts at acts of agency which they can exercise.

Caregivers explained how suspicions about the causes of deafness, such as bewitchment, result in unease in the community. Some caregivers feel that, in order to protect their children, they may have to hide and lock their children in their houses so that their neighbours do not know that they have deaf children because children with disabilities may not be accepted in the community. Deaf children's status as '*pewu*' is a cause for unease in the caregivers because it is a threat to the support from the community due to the associated stigma and suspicions about the cause of the deafness in the children. Due to these faith-related structures, in the assumption of the caregiver role, caregivers, both biological parents and other caregivers, explained how they had to convey to their community that their children are supernatural gifts so as to reduce unease around their caregiver role and their children's deafness. The caregivers appear to have done so in order to try foster acceptance of their deaf children (Ahlert & Greeff, 2012). However, this assertion by caregivers that their children are supernatural gifts may, in itself, perpetuate other people's suspicions around the supernatural dimension to the deafness.

The diagnosis of children's deafness may result in caregivers questioning their faith and they may experience a sense of supernatural abandonment. It appears as though certain faith system practices can challenge caregivers' agency when caregivers feel pressured to engage in practices which cause them unease or when they engage in these faith-based practices out of desperation to address their children's deafness rather than their belief in them. Caregivers explained how they accept their children as gifts from God and as supernatural gifts which may be a personal psychological resource so as to accept the challenges that come with the caregiver role (Ahlert & Greeff, 2012) and in order to garner strength from that acceptance of the gift in their caregiver role.

8.3.3. Caregivers' gender is a structure which impacts on their experience.

This study confirms that the caregiver role is gendered in the assumption of the caregiver role as well as in the devolution of the role where grandmothers and aunts appear to step into the caregiver role, notwithstanding the financial strain on them and their existing families. Participants also spoke of paternal absenteeism and absent spousal support. This finding points to the vulnerability of women and the expectations placed on women, especially single women (Meintjes & Hall, 2013). The results of this study confirm that women are expected to forego their lives and move to look after the deaf children and the participants spoke of absent fathers or uninvolved fathers. Women caregivers spoke of the expectation placed upon them to juggle the role of caregivers to deaf children with their other roles within their families and society. Especially with regard to their hearing children, caregivers spoke of the need to mediate between their deaf children and their hearing children in terms of fostering acceptance and understanding of the deaf children by the hearing children, even more so when the deaf children move into the house when the caregivers assume the caregiver role over children who are not their biological children.

This study confirmed the value of spousal support and the intensification of the caregiver challenges without that spousal support especially from the fathers of deaf children (Hintermair, 2006) and that the non-support of spouses can negatively impact on self-efficacy (Bandura, 1982). The findings of this study suggest that spousal support did not need to be from the children’s biological fathers but from father figures and men who assume the role of the children’s fathers. It appears as though mutual decision making between spouses gave the caregivers more agency because they could feel more confident in their decisions which came about due to discussions between the spouses and it suggests a collaborative effort with regard to the caregiver responsibilities and a sharing of the load. The spouses’ involvement in the children’s lives together with an acceptance of the children’s deafness and unconditional love seemed to support the caregivers themselves and this acceptance of the children may enable caregivers’ agency in that they feel empowered and strengthened by this support, even if the spouses are not the deaf children’s biological parents.

Caregivers, especially women caregivers, in the context of this study where there are accepted male and female roles (Goudge et al., 2009), who did not receive spousal support, seem to feel alone and therefore appear to have a weakened sense of agency. In their caregiver roles, they have to fulfil multiple responsibilities, which can add to the caregivers' stress (Hintermair, 2006) and they have to assume responsibilities and roles that could have been shared with their spouses. Female caregivers' agency appears to be further limited because there may be some roles which they cannot fulfil as they are deemed to be masculine role. However, out of necessity, these have to be performed by women caregivers. The assumption of gendered roles and responsibilities is a show of agency by the caregivers but, in this study demonstrated that such agency may be restricted in the eyes of the community when they do not agree with such actions and assertiveness. The power which men hold in this rural context where the study was conducted can influence the way women are able to act and "the less they bring their influence to bear on others, the more control they relinquish to them" (Bandura, 1982, p. 144). It seems as though the fathers' non-acceptance of their deaf children may be taken out on the children's mothers and so they have to contend with the challenges of the caregiver roles as well as the resultant spousal conflict and power.

8.3.4. Tenets of qualitative research are opportunities for supportive structure.

Besides the established structural mechanisms, this study emphasised the role of research itself as a structure, specifically qualitative research. The potential to enhance caregivers' self-efficacy and agency may come from the opportunity to establish life-plans and set goals that comes from the reflexivity offered by interviews (Côté, 1996). Participants in this study referred to the beneficial aspects of the qualitative approach used in this study and the interviews in particular in being able to talk about their experience. This reference suggests that the qualitative approach, ethnographic interview, and snowball sampling technique may have validated their experience and gave them the opportunity to reflect on their caregiver experience. The favourable references to the interviews intimate to their value "as an emotion-focussed coping strategy" (Funk & Stajduhar, 2009, p. 861). The qualitative approach seems to be in tune with the notion of ubuntu and the recognition of the humanity of people and their collaborative contribution to research endeavours rather than focussing on their value as research subjects and devoid of intrinsic, personal, and experiential worth.

This finding is in line with the qualitative and participatory nature of this project which acknowledges that the research process is a collaborative one and where meaning is co-created (Denzin & Lincoln, 2011). It also suggests the need for the inclusion of researchers in the field of deafness into a broader COP as, by its definition, a COP includes all people interested in the phenomenon, and in this case, the phenomenon of childhood deafness. However, within this community of practice there is a need to maintain a power balance so that the COP does not become an opportunity for researchers to use it for research only but so that the input is equal and contributory.

Caregivers in this study said that, unlike the government's dis-identification with its people and its imposition on caregivers without personally engaging with them, this project with its qualitative leanings and its respect for people and contexts, could serve an example to government of how to support caregivers. The participant caregivers seemed to appreciate the researchers' active seeking-out of caregivers of deaf children and speaking to them about their experience and suggested that, this way, their experience is being validated and recognised.

They referred to the interview as a unique opportunity for them to talk about their experiences as they do not seem to have similar opportunities at other times and the interviews themselves were described as activities which ought to be conducted with other caregivers of deaf children because of the benefit they offered. It seems as though, especially in this context where such opportunities may be lacking, "women in resource-poor settings, for example, who do not generally have access to interventions of this kind may react positively to an intervention merely because they had access to one" (Mundell et al., 2012, p. 183). Also, the particular interest and attention from the university in itself may have carried weight with caregivers and given validation to their experience is given credibility.

Moreover, the potential benefit to the caregivers' agency through their participation and contribution to research became apparent in that the caregivers get the opportunity and structure in which to discuss their experience and to cognitively explore possible action they can enact as a result of reflecting on their caregiver experience (Coleman & Karraker, 1997). This thesis does not insult the participants and caregivers in general by suggesting that they do not think about their experience: they cannot escape that reality and they live it daily, constantly. Instead, I suggest that the interview offered a mediated and safe space for caregivers to verbalise their experience which can have a transformative effect. This study confirms the value of the interview as transformative (Squire, 2009) in that participants are empowered with "vitalities and capacities with which to understand and negotiate the various social, occupational and personal obstacles and opportunities they are likely to encounter" (Côté, 1996, p. 426) as exemplified by the participants' responses in the results section of this thesis.

Through the snow-ball sampling and the group interviews, caregivers got to meet other caregivers of deaf children thereby creating a new social network of caregivers of deaf children who can serve as resources for each other and could grow their agency. Because this project interviewed caregivers from across the whole district, caregivers from different parts of the district were able to interact, an interaction which may not have occurred otherwise. The age range of their children meant that caregivers of older children could share advice and information based on their experience with caregivers of younger children who have very little experience with childhood deafness. This opportunity for caregivers to broaden their social support network has the potential benefits of "accessibility, resistance to depletion, variety of perspective, breadth of information, and facilitation of personal change" (Vaux, 1990, p. 515).

Their participation in this project broadened caregivers' social network in terms of the number of people they met but also the diversity of experience and abilities. For example, the inclusion of deaf caregivers in the sample meant that caregivers could interact with deafness in adults and envisage their deaf children's potential for participation and contribution in adulthood because previous research has suggested that hearing caregivers "expressed positive feelings about the advantages of a group that included deaf parents, noting that they learned a great deal from them" (Meadow-Orlans & Sass-Lehrer, 1995, p. 322). It is acknowledged that "many individuals find participation in research a positive experience personally in that it gives them a chance to express their opinion or unburden themselves to a sympathetic outsider" (Davies, 2001, p. 48) without necessarily creating a "pseudotherapeutic relationship" (Ramos, 1989, p. 59) between the interviewer and the participant. Participants may find themselves in a position where "they become empowered" (J. S. Jones, 2010) and the interview "can be both empowering and illuminating because one can reflect on and speak about one's life in ways not often available" (Miller & Glassner, 2004, p. 132).

Participants have their lived experiences whether they choose to participate in research or not but participation may have opened an opportunity to reflect on it (Miller & Glassner, 2004). This re-presentation of their experience appears to have offered participants the opportunity to verbalise their experience in a way that could not be done with a familiar audience since this familiar audience has already shared in the experience and in the presentation of the experience, not its re-presentation. I am suggesting that through the language and culture mediator, the participants could be given the opportunity to re-present their experience to a new audience. Moreover, although the value of the mediator was acknowledged from the outset of the study, her participation in the interviews proved that she served more than the role of mediating cultural and language aspects. Her knowledge and familiarity with the context meant that she was mediating history, gender, race, ethnicity, life-world, and caregiving experience, not just language and culture. Her contribution confirmed the valuable role of the mediator in qualitative research to appreciate the contextual nuances and re-affirmed the need for contextual congruence in the mediator role over and above familiarity with the culture and language.

8.3.5. Self-Efficacy and Agency.

The thesis confirmed that agency is the complex and socioculturally mediated capacity of people to exert power or produce an effect within their contexts and with available resources, is related to history while oriented to the future, and is most completely achieved when it can be enacted for others and not only the agents themselves (Ahearn, 2001; Emirbayer & Mische, 1998; Luck & d'Inverno, 1995; Sewell, 1992). Very importantly, this study also showed how self-efficacy and parental self-efficacy in particular is reduced in contexts of disadvantage and vulnerability, as is the case with deafness. It was revealed that, for caregivers of deaf children, self-efficacy as a mechanism of agency is constrained in the five domains described earlier but it also confirmed that it is “dictated largely by the types of behaviours involved as well as by the environmental context” (Coleman & Karraker, 1997, p. 51). Caregivers are agents who are expected to act for other people, in the case of this study, their deaf children. However, they are constrained in their agency because this context and its structural insufficiencies, restricts their ability to be agents who “are capable of putting their structurally formed capacities to work in creative or innovative ways” (Sewell, 1992, p. 4).

Even though access to human and nonhuman resources can be considered to enable agency (Sewell, 1992), caregivers in this study revealed that weak structural support disables their self-efficacy. The link between the self-referential constructs of self-efficacy and self-agency (Coleman & Karraker, 1997) suggests that, because of their reduced self-efficacy in the different domains, women especially, are not able to enact agency. In the context where this study was conducted, there appear to exist power differentials between men and women and women caregivers may experience particular challenges to the growth of self-efficacy because they may not be able to exert control over their experience, a necessary component of self-efficacy (Bandura, 1982).

Caregivers' repeated instances of constrained agency in this may create a sense of despondency within the caregivers. They seem to express a sense of fatalism about their circumstances and the multiple roles which they have to fulfil (Coleman & Karraker, 1997). Although there may exist opportunities to re-envision their agency through vicarious experiences (Bandura, 1982), the caregivers' experience of this sense of despondency cannot be dismissed because, for caregivers of deaf children in the Ehlanzeni District, they cannot seem to enact change. Due to the structural imbalances within their contexts and histories, they do not have the power to bring about change and therefore may struggle to fulfil their caregiver roles: they cannot envision a different outcome. Their agency, therefore, may be compromised by their low sense of competency which contributes to the stress of the caregiver role (Hintermair, 2006; T. L. Jones & Prinz, 2005).

8.3.6. Unemployment impacts on caregivers' sense of self-efficacy and agency.

This study highlighted unemployment as a structural restriction to caregivers' self-efficacy and agency. It has been reported that people who are unemployed may experience greater challenges relating to their agency than people who are employed (Zhao & Cao, 2010), a finding supported by this study which went on to show that these contextual factors in the caregivers' lives resulted in the need to devolve agency, especially by unemployed, single women caregivers. Caregivers explained how their agency is reduced when they have to ask others to fulfil certain roles for their deaf children on their behalf. A pervasive sense of helplessness in their agency with regard to envisaging a different future as well as a heightened vulnerability and survival anxiety was noticed in the caregivers' experience, characteristics associated with low self-efficacy (Coleman & Karraker, 1997). Their unemployment removes their agency in providing for their families which may result in an undermining of their confidence and sense of ability (T. L. Jones & Prinz, 2005) to be capable caregivers.

Although this study suggests that caregivers' unemployed status may reduce their agency in fulfilling their caregiver role, a finding which is consistent with other research in this rural district of South Africa (Goudge et al., 2009), employment and access to finances do not guarantee the employed caregivers absolute agency with regard to financial matters. Caregivers of deaf children incur costs related to their children's deafness which caregivers of hearing children do not incur and so the employed caregivers of deaf children may have less relative disposable income because of their greater expenditure with regard to their children's deafness. Unlike the highly vulnerable unemployed caregivers, when the employed caregivers spoke about their financial limitations, they referred to the deafness aspects which suggests that they are able to address their children's basic and necessary care needs. It also suggests that they require structural support in the provision of deafness related aspects and also alludes to their relative agency in addressing their children's needs in relation to the unemployed caregivers.

Within this rural context, previous research has shown that caregivers who may be employed and financially stable have to adjust their spending to account for the additional costs they now incur with regard to, for example, the long distances that they have to travel to hospital appointments (Goudge et al., 2009) which destabilises their financial stability. Therefore, even though caregivers who are employed have relatively more financial agency than unemployed caregivers, they still encounter financial constraints. Caregivers of deaf children seem to experience relatively greater poverty because they have additional costs which the other caregivers do not. These costs may include repeated appointments, hearing aid aspects not covered by the state, time away from work, ineligibility for financial subsidy, transport costs, additional schooling costs, and the costs associated with residential schools far away from home. Although poverty is at the nexus (Graham et al., 2013) of the interaction with disability and, therefore, cannot be ignored in understanding deafness, even employed caregivers' agency is reduced because of their reduced self-efficacy in relation to deafness particularly. The employed caregivers' financial concerns and challenges only serve to further highlight the vulnerability of the caregivers who are unemployed. Moreover, when the unemployed caregivers see what agency the employed caregivers possess, their unemployment status may further reduce their percepts of self-efficacy and, therefore, inhibit agency by reinforcing their possible sense of inadequacy in providing for their children in comparison to other caregivers (Coleman & Karraker, 1997).

8.4. Role reversal impacts on caregivers' sense self-efficacy and agency

During the interactions with caregivers of deaf children, they described occasions when roles became reversed in various domains of their experience. Due to their reported difficulties in communicating with their deaf children, hearing caregivers related how they devolve communication to others. However, caregivers' devolution of communicative agency takes a particularly poignant dimension with regard to deafness when they have to devolve their agency in communicating with their deaf children to other children. This devolution of adult roles to children has inherent power differential dynamics which may threaten caregivers' agency and create a sense of unease in that reversed power status. Therefore, a role that ought to belong to the adult caregivers', the role of proficient language users, is now diminished and caregivers have to rely on other children to serve as intermediaries. They, as adults, seem to experience a reduction in their agency and empowerment because they have to call on children to perform a task which they see as theirs.

The asymmetry in language abilities between the deaf children and their hearing caregivers creates a situation where the children and caregivers experience a role reversal in the teaching of language. Besides the effects on agency associated with communication, it also impacts on the family's role as a socialisation structure and "how social change affects the relationship between socialisers and socializes, thereby influencing cultural continuity" in which children become teachers to their caregivers and where the caregivers' identity can consequently be jeopardised (Côté, 1996, p. 418).

Usually, adults teach language to children. However, deaf children themselves seem to take the role of teaching their caregivers language. Because the children learn SASL at school, learn in SASL, and communicate in SASL, they know more SASL than their caregivers and so they have to teach SASL to their caregivers. This role reversal arising from the caregivers limited personal and other resources to learn SASL may reduce the caregivers' agency because the role that is usually theirs has now been devolved to their deaf children.

In the case of hearing caregivers who communicate via a different modality to their deaf children, it appears as though it results in a prefigurative culture where the children assume roles of teaching caregivers (Côté, 1996). This prefigurative culture may put a considerable strain on the relationship between caregivers and their children because caregivers, due to low self-efficacy in the communication domain, are denied their agency in conveying family values, traditions, customs, histories, and anecdotes that have been communicated between generations.

The caregivers’ sense of self-efficacy is further threatened through role reversal when children, through their receipt of financial grants, fulfil the role of financial providers when unemployed caregivers are unable to do so. The caregivers’ inability to provide financially for their children may challenge the caregivers’ notions of their worthiness, competence, and personal control (Coleman & Karraker, 1997). There is also the sense that the caregivers’ unemployed status and subsequent reliance on their children’s financial grants means that they are not fulfilling their roles as providers for the deaf children which also detracts from their sense of agency and may present in a form of individual anomie and unease related to the caregivers’ prevailing socio-economic context (Zhao & Cao, 2010).

It seems as though the financial grants get used for other purposes, for “survival costs” (Graham et al., 2013, p. 331) incurred by feeding and clothing the rest of the family and not specifically for their deaf children which suggests an element of agency in the bigger picture where other children, not just the deaf children, benefit from the financial grants intended for the deaf children. This study confirms that caregivers have to make very difficult decisions which can leave them uneasy about the necessity to spend the money meant for their children’s deafness needs on their family’s survival.

8.5. The multiplicity of caregivers’ responsibilities challenges their sense of self-efficacy and agency

Caregivers appear to struggle in ensuring their children’s health and have significant concerns about their children’s wellbeing. Within this district, health access is limited and caregivers may feel that they are not fulfilling their caregiver role in ensuring their children’s health and wellbeing. Despite the general anxiety around their ability to fulfil their caregiver responsibility of ensuring their children's safety, caregivers of deaf children appear to have particular concerns about their children's safety because of their particular deafness-related vulnerability. Because of their children's deafness, caregivers are concerned that they cannot protect their deaf children and they are, consequently, hyper vigilant in this regard which contributes to their constant sense of unease. Caregivers, therefore, appear to have very little agency in protecting their children because of the general safety concerns in this district, but specifically with regards to their deaf children and this absent agency results in their sense of unease.

Within this rural context, the very long distances, hundreds of kilometres in some instances, which caregivers and their children have to travel take on a particular dimension. This district and the caregivers' places of residence are characterised by untarred roads, hilly terrain, potholes, rain-induced soil erosion of the roads, and limited public transport services as well as limited financial resources with which to access transport facilities may limit their agency in this regard. Furthermore, their lack of access to personal and private transport may limit their agency to make appointments and attend appointments when it suits them or when they are able to. These geographical and logistical challenges with regard to the caregiver experience may mean that, besides impacting on the caregivers, deaf children may not access these different medical, audiological, and other services which may then become embodied in the children's development because the children did not have access to the services the caregivers were trying to access on their behalf.

The high incidence of HIV/AIDS in South Africa and in this district adds particular responsibilities to the caregivers' already loaded role. Because of their and their children's HIV/AIDS, they have to attend more medical appointments, they have to attend to HIV/AIDS related responsibilities, and deal with the stigma in their community around HIV/AIDS. These additional responsibilities which are loaded onto the caregivers may result in their need to devolve their agency because they may face even greater challenges to agency in their fulfilment of the caregiver role than the caregivers who do not have to address HIV/AIDS responsibilities in their caregiver role, especially if the caregivers themselves have HIV/AIDS.

The caregivers' experience is heavily laden with their concerns about their own wellbeing and death. The setting where this study was conducted has a reduced life expectancy (Goudge et al., 2009) and this concern about their death results in sense of unease in the caregivers about the impact of their death should they die before their children are grown up and independent. This particular concern appears to be gendered towards women as caregivers in this study who appear to be very concerned about their death and what impact that would have on their children and there is a sense of unease which accompanies these thoughts about what will happen to their children should they die, not to mention the embodied physical manifestation of that unease. There is also a very palpable unease about their deaf children's independence if the caregivers should die.

8.6. Caregivers' self-efficiency and agency are influenced by language and literacy

Caregivers' agency in their caregiver role appears to be mediated by their ability to communicate in a spoken language other than their home language, especially English. The fluent and successful use of English appears to be especially agency-enhancing with regard to their children's deafness because caregivers are then more able to precisely detail the audiological and medical aspects of their children's deafness which suggests that they may understand and explain their children's diagnosis more completely, especially in a context where there is a great deal of suspicion and mistrust around deafness. Subsequently, with this information, it suggests that caregivers can use the relevant terminology consistently across settings so that when speaking to different medical or allied medical personnel, they can reflect more accurately the events and actions from the other appointments.

The corollary of this enhanced agency offered by the proficient use of English is that there appears to be a reduced agency by caregivers in communicating with hearing care personnel because of their limited access to the language and terminology of their children's deafness in English. Because language, culture, and society are mutually constituted, unequal power relations can result in symbolic violence, that is symbolic power and symbolic domination (Ahearn, 2001, pp. 110-111), to which caregivers in this context are susceptible. Caregivers appear to have communication difficulties in communicating with other people, not just with their deaf children. This communication challenge arises from a mismatch between the languages spoken by the caregivers and those spoken by hearing care personnel, which, it could be argued, creates in both parties, the caregivers and the hearing care personnel, a disabling effect. The services of language and culture mediators are therefore required to facilitate communication between the two parties and this "third-party translation" (Esposito, 2001, p. 568) may create in hearing care personnel the sense of a third-party disability which arises from an inability, or even disability, in understanding other people's languages, the nuances of the language, and the meaning conveyed by people for which there is the need for the services of mediation, or even assistance.

Caregivers' agency appears to be threatened by literacy demands too, especially amongst older caregivers who, due to historical and contextual factors, may have limited literacy. The caregiver role appears to require literacy in order to communicate with their deaf children as exemplified. These demands on the caregivers' ability to read may contribute to their sense of lack of agency in fulfilling their caregiver roles in that they are not able to meet these demands placed on them and their need to devolve agency. Were the caregivers more literate, there could be more opportunities for agency since

> investment even in basic education has been shown to have a dramatic impact on other development outcomes such as overall mortality, child mortality, fertility rates and economic growth. But education is seen as integral as a freedom in and of itself and not simply as a means to an end, since education contributes to the ability of 'people to help themselves and also to influence the world' (Graham et al., 2013, p. 329).

8.7. Similar Others and Community of Practice

This study revealed that the support from similar others transcends support from formal support sources because it seems as though caregivers appreciate the empathic and shared understanding of their experience. The literature suggests that support from enhanced social networks (Hintermair, 2009), especially from similar others (Thoits, 2011) and communities of practice (Moodie et al., 2011) can offer structural opportunities for agency empowerment when "enough people or even a few people who are powerful enough act in innovative ways, their action may have the consequence of transforming the very structures that gave them the capacity to act" (Sewell, 1992, p. 4). The idea of community support, especially amongst caregivers of deaf children, could reinforce the value of a community of practice, a "structural unit that can easily be viewed as both constitutive of, and constituted by, its participants" in mutual endeavour (Ahearn, 2001, p. 127) through collective action (Moodie et al., 2011) and is in alignment with the concept of ubuntu, which in this setting, may not always be attained due to the limited resources within the community.

The caregivers who participated have a shared history of oppression under apartheid and live the fall-out and consequences of that hurtful policy. Through their shared history and shared understanding, there appears to be a social assonance where, in this context, they have a shared contextual identity which precludes their need to explain their poverty and its consequential embodiment and third-party disability to each other since they all experience these consequences in different forms.

8.7.1. Validation of the caregivers' contribution by similar others can boost their self-efficacy.

Besides the very real and tangible constraining effects on self-efficacy agency which the caregivers of deaf children may experience within their contexts and structural limitations, the caregivers' role with regard to their deaf children may also offer opportunities to boost their agency. The caregivers spoke of the growth that comes with this role of being caregivers to deaf children when they said that they learn from their own experience and grow in that regard which they can potentially share the insight which they develop from their experience with other caregivers of deaf children. Furthermore, caregivers gained social recognition for their caregiver role and that recognition could be beneficial to their agency because the social recognition could serve as a structure on which to build the foundation of agency, especially in their attempts at being caregivers within particularly constraining contexts.

Through this vicarious experience (Bandura, 1982), caregivers with high self-efficacy can model strategies and adaptations and offer the opportunity for caregivers with lower self-efficacy to learn from and emulate those positive strategies (Coleman & Karraker, 1997). This validation from their community and society can serve to enhance their sense of capability and agency within their limited structures and can also serve as reinforcement for the good that they are doing which can strengthen them in their caregiver roles, especially because "this sense of 'altruism' is a powerful therapeutic tool that can greatly enhance a member's self-esteem and feeling of self-worth" (Mundell et al., 2012, p. 183).

8.7.2. Support from similar others can enhance ubuntu.

The support from peers offers the potential for COP and for ubuntu. Caregivers in this study expressed a desire to engage in a type of vertical consultation with formal structures such as government, social workers, and hearing care personnel. However, they do not seem to recognise the value and benefit of a type of horizontal engagement that is available from their peers and similar others (Thoits, 2011) through other caregivers of deaf children. Caregivers in this study spoke of how their agency can be enhanced by interacting with other caregivers of deaf children and alluded to the potential for the support from similar others to operate within a COP. During their interviews, caregivers referred to the potential to pool resources and to demonstrate collective efficacy (Bandura, 1982) amongst similar others and to express agency through these collective resources and from each other's experience in order to counter collective powerlessness (Bandura, 1982; Coleman & Karraker, 1997) and to effect the change their context. There was also a call by caregivers in this study for greater displays of self-efficacy when they expressed their need and desire to bolster resources and strength within themselves so as not to rely on inefficient or inaccessible structures such as government and hospitals. This study also revealed that these potential networks may already be in place, although they appear to be informal and may not be recognised by caregivers themselves.

Through similar others, caregivers have the opportunity to express intra-group ubuntu amongst caregivers of deaf children in which caregivers identify with each other, support each other through their identification with each other's' feelings and experiences. They said that they can support each other emotionally by providing an attentive ear to hear other caregivers' concerns because they are similar others and peers. Caregivers referred to how they have the duty to accept other deaf children as theirs too and spoke of the collective responsibility of caregivers for assisting other caregivers, especially grandmother caregivers who may have more limited literacy and other resources, which also fits with the notion of ubuntu.

However, despite caregivers' reference to the potential benefit and agency enhancing effects of peer support from similar others, this support from similar others may not necessarily always be available. In the interviews, caregivers referred to their inability to share their resources and contribute to the needs of other caregivers due to their own limited resources and access to resources. Therefore, when caregivers find themselves in a position of not being able to support themselves, they find it difficult to support other caregivers of deaf children. As a result, caregivers' expressed a sense of helplessness and fatalism. These findings confirm previous research which has shown that a reduced sense of the external locus of control in caregivers may add to the stress of their experience (Hintermair, 2006) and may reduce self-efficacy (Coleman & Karraker, 1997) which is contradictory to the notion that ubuntu is practiced due to obligation to others in the community.

8.8. Devolution of Agency

Caregivers' absent or reduced agency results in their reliance on other people to act on their behalf within the different domains identified in Chapter 7 and they, therefore, appear to devolve agency especially within their contexts because "agency was not ontologically prior to that context but arose from the social, political, and cultural dynamics of a specific place and time" (Ahearn, 2001, p. 113). The caregivers in this study seemed to have to devolve their agency across domains while, at other times, they were recipients of the devolved agency from others. This devolution of agency is distinct from seeking assistance from others in accomplishing tasks: devolution suggests that, due to their structural constraints and subsequent limited agency, caregivers need to devolve their caregiver roles across domains to others. However, this devolution of agency is an act of agency in itself where caregivers have to, despite their reservations about doing so, approach others to act on their behalf.

Caregivers seem to capitalise on their abilities and the resources in their possession, no matter how limited, to enact agency within their capabilities. There is a devolution of agency when the demands on them exceed their ability to meet those demands (Bandura, 1982; Coleman & Karraker, 1997). This devolution is an adaptation to their context so that their children's needs can be met through their manipulation of accessible structures. During the interviews, it was conveyed that there is the need to shift the agency from other structures to the caregivers themselves by utilising the structural support that is available, rather than passively awaiting for other structures to act on caregivers' behalf.

The results of this study suggest that the caregiver role appears to be devolved out of necessity where caregivers' sense of despondency and sense of reduced competence may result in the devolution of caregiver role in the different domains. Caregivers may feel that they are unable to completely fulfil their role, especially because of the embodiment of their structural limitations even though this devolution can restrict their own efficacy due to their reliance on others (Bandura, 1982).

This study also showed that the assumption of the overall caregiver role is characterised by devolution of the caregiver role to others, for example, by biological parents to other caregivers or by caregivers to other caregivers due to the caregivers' death or due to abandonment of the deaf children by the children's parents or other caregivers.

8.8.1. Communication between hearing caregivers and deaf children.

Caregivers in this study said that, due to asymmetries in their communication with their deaf children, they need to use intermediaries to communicate with their children and that they have to devolve communication to others because of the discrepancies between the caregivers' and children's communication modes and abilities as well as their reduced self-efficacy in using SASL. This devolution of agency to others may compromise hearing caregivers' sense of agency and their sense of worth because they cannot communicate with their deaf children or teach language to their children, roles usually ascribed to caregivers

Within a context of insufficient or unavailable structural support systems for them to learn SASL, especially when the communication relates to more complex topics results in the caregivers' need to devolve those conversations to other people. Caregivers lamented that they have to entrust the responsibility of communicating very personal and intimate conversations to others because they cannot communicate with their deaf children. They especially seemed to express a concern about devolving these responsibilities to strangers or people outside of their family. Devolution of communication can be considered as detracting from the caregivers' agency and they experience unease which comes from that devolution, as well as a third-party disability related to their inability to communicate with their children.

Nonetheless, caregivers felt that the devolution of teaching of deafness related topics and SASL at hearing schools can assist with the socialisation of deaf children within the predominant hearing society so that hearing children can learn to communicate with deaf children and accept deafness, thereby reducing the unease in the community about deafness and, thereby, reducing the caregivers' anxiety about their children's acceptance in society.

8.8.2. Conditions of poverty and limited resources necessitate devolution of agency.

Within a context of poverty, ecological disadvantage (Coleman & Karraker, 1997), and insufficient deafness-related infrastructure, where the domains of the caregivers' experience around deafness are interrelated, interconnected, and cascade into each other, caregivers seem to feel overwhelmed. With regard to deafness, "the diagnosis usually creates turmoil and anxiety. Questions about the exact nature of the loss, educational and communication options, and expectations for achievement often leave parents confused and overwhelmed" (Meadow-Orlans & Sass-Lehrer, 1995, p. 326).

Caregivers' financial constraints were found to be an influence in their need to devolve agency. The structures which are meant to provide financial support to caregivers of deaf children, and thereby enhance the caregivers' agency in providing for their children, appear to fall short of their remit. For caregivers who find themselves unemployed and in very difficult financial situations, structures such as government and family do not offer consistent opportunities for agency growth: instead caregivers are in such a difficult financial position that the devolution of agency is necessary for survival. When parental self-efficacy is exceeded, there is a tendency to give up and to transfer responsibility to structures which are perceived to be more capable (Hess et al., 2004) which was demonstrated in this study where caregivers seem to have resigned themselves to their circumstances and there is a sense that they do not have the financial means and capacity with which to provide for their children. They, subsequently, feel that they have to use government financial support in order to fulfil the roles which they are expected to fulfil.

Similarly, with regard to schooling, caregivers appear to be unfamiliar with the schooling options for their deaf children and they devolve agency to their family and community structures. Unfamiliarity of situations reduce the potential for agency because of a reduced sense of self-efficacy (Bandura, 1982). This sense of being more approachable can be agency-enhancing because there may be less trepidation and greater identification with similar others in the family and the community. Moreover, the familiarity of the family and community members with the caregivers' experience and context seemed to facilitate the caregivers' agency because they were able to identify with the caregivers' needs and their available resources and relate to their vulnerability.

Due to their unfamiliarity with deafness and because of the inadequate formalised and routine hearing screening processes for the identification and confirmation of the suspected deafness, hearing caregivers appear to devolve the role of identifying their children's deafness. Current caregivers of deaf children are not necessarily the children's biological parents or were devolved the caregiver role by other caregivers who forewent the caregiver role. The current caregivers did not notice the deafness because they did not know the children from birth or were not familiar with the children's abilities when they assumed their caregiver role. Caregivers in this study suggested that the early identification of deafness would have been of benefit to them because, as has been reported, "early diagnosis and intervention seem to be the best prevention strategy against stress for the parents of deaf and hard of hearing children" (Hintermair, 2006, p. 498).

As has been highlighted throughout this thesis, poverty is a distinguishing feature of the Ehlanzeni District (Harris et al., 2011) and the experience of participants in this study reveals that unemployed, female, single-parent caregivers are especially financially vulnerable. Consequently, the caregivers of deaf children have to devolve their financial agency to government structures for the provision of clothing, food, schooling, and medical intervention to their deaf children, responsibilities usually associated with the caregivers themselves. Therefore, this thesis demonstrates that, in this context, structures impact negatively on caregivers' agency and that, out of necessity, they capitulate to the structural limitations and have to devolve their agency which participants said resulted in a third-party disability when they described the physical and psychological manifestations of that devolution and their caregiver experience. Moreover, caregivers' spoke of the mistrust of formal structures which may have arisen from their repeated negative experiences of those structures. These repeated attempts to bring about change and the considerable delay in seeing change may discourage caregivers from acting again because of their previous inability to succeed in their agency (Bandura, 1982).

8.8.3. Caregivers' own disabilities require devolution of their agency to act on behalf of their deaf children.

It appears necessary to consider caregivers' who have disabilities because their disabilities may impact on the fulfilment of their caregiver role. They have to show particular agency in addressing their caregiver challenges within a context of poverty, limited resources, and structural barriers. This thesis has outlined the particularly challenging experiences of caregivers of deaf children. However, for caregivers with disabilities, these challenges may be compounded and they have to show additional agency in addressing their disabilities in relation to their caregiver roles. For example, as presented in the results chapter, the two deaf mothers said that their deafness facilitated communication with their deaf children. However, their deafness poses challenges when they have to communicate with hearing people about their deaf children which suggests that at home and within the Deaf community they may not be considered disabled but that they are considered so in other settings. Caregivers who have disabilities, therefore, also have to overcome society's perceptions about their disabilities.

The caregivers' own disabilities together with their children's deafness adds another dimension which may impact on their sense of agency in completely and most adequately fulfilling their caregiver role where their own disabilities may require that they devolve certain roles to others which may even further detract from their vulnerable agency. Therefore, caregivers' disabilities, although not preventing them from carrying out their caregiver activities, could have a reduced sense of self-efficacy which could reduce caregivers' sense of agency in fulfilling their caregiver roles, especially if they have to devolve their caregiver roles to others because they cannot always enact agency within the structures available to them.

8.8.4. Caregivers of Deaf Children Experience Embodiment and Third-Party Disability

This thesis has followed a qualitative and contextually considerate approach in order to better understand the experiences of caregivers to deaf children in the Ehlanzeni District of Mpumalanga because “the people we study are simultaneously social beings and biologic organisms – and we cannot study the latter without taking into account the former” (Krieger, 2007, p. 658). It is acknowledged that there are social and ecological dimensions to human experience (Krieger, 2005) and, therefore, when interrogating aspects related to deafness, the same would apply. Mindful of this potential embodiment of context, caregivers in this study provided examples of such embodiment of a third-party disability, that is, they described the impact of their children’s deafness on other people in the deaf child’s context. More specifically, third-party disability describes the disabling effects of one person’s disability on those around that disabled person (Scarinci et al., 2012; WHO, 2007).

It appears as though the children’s deafness, experiences, and needs become embodied in the caregivers too across the domains identified in the data analysis. Their children’s deafness, experiences, and needs become physically manifest in the caregivers which suggests that caregivers may experience a third-party disability in that they experience a transfer of the children’s disability arising from the deafness and its related aspects.

8.8.5. Caregivers of deaf children experience third-party disability through exclusion.

This study demonstrated how caregivers of deaf children experience third-party disability subsequent to their exclusion. They seem to experience a sense of anomie or alienation (Veehoven, 2008) from their society or community because of their children's deafness or from society's suspicious engagement with deaf children and with their caregivers. Therefore, their social conditions have become embodied and they may experience a subindividual (Ahearn, 2001) conflict, an internal unease linked to an embodied sense of "anxiety and deflated self-esteem" (Hoffmeister & Harvey, 2009, p. 88). Their capacity to act, consequently, may not match the demands placed on them which becomes embodied in the experience of third-party disability by the caregivers of deaf children. During the interviews, employed and unemployed caregivers spoke about the restrictions on their agency to find and to keep employment due to their caregiver responsibilities to their deaf children notwithstanding the high unemployment and poverty endemic to the area for all people (Harris et al., 2011; Mpumalanga Department of Finance, 2014). Previous research suggested that elderly spouses may experience such a third-party disability (Scarinci et al., 2012), but this thesis has demonstrated employment difficulty for younger caregivers who, because of the time and the extra input required for their deaf children, are excluded from employment.

This exclusion is compounded by the caregivers' attendance to their children's general developmental and health needs, including HIV/AIDS treatment. It seems as though caregivers of children with other disabilities or health concerns in addition to the deafness may be even more susceptible to higher stress (Hintermair, 2006) which may contribute to their experience of third-party disability. The need for caregivers' attention to their deaf children impacts on the already stressful activity of seeking employment within an economically and employment depleted context such as the one where this study was conducted and where the caregivers live and confirms that the context contributes to the third-party disability (Scarinci et al., 2009).

Caregivers' own experience of exclusion from schooling opportunities during apartheid seemed to cause them unease. They seemed to identify with their children's vulnerability to educational exclusion. Their anxieties around the consequences for their deaf children of an incomplete or inferior education could resonate with the caregivers' experience of the apartheid Bantu Education system which appears to serve as motivation in the search for schooling for their children. There was also unease about the children's risk of not completing schooling.

To add to their embodied unease, they physically experience unease about the exclusion of children from the household when the deaf children attend residential schools away from home, sometimes in other provinces. They also expressed concern about a reduction in influence over their children and the possible exclusion of the caregivers from their children's lives because of the recognised differences in language and culture which may affect the relationship between caregivers and their children. Caregivers' embodied unease may arise from their realisation that there is the possibility of exclusion because, within a "prefigurative culture there is less conception of what the future holds for offspring, and the life-experiences of parents are of less use to offspring, so their guidance is less highly regarded" (Côté, 1996, p. 418). Notwithstanding their concern, caregivers seemed to feel that, in their context of limited resources, schooling is a vehicle for socialisation, both for their children and for their communities where caregivers said that deaf children can learn to interact with other children by attending school and that their attendance at schools with other deaf children fosters an understanding of their own deafness and possible identity as a deaf, Deaf, or deaf and Deaf person which may go some way in reducing caregivers' embodied unease with regard to their children's psycho-emotional wellbeing and future independence.

8.8.6. Caregivers embody the emotions they experience within the different domains of their experience.

It has been suggested that the "inability to influence events and social conditions that significantly affect one's life can give rise to feelings of futility and despondency as well as to anxiety" (Bandura, 1982, p. 140). During the interviews, caregivers made reference to various emotions with regard to the various domains of their experience. For example, with regard to communication, caregivers seemed to embody the emotions of impatience, annoyance, frustration, pain, fear, and exasperation which arise from the differences in their language modalities and the limitations of their SASL. This difficulty in the communication domain is especially noticeable as a third-party disability when it restricts the participation and communication of hearing caregivers with their deaf significant others (Scarinci et al., 2009) because "language constitutes our sense of self as well as enabling us to communicate the ways in which we are similar to and different from others" (Temple & Young, 2004, p. 174). This study shows that hearing caregivers become disabled in their communication with their deaf children. In the same way that people with disabilities may require intermediaries or assistants to reduce the disability, hearing caregivers rely on similar assistance because their context and support structures do not enable them to adequately learn SASL whereas deaf parents who communicate in the same modality as their deaf children experience less communication stress (Hintermair, 2006).

It seems as though the caregivers' experience of searching for schools for their deaf children within resource-poor settings (Graham et al., 2013) can have a disabling effect on the caregivers, especially as they have major concerns about their children getting to schools which are far from home because there are no schools for deaf children in their settings. Their unease, anxiety, and distress about their children's schooling is compounded by the combination of their children's deafness and the rural terrain in this geographical setting where the poor condition of the road infrastructure and the great distance of the houses from the main roads can pose challenges for the deaf children who have to catch the bus as far as the main road before having to walk the rest of the distance home.

Caregivers revealed that they feel alone and do not have people with whom they can talk about their experience and they seem to have embodied a sense of loneliness which can contribute to the third-party disability (Scarinci et al., 2009). As a consequence, not talking about their emotions, experiences, and challenges becomes physically embodied. They used descriptors such as "*hurt*" and "*painful*" when referring to this particular embodiment in a third-party disability which arises from the caregivers' not being able to talk about their experience.

Caregivers recounted how the loneliness subsequent to the death of a significant other, spouse, or family member became embodied in themselves because it took away the opportunity to share with others. Moreover, the findings of this study suggest that the embodied sense of loneliness appears to take on a different dimension when the caregivers have been abandoned by their spouses who are still alive but who left them. Caregivers appeared to particularly embody a sense of abandonment and guilt when the children's fathers blamed the mothers for the children's deafness and fathers distanced themselves from the children's deafness. More specifically, it suggests that the caregivers have also embodied the fathers' abandonment of their children in themselves in addition to their own sense of abandonment by the children's fathers.

During their interviews, caregivers spoke about the responsibilities, challenges, practicalities, and logistics of being caregivers to deaf children but did not seem to consider their own wellbeing and the possibility of offloading by talking about their experience. It almost seemed superfluous to talk about their needs and their psycho-emotional wellbeing. Instead, they spoke about the need to address the practicalities of being caregivers to deaf children. It may suggest that the notion of talking about problems is a luxury concept and not one for people who experience vulnerabilities such as food security (Harris et al., 2011): within a context of limited resources talking about people's problems may not be a priority because the priority is survival. The caregivers could be demonstrating that they are concerned with their children's ultimate wellbeing rather than the caregivers' own emotional wellbeing. Also, it demonstrates that counselling services are limited within their context and that caregivers may have access to social workers but not necessarily psychologists with whom they could undergo formal counselling which, within a resource-poor context, could be beneficial, especially for women who find themselves marginalised within a context of poverty (Mundell et al., 2012).

However, on the contrary, there appears to be a positive embodiment of being able to talk about their emotions, needs, and experiences. Caregivers spoke of the improvement in their physical state which arises from talking about these aspects and they referred to the psychological alleviation which came from talking about their experience. They pointed to the embodied good that comes from speaking to social workers whom they feel can help them see their challenges in a new light because the social workers have special training. The caregivers' participation in this study seems to have created the opportunity for positive embodiment which came from this study's qualitative approach. They said that the opportunity to discuss their experiences had positive bodily effects which coincides with other research which revealed that participation empowers caregivers, especially women (Mundell et al., 2012).

8.9. Physical embodiment of the caregivers' experience

Caregivers made reference to the embodiment which comes from the differences between them and their children in their experience of deafness, especially because the caregivers are hearing and their children are deaf. The hearing caregivers' unfamiliarity with deafness and the aspects relating to the experience of deafness may contribute to the physical embodiment of their role. They referred to the embodied physical pain, hurting, insomnia, heart disease, high blood pressure, and even contemplation of suicide. Also, the insulting terminology used for deaf children and other people's negativity towards their children becomes embodied in the caregivers because they, as caregivers and through association with their deaf children, internalise the negativity directed towards their children as exemplified by the caregivers' pain at hearing their children being called '*imbhebebe*,' a derogatory term for deaf people. However, there was also the suggestion that as time has gone by, this embodied pain seems to subside when caregivers accept their children's deafness and when they internalise that there are other children, besides their own, who are deaf.

8.10. Chapter Summary

This study suggests that the caregiver experience as it pertains to deaf children is about more than just the surface aspects of deafness, hearing amplification devices, and SASL. Generally, caregivers, of deaf children may experience a range of challenges although these appear to be compounded when caregivers have limited resources, inaccessible structures, low self-efficacy, and curtailed agency. In this thesis, it can be seen that audiologists and other people who interact with deafness, caregivers of deaf children, families of people who are deaf, communities in which deafness is experienced, formal deafness structures, and government structures and policy, cannot and ought not be reductionist in the understanding of deafness.

In this thesis, it also became apparent that hearing caregivers seem to display low self-efficacy with regard to their children's deafness which, in turn, impacts on their mechanism of agency due to the intimacy between both. Also, it appears as though agency needs to be bilateral because it is not only up to the caregivers to show agency. Structures were identified as being unsympathetic, unaccommodating, inaccessible, inefficient, and incongruous to the caregivers’ abilities. The analysis of the interviews suggests that caregivers need structures which can bolster self-efficacy and facilitate caregivers’ agency in bringing about change. As the caregivers in this study pointed out, structures in their context need to know and understand the caregivers’ needs and experiences directly and that they should imitate this study’s approach in speaking to caregivers directly so as to best support them and their deaf children.

Chapter 9: Conclusion and Implications

“Under love's heavy burden do I sink.”

(Shakespeare, p. 1011)

Figure 9.1. Caregivers of deaf children experience various challenges which may impact on them and on their wellbeing.

By identifying these contextual challenges and the domains in which they operate, there is the potential to open the gate to a smoother path which caregivers of deaf children can travel.

9.1. Conclusion: The Beginning, Really

In writing up the conclusion chapter to this thesis, I recognise that, actually, ‘conclusion’ is an oxymoron because the results of this study suggest, instead, the need for a new engagement with caregivers of deaf children and with deafness too, and the beginning of a deeper and encompassing appreciation of caregivers’ experience in context.

Within a qualitative research approach and human rights perspective, caregivers were identified and recognised for their own worth and not only in relation to their value for their children. The interviews conducted within this qualitative study yielded valuable insights into the caregiver experience while also offering a reflective space mediated by the contextually congruent siSwati language and culture mediator. Deafness, and childhood deafness in particular, is often experienced in the medical paradigm while this study confirmed that it as a complex and multi-dimensional phenomenon which encompasses a range of different paradigms and is shaped by the context in which it is experienced. Moreover, the caregivers’ experience cannot be compartmentalised and differentiated into discrete units because they are all interconnected and these multiple domains which interconnect with the childhood deafness and the caregivers’ experience of their children’s deafness. Caregivers, especially women, seem to experience personal tumult in which they are unable to match the necessary agency with their available agency within their limited structural constraints where they have to mediate that which they can do with what they feel they ought to be able to do. Contextual factors influence the caregivers’ agency and self-efficacy and the limitations in caregivers’ structure and agency occur in five domains of their experience: communication, financial aspects, schooling, psycho-emotional support, and the caregiver role. The experience of caregivers of deaf children is, consequently, characterised by their need to devolve agency and the embodiment of a third-party disability within these domains.

9.2. Limitations of this study

The limitations of this study are acknowledged and were considered throughout. Particular aspects relating to the credibility and quality of this study were discussed in detail in Chapter 6. Furthermore, the following limitations of this study are recognised:

- The power differentials, although accounted for and considered in the different steps of this research study, cannot be ignored and there is the need to account for the underlying racial, linguistic, educational, geographical, and economic differences between me as the principal researcher and the participants, as well as the culture and language mediator, notwithstanding the different steps taken to address these differences which are detailed in the methodology of this thesis. While cognizant of these differences, they cannot be excluded completely and, if anything, it is more representative of the caregiver interactions with other people with whom they have to interact with regards their children's deafness where the caregivers and the people with whom they interact experience these asymmetries.
- This study relied on translated transcriptions which the language and culture mediator interpreted in terms of literal content, figurative meaning, and context. Nonetheless, research conducted by people of the same language, culture, and, importantly, context, may be in a position to give an unmediated account. Nonetheless, the mediation offered by the language and culture mediator created reflexive opportunities to look at concepts, metaphors, explanations, and experiences in a new light with a broader understanding which was offered by the opportunity to interrogate those accepted notions within the same context. In other words, the language and culture mediation allowed for an analysis of the everyday (Thoits, 2011) experience which in other circumstances could have been overlooked.

- This study was purposefully cross-sectional for the reasons set out in the methodology section of this thesis. However, as is discussed in the implications for future research, longitudinal research methods could have shed more light specifically on the experience over time, even though that was not the focus of the study. Yet, the inclusion of longitudinal aspects could have yielded more information about the argued benefit of participation in the interviews and in the group interviews.
- The participants in this study were predominantly female which may reflect a gendered description of the caregivers' experience. However, this gendered participant demographic profile seems to reflect the South African context (de Villiers & Giese, 2008).

Notwithstanding the identified limitations at different stages of the project, this study has highlighted the experience of caregivers of deaf children and has offered some insight into that experience.

9.3. Implications of this Study

This study offered caregivers of deaf children an opportunity to reflect the sum of their experience. The findings of this study suggest the need for an ethnographic and contextually sensitive interaction with caregivers and similarly contextually relevant and accessible support and resources to strengthen their agency within weak structures. Therefore, this study holds implications for a simultaneously respectful, contextual, bidirectional, interactively ethnographic, multi-domain attuned sensitivity and partnership with the caregivers of deaf children necessary so as to more fully and personally engage and interact with caregivers of deaf children so as to foster moves towards structural developments and agency enhancement. This study confirmed that, in a rural context, characterised by severe poverty, the role of the audiologist should be to profoundly interrogate and address domains and issues of relevance. The appeal to caregivers of deaf children, people who interact with deafness, and to structures in which deafness manoeuvres is to respond proactively in the experience of deafness rather than to react to it. The section which follows offers some suggestions.

The results of this study suggest the need for caregivers to encounter opportunities in which they can enhance their self-efficacy and agency within the structural limitations of their context. There are, therefore, implications for practice, policy, education, and further research within various fields. Within a complex and multi-dimensional understanding of deafness, this study embraces audiology, education, social development, social work, psychology, disability studies, diversity studies, sociology, anthropology, economics, politics, human rights, health, paediatrics, deafness studies, and a range of others fields and paradigms. It has the potential to offer a broader, personal, sensitive, attuned, multidisciplinary, and practical framework for engaging with deafness. In line with the overlapping character of the results of this study, the implications are similarly presented in an overlapping fashion in order to give a broader perspective on them.

9.3.1. Multi-domain structural stability within a context of rurality needs to be addressed.

This study has revealed that caregivers' experience with regard to their children's deafness is not independent of the caregivers' context and that agency is facilitated by structures, both human and nonhuman, which are accessible but also useful to them at micro and macro levels. Also, it showed that poverty is not just about money and that, for caregivers of deaf children, poverty extends beyond the financial aspects since it includes a poverty of agency too. Because the deafness component of the caregivers' experience is interconnected with the communicative, financial, schooling, psycho-emotional support, and overall caregiver role, structures need to be in place to reduce caregivers' challenges, especially for women caregivers who appear to be responsible for deaf children.

Therefore, more than addressing the consequences of these structural insufficiencies, this study shows that caregivers particularly call for increased accessibility to resources and practical opportunities for them to enact agency in their caregiver role. Caregivers want and need increased access to more nonhuman resources such as infrastructure for schooling of deaf children in rural settings, better transport of people who live in rural areas and improved access to services which are situated very far from their homes, increased resources for deaf children and their caregivers such as clinics and hospitals near to where people live, and information resources for people who may live far from centres where the information could be accessed or who are illiterate and cannot access information. Additionally, there is a need for the human resources such as the structural recognition by their communities, faith systems, families, and spouses of their impact on the caregivers' agency so that these structures in the caregivers' experience can be included in programmes of deafness awareness in an attempt to dispel suspicions around deafness and to foster greater acceptance of the deafness, deaf children, and caregivers of deaf children.

Especially within a context of poverty, high unemployment, and resultant survival vulnerability, there is a need to strengthen and consolidate caregivers' financial situations. There is a great need to facilitate the acquisition of hearing amplification devices if caregivers should want to acquire them for their children. More specifically, these devices ought to be made more affordable and there ought to be more concerted efforts to manufacture hearing amplification devices within the contexts where they are needed in order to increase their accessibility and to match the need for them (McPherson, 2011).

If caregivers are recipients of the CDG, “programmes need to better facilitate grant access by providing information on eligibility, accompanying caregivers to court and social services, and advocating for administrative changes” (Kidman & Thurman, 2014, p. 242) especially because it has been established that there is a relationship between improved food security and caregivers’ wellbeing (Marais et al., 2014). The uncertainty associated with irregular employment and irregular government grant allocation and receipt means that caregivers may be uncertain about the consistency of their financial aspects and therefore the consistency in which they can provide input with regard to deafness related aspects such as battery provision and attendance at hospital appointments but also with regard to their general caregiver responsibilities. Therefore, there is a need to offer such support to caregivers who may not have the agency to request such support through efficient and available structures in which to express their agency.

However, this study has emphasised the need for caregivers’ literacy enhancement and how illiteracy, especially in the current and historical background of South Africa, can disempower caregivers and necessitate the devolution of agency to others people. Therefore, not only should the practical aspects of the grant application be addressed, such as the correct documentation and access to grant offices (Graham et al., 2013) but, in addition, there is a need to offer support in related areas, for example, offering illiteracy-friendly access to grant funding information. Strong social networks and COPs were identified in this study as potential sources for illiteracy-related support and for the necessary sharing of information by caregivers, and the implication is that within the COPs which can be constituted by a range of people, those with literacy development skills, such as social workers and audiologists, be included so as to bolster caregivers’ access to information.

9.3.2. The call for an enhanced and expanded role for audiologists.

Audiologists ought to continue in their role as facilitators of communication through the early identification of deafness, the offering of hearing amplification devices, providing aural rehabilitation services, and making counselling services available. However, this role ought to be expanded so that particular cognisance is taken of the context in which audiological services are offered within a qualitative and human rights perspective. There ought to be an increased provision of awareness about deafness within communities so that, in this way, attitudes towards deafness can be improved and “hearing disability can be mitigated” (McPherson, 2014, p. 362) through dedicated deafness awareness programmes in all areas of the country.

Furthermore, audiologists ought not feel that there are domains outside of their control which they cannot influence. In their interactions with caregivers, audiologists have to accommodate the caregivers’ language, cultural, financial, geographical, transport, literacy, and other contexts. For example, within audiological interactions with caregivers of deaf children in contexts of poverty and limited financial agency, audiologists can advise caregivers about the financial support that is available and help to facilitate their access to such support in light of the caregivers’ literacy and language issues raised in this study. Audiologists can refer caregivers to the appropriate structures to facilitate the process but also the social networks of other caregivers who have gone through the process because the caregivers can advise each other about what worked for them and how they navigated the process so that the caregivers can learn from each other and can give each other particular strategies which they found useful having gone through the process. Moreover, information received from other caregivers with whom caregivers can identify, may hold greater value because of the emic and etic considerations. Caregivers may accept the advice from other caregivers differently to the same advice from audiologists, social workers, government department employees because the caregivers identify with their peers as similar others (Thoits, 2011) in terms of experience and in terms of context. This mutual support which caregivers can provide may offer the structure in which caregivers can enact agency thereby reducing the individual, subindividual and social unease which this study has identified. Familiar social networks may be preferred over non familiar networks as evidenced in this project when caregivers spoke with each other and were able to bounce ideas off each other, advise each other, and caregivers were able to get advice from other caregivers who had already gone through those processes, and supported each other that way. Therefore, as per this preceding discussion, audiologists are not called upon to only be involved in the audiological aspects of deafness but in the overall experience of deafness. This broader perspective across various domains of the caregivers’ experience can enhance caregivers’ agency and this study demonstrates that through the implementation and application of the principles of qualitative research, caregivers can be empowered with opportunities to talk about their experiences and to connect with other caregivers of deaf children, including caregivers who have disabilities themselves.

Because of their interaction with families of deaf people, audiological knowledge, and understanding of the deafness related aspects of children and their caregivers, audiologists can collaborate with social workers, who, because of their role, accessibility, and approachability, could, together, serve as facilitators of that information. This study revealed that caregivers appear comfortable approaching social workers and because of the greater accessibility to social work services, it calls for the specific cooperation between audiologists and social workers. It also suggests the need for deafness training for social workers so that they can be more fully informed about the multiple dimensions of deafness with regard to the medical, disability, cultural, audiological, educational, communicative, and identity aspects of deafness and how to accordingly advise caregivers. The particular intersection of disability, cultural, and other aspects of deafness require an approach to deafness by social workers that is considerate of this particularity and how deafness cannot and ought not be conflated with disabilities such as blindness (Parkin, 2010) or others by social workers in their interactions with caregivers of deaf children.

It is imperative to foreground the caregivers' communication needs, including literacy and health literacy, and audiologists are well placed to attend to these literacy demands because of their insight into the value of communication but also because of their interactions with the powerful medical hegemony and so "audiologists are a critical link" (Nair & Cienkowski, 2010, p. 74) in improving health literacy by reducing the "feelings of shame or inadequacy" (Nair & Cienkowski, 2010, p. 72) which may accompany the caregivers' literacy limitations. This need for health literacy is crucial in order to increase caregivers' self-efficacy in communicating about their children's deafness. Caregivers ought to be empowered with the terminology and information around their children's deafness so that they can interact with others about their deaf children within medical and audiological consultations (Nair & Cienkowski, 2010) but also within their communities so as to increase the profile of deafness within communities where there may be insufficient deafness awareness (Clark & Newton, 2008; McPherson, 2014).

9.3.3. The need for early identification of childhood deafness.

For the reasons pointed out earlier, it is essential for deafness to be identified early in children of all ages. Caregivers' agency appears to become compromised due to the poorly resourced audiological services and the absence of universal newborn hearing screening services. In light of the subsequent reduced sense of self-efficacy within this context of structural limitations, "support services during this period are critical. Early intervention must proceed from the broader context of family experiences and resources" (Meadow-

Orlans & Sass-Lehrer, 1995, p. 326). Caregivers may experience the need to devolve their role of noticing the children's deafness to others around them because a formalised hearing screening service is not available to provide an accurate and timely diagnosis of the deafness. This poorly resourced infrastructure means that the parents are uncertain about the processes to follow to address their children's deafness requirements thereby limiting their self-efficacy and agency. If a newborn hearing screening programme were available for congenital deafness or if there were a rigorous and universal audiological monitoring programme for acquired childhood deafness, then caregivers would have agency to act upon their children's deafness as opposed to not being able to act because they do not know that their children are deaf, or what to do about concerns raised with regard to their children's deafness.

This study showed that even in families with confirmed hereditary deafness, there is no structure to screen and diagnose the possible deafness unless the caregivers themselves request these. The structures, even when the deafness is so obvious, are not in place to guide caregivers. Therefore, caregivers who have no previous experience of deafness need to rely on other people's previous experience in identifying children's deafness, getting children hearing aids, and sourcing schools for deaf children to guide them in their caregiver role. This reliance on others may challenge their sense of agency because they may feel that they are inadequate caregivers for not noticing their children's deafness and this perception of themselves as inadequate may extend to other aspects of their caregiver role due to the effect on their perceived capability. This challenge to their perceived capability may be alleviated through the implementation of formal screening structures to identify childhood deafness and the expansion of programmes which advise caregivers on how to interact with deafness. Such structures may give caregivers agency to act in relation to their children's deafness within the different domains.

Advocates of newborn hearing screening point out that the age of identification of deafness in children drops dramatically when such a programme is implemented and practiced while recognising the financial restrictions in acquiring the expensive diagnostic equipment and the limited personnel to conduct such a newborn hearing screening, especially in rural areas (McPherson, 2012). Currently, cognizant of these considerations, the Health Professions Council of South Africa (HPCSA) is taking steps towards formalising the screening of newborns' hearing and this infrastructure can scaffold caregivers' actions and agency with regard to their children's suspected and possibly confirmed deafness through the establishment of the aforementioned structural scaffolding where "EHDI programmes must be instituted at community and district levels of health care integrated with early childhood development initiatives by the departments of social development and education to provide an ongoing measurement of EHDI status and development" (Professional Board for Speech Language and Hearing Professions, 2007, p. 4). Therefore, early identification is not just about the identification and diagnosis of deafness but, crucially too, about the subsequent information sharing, psycho-emotional support, resource sharing, and access to deafness related activities and support early on in the children's lives and in the caregivers' experience.

In advocating for newborn hearing screening, this thesis encourages the establishment of a structure which can offer caregivers more agency in that a comprehensive newborn hearing screening means that caregivers can know early that their children are deaf and, in so doing, they can be more informed in terms of language, schooling, support, and other options for their deaf children. For example, as per the experience of caregivers in this study around communication in SASL with their deaf children, early identification means that those caregivers who want to follow a SASL path for their deaf children can do so more fully informed and knowledgeable of SASL. Caregivers can learn SASL themselves so that their

SASL skills are more developed than the participants in this study revealed, and gives them the opportunity to learn over time rather than rushing it when the children are older and the caregivers struggle to communicate with their deaf children. Caregivers can learn the necessary SASL syntax and vocabulary so that they can more competently discuss complex and deep issues raised by the caregivers in this study such as adolescence, poverty, and emotions, amongst others, especially because the caregivers in this study conveyed the sense that these structures can reduce the risk of intrapersonal communication frustrations which deaf children may experience in wanting to communicate with others but it also may reduce the interpersonal frustrations in communication between caregivers and their deaf children.

Therefore, at first and on the surface, the promotion of a newborn hearing screening may seem to favour the medical model agenda in terms of diagnosing deafness and labelling deafness. However, I suggest that early identification is congruent with the social model and with the promotion of SASL because early identification suggests the early development of language, any language, be it SASL or spoken language. Early identification means that children can start learning language early rather than experiencing delayed language acquisition which may result from the late identification of deafness and impacts on the late acquisition of SASL or spoken language because the deafness was unidentified. It means that different language options can be explored rather than having the caregivers settle for a language because there is now a sense of urgency in getting their children to learn language. Therefore, it is beneficial for deaf children to be identified early and is good for the caregivers too, because they can learn language, communication enhancement and repair strategies and because they can develop social networks and communities of practice. Caregivers, within their shared experience, can support each other early on if they are part of a formal and established newborn hearing screening programme and they can provide psycho-emotional support to each other in light of their limited resources.

Also, through the early identification of deafness, there is a structure within which caregivers can enact agency because if the children's deafness is identified within a formalised and organised screening programme, it suggests that there are referral pathways in place so as to improve caregivers' agency because they can feel more empowered with information, people and structures which they can approach so that they do not feel as lost as the participants in this study reported. Additionally, caregivers who participated in this study said that it was because their children were not talking that other people suggested that the caregivers take their children for assessment which implies that if the structures were in place to monitor the baby’s development and to advise caregivers about their children’s developmental milestones then they could have been more informed about deafness and acted accordingly, rather than being concerned, for example, about their children’s tongues being glued and seeking treatment for cutting their children’s tongues rather than going for audiological assessments.

Therefore, early identification of deafness and the access to appropriate, direct, and contextually sensitive structures can enhance caregivers’ agency in fostering their children’s language development, regardless of the language modality, be it SASL or spoken language, so that the children have a language. This study has demonstrated that caregivers have a need for these contextually sensitive structures and caregivers can access structures necessary for applying for social grants, resources for schooling information without having to hunt for schools, communication information, counselling options, meeting other caregivers at audiological appointments or language enhancement or sign language classes. Caregivers can have more resources relating to the deafness, even if they do not have the financial resources or employment resources and by giving agency in some domains means that caregivers can feel less uneasy about those aspects and therefore it can impact on their experience of being caregivers to deaf children within this rural context and there is potential of the cascading of agency into other domains too.

9.3.4. Caregiver's capacity-building and empowerment is necessary through the bolstering of self-efficacy and agency.

Audiologists and others who interact with caregivers of deaf children need to empower caregivers by developing caregivers' self-efficacy, not only by developing caregivers' knowledge and skills but by fostering caregivers' sense of competence and, ultimately, their autonomy. When caregivers "internalise a sense of competency in the role, satisfaction and pleasure in parenting become attainable even under marginal ecological conditions" (Coleman & Karraker, 1997, p. 79). This study highlighted the reduction in caregivers' self-efficacy and agency due to structural inefficiencies in their context and suggests the need for opportunities where caregivers can engage in capacity building and empowerment opportunities, especially for women who, in this context, appear especially vulnerable (Goudge et al., 2009; Mundell et al., 2012). It is argued that counselling and empathy can lead to an improved quality of life, empowerment, and confidence (Chiegil et al., 2014) and thereby impact on self-efficacy. In addition, there is a great need to increase the knowledge about deafness (McPherson, 2014) amongst caregivers of deaf children because an improvement in knowledge and sense of competency (Coleman & Karraker, 1997) can improve their self-efficacy and consequently their agency. For people who live in difficult situations, it is important to organise and offer opportunities for the development of self-efficacy because it

> may operate as a protective factor against risk factors associated with poverty and elevated stress. Under such circumstances, when alteration of environmental conditions is a long-term and difficult challenge, enhancing parental self-efficacy may

> serve as one potential mechanism by which to improve the well-being of parents and children (T. L. Jones & Prinz, 2005, p. 359).

Particularly within the context of poverty, caregivers could be empowered to benefit more completely from the government grants which they may receive as demonstrated by some caregivers in this study who spoke about how they save and invest the grant money for their children’s later benefit or for medical emergencies. It has been suggested that, without changing the amount of grant funding paid by the government, caregivers can be empowered to continue utilising the grant money for their necessities while

> packaging the grant in such a way as to facilitate disabled people’s access to small business loans, assistive devices, and skills training programmes may be an option that significantly increases the impact of the grant and facilitates beneficiaries being able to forge opportunities for themselves through self-employment or in the labour market, thus decreasing reliance on the grant (Graham et al., 2013, pp. 334-335).

This study revealed that caregivers of deaf children are not only the children’s biological parents. The caregiver role is often devolved to caregivers when the biological parents pass away which suggests a particular caregiver portrait in South Africa that is characterised by orphanhood. Therefore, for caregivers who have had to unexpectedly assume the caregiver role, often later in life, capacity building programmes could be beneficial and this implies a greater role for the Department of Social Development in the preparation of caregivers of orphans, especially for caregivers of orphans with additional needs. HIV/AIDS in the orphaned children has been highlighted in this study as a feature of the caregiver role but this study also revealed that orphanhood together with HIV/AIDS and deafness requires particular and specific support from social workers in conjunction with hearing care personnel to ensure that appointments and services are complementary in order to avoid multiple visits to hospitals. Moreover, caregivers in this study showed their openness to attending information sessions on capacity building and empowerment in their caregiver role, provided that their deaf children can be accommodated and when transport costs and distances are not prohibitive since "proven interventions that may have relevance to orphan caregivers include training to increase knowledge and coping skills, increasing social contact and expanding links to social assistance programmes (Cooke, McNally, Mulligan, Harrison, & Newman, 2001; Schulze & Rössler, 2005).

Especially in a context where caregivers are already vulnerable to the disabling effects of poverty in South Africa, when caregivers themselves have HIV/AIDS they may need particular capacity-building and empowerment activities because "the AIDS-related illness of the primary caregiver was also associated with heightened burden … (and) … intervention should be targeted at dually affected caregivers and include both medical and psychosocial services, in an effort to alleviate burden" (Kidman & Thurman, 2014, p. 242). Moreover, in recognising the effect of HIV/AIDS on the caregiver role, this study has also demonstrated that in relation to their children's deafness, caregivers can benefit from support from their network and, especially for caregivers who may have HIV/AIDS themselves, so as to address their caregiver burden over and above their experience of being caregivers to deaf children. There is a call for the recognition that people living with HIV appreciate interacting with their peers, and create opportunities for such interaction as part of the continuum of care process" (Chiegil et al., 2014 p. 144), especially when caregivers, as they did in this study, are concerned about their children's wellbeing should the caregivers die. Through interaction with other caregivers and the subsequent group support and motivation, there is an opportunity for caregivers to be "empowered to live their lives and not simply anticipate an inevitable death" (Mundell et al., 2012, p. 183).

In capacitating caregivers, there is the need to prepare caregivers for the devolution of agency with regard to certain roles and the empowerment of caregivers with regard to roles which they may not need to devolve, especially in a context where caregivers experience barriers to accessible resources. For example, through early identification of deafness and early support of caregivers of deaf children, caregivers may get opportunities to learn how to most effectively communicate with deaf children and, if they choose a SASL option for their children's communication, they can be offered accessible and consistent SASL interactions interacting with deaf adults and other caregivers who are learning SASL. By expanding a programme such as HI HOPES to other parts of the country, caregivers in rural Mpumalanga can also benefit from the language models and language learning opportunities offered. This preparation for devolution can be empowering for caregivers and can increase their agency in choosing how they respond to that devolution in trying to reduce the need for devolution through their capacity building and information and resource empowerment so that caregivers do not have to always turn to others to fulfil those roles.

This study revealed that caregivers who are employable may not be able to participate in employment seeking because of their caregiver responsibilities and suggests that they, consequently, experience a third-party disability when they become disabled by their children's disability and have to devolve financial agency as a result. This inability to engage in employment due to missed opportunities may compound the caregivers' and their family's poverty and, therefore, there is a call for

> systems to help family members access support services such as skills training, assistive devices and finance might enable the household to utilise their human capital residing in both disabled and non-disabled members to forge self-employment prospects. Innovative, grassroots-located programmes that recognise and enhance the

> assets of all household members might lead to these households being able to enhance their outcomes (Graham et al., 2013, p. 335).

Therefore, in empowering caregivers, there is a need to provide opportunities for caregivers to feel competent in what they do and in their decision making. It is necessary to offer strategies designed "to alter internal working models through positive relationship building and development of high self-efficacy through direct child care instruction, modelling of appropriate parenting, and opportunities for success in performance of role behaviours" (Coleman & Karraker, 1997, p. 72).

9.3.5. Communities of practice and engagement with similar others offer opportunities for caregivers' self-efficacy and agency enhancement.

Hearing caregivers of deaf children expressed unfamiliarity and inexperience of deafness in children and so it appears beneficial to offer opportunities for collective efficacy. These opportunities are necessary because, "in ecologically disadvantaged communities, the culture of poverty conveys a message of reduced opportunity to exert personal influence in many facets of life … (and) a collective sense of powerlessness may also impair personal efficacy in such environments and the cultural climate may also need to be addressed in efforts to help parents living troubled lives achieve a sense of personal effectance" (Coleman & Karraker, 1997, p. 72). It therefore is essential to build caregivers' capacity at the level of the self, but also at the level of the collective with regard to the deafness aspects of their caregiver role. It is not to say that such programmes should assume a position of dominance and superciliousness in assuming that caregivers do not know how to raise children. Instead, such programmes should revolve around the deafness and the domains which are also related to deafness. Caregivers may find that because of their unfamiliarity with deafness, such information is welcome, especially in relation to the findings of this study which revealed that caregivers do not always have the necessary information or accurate information. Moreover, “attitudes towards disability may only shift over time and with sustained input at the societal and individual levels” (McPherson, 2014, p. 362). Programmes such as HI HOPES (Störbeck & Moodley, 2011; Swanepoel & Störbeck, 2008) could, in cooperation with audiologists, facilitate such a change through their provision of deafness-related information. In addition, the establishment of formal COPs in which different agents participate, including caregivers of deaf children, audiologists, teachers of the deaf, amongst others. In light of the criticism hearing caregivers may face by Deaf people about the way they raise their deaf children (Meadow-Orlans & Sass-Lehrer, 1995), this COP can also be useful to empower caregivers to be more assertive in their caregiver roles and to recognise their contribution to their children’s identity and sense of belonging in hearing families.

Within a COP there is the opportunity to build self-efficacy through the sharing of information via word-of-mouth between caregivers, especially in a context of high illiteracy. COPs can foster opportunities for caregivers to offer each other material and psycho-emotional support. The creation of a COP and a structured, rather than ad-hoc, social network of caregivers of deaf children, can offer such a structural frame in which caregivers can garner support and thereby build on their agency. This agency enhancing component of COP is reinforced by the sharing of tacit knowledge which “makes it possible for them to be advocates and facilitators in the development of resources that reflect accumulated ways of knowing and experiences” (Moodie et al., 2011, p. 15). It seems as though this sense of caregivers being able to contribute to the COP may be beneficial to them, especially because they may often be subject to other people and structures’ contributions, whereas, now they have agency in contributing themselves.

Despite caregivers' sense of limited peer support, the evidence from the interviews suggests that even small amounts of understanding and empathy are supportive and beneficial. Therefore, it suggests the value of pointing out and making more salient these everyday acts of support which may be overlooked by the caregivers but which all add up and contribute to the greater sense of support (Thoits, 2011**)**. The opportunity for caregivers to talk about their experience may create an opportunity to translate the talking about the experience into acting upon it, in whatever small step is possible with the support of the COP and social resources at their disposal while harnessing their own personal resources.

However, in providing support to empower caregivers, it is suggested that caregivers' confidence be fostered "so that they can make decisions, learn new skills, and benefit from information about resources and options" while cognizant of the risk that, in providing support to caregivers, there is a danger that such "professional behaviours can actually create dependency, self-perceptions of incompetence, or negative reactions toward the help giver" (Meadow-Orlans & Sass-Lehrer, 1995, p. 323).

9.3.6. Qualitative research can add value the field of deafness.

This study has revealed the need and the potential benefit for caregivers offered through their participation in a project which has a qualitative orientation. Very importantly, it highlights the need to strive for a change in people's situation and to change the lens through which we look at people's situations and realities. Additionally, this study calls for the development of caregivers' self-efficacy which is in tune with this qualitative study's humanist leanings where, in developing their self-efficacy, meaning is co-constructed (Ahearn, 2001; Lincoln et al., 2011) in a joint collaboration between audiologists, for example, and caregivers of deaf children. Therefore, strategies in the different domains of their experience can be targeted in way which is respectful of caregivers' contexts without exerting power over people (Munford, 1994) and without forcing them to engage in activities with which they may feel uncomfortable.

This study showed that the caregivers felt that the sampling procedure used for this qualitative study was more inclusive and respectful of caregivers and showed that they mattered. They also spoke about the benefit they felt from participation in the interviews and the opportunities offered by the interviews to reflect on their experience. Therefore, this study has implications for further qualitative studies in deafness, especially from the field of audiology because, despite the existing knowledge,

> one feature of this knowledge, of course, is its incompleteness, its implicit and tacit dimensions. … Even the most ardent social science wordsmiths are at a loss to transform the nuances, subtleties and the sense of the sublime into symbols! For this reason, we acknowledge the realm of tacit knowledge, the ineffable truths, unutterable partly because they are between meanings and actions, the glue that separates and joins human intentionality to more concretely focused symbols of practice (Altheide & Johnson, 2011, p. 592).

Qualitative studies may be more attuned to people’s contexts and respectful of them as people and of their human rights. This qualitative stance may fulfil social justice prerogatives through the potential for empowerment and agency enhancement, not to mention the egalitarian sense offered by the collaboration between researchers, language and culture mediators, and participants, amongst others. By being inclusive and respectful of people’s human rights, the qualitative approach takes all experiences into account, including caregivers who themselves may have disabilities because it has been found that if information and support services focus exclusively on the interests of hearing parents, those who are deaf may feel disenfranchised” (Meadow-Orlans & Sass-Lehrer, 1995, p. 322).

This study shows that qualitative research appears especially valuable because, by conducting the study, engaging in community of practice with caregivers of deaf children and others, and by reflecting on our practice we are able to recognise, define, label, and legitimise the work we do so that it can continue to be practiced and can continue to grow. By including aspects of the caregivers' experience gleaned from this study within undergraduate, postgraduate, and continuous professional development programmes, then there is a concretisation of the concepts such as third-party disability and the devolution of agency. In turn, they become units of interest and study so that they can be converted from units of interest and study into units and elements of practice. Participation in this study may validate the caregivers' experience and recognise the parallel experience of caregivers, not only of their deaf children, and the needs of the caregivers when interacting with their deaf children in our audiological practice.

As mentioned earlier in Chapter 5, qualitative studies are not only transformative for the participants but for the researchers too and within this approach, qualitative researchers are also able to engage in the meta-analysis of practice, that is, to reflect on how we are considerate of the caregivers' experience in our practice and interactions with deaf children and with their caregivers. The different approaches to research, including quantitative and mixed-methods approaches, make valuable contributions in their own way which suggests that there ought not be a hegemony of one approach over others and that qualitative research, which has often been relegated, can be seen as contributing equally to the research landscape and offer the segue into new understandings of deafness.

Moreover, research itself was identified as a structure in which deafness is experienced in the way that the data and the participants are portrayed which can impact on policy, practice, and training. Therefore, research appears to be a powerful structure which can be used to influence the caregivers' experience. The participation in the research interviews may be an ideational resource where caregivers can envisage a different outcome based on a new set of actions which they can explore based on information sharing and reflection. Caregivers may have the opportunity to explore the fantasy of the type of caregivers they could be versus their current reality of them being caregivers to deaf children so that they can envision a different outcome using the available resources to their maximum efficacy, despite their limitations. This envisioning offered by speaking and listening to caregivers of deaf children can foster self-efficacy because caregivers get the opportunity to engage with the "visualisation of success scenarios in the relevant domain which conveniently serve as a model for positive solutions to future troubling situations" (Coleman & Karraker, 1997, p. 70).

9.3.7. Communication is a way of attaining self-efficacy and agency.

This study demonstrated how communication can impact on self-efficacy and agency. Through the interaction between similar others or peers, caregivers can get information and psycho-emotional support while also demonstrating agency when talking with hearing care personnel, community members, spouses, family members, government representatives, school representatives, and faith representatives. This study corresponds with previous research which found that "participant talk about the caregiving experience is simultaneously an articulation of experience that draws on broader ideologies and an attempt to cope with perceived experience" (Funk & Stajduhar, 2009, p. 866). Furthermore, there is the call to foster sessions and opportunities for successful interactions between caregivers and their children as well as guiding caregivers on how to effectively communicate with their children which can enhance the relationship between them (Coleman & Karraker, 1997).

The value of every interaction, no matter how small and apparently unimportant, appears to be imbued with great importance and embodied by caregivers. They seem to internalise the things which people say to them, about them, to their children, and about their children. Also, there is an embodied and tangible benefit of being heard, the listening ear of others can be therapeutic and can validate their experience as pointed out earlier in this thesis because the interview can offer “healing, unburdening and catharsis, a sense of helping others, and means to make sense of experiences through speaking about them and refining thoughts through the interview” (Funk & Stajduhar, 2009, p. 860). As suggested by caregivers in this study, the interaction between caregivers can allay other caregivers’ anxiety about their supernaturally based concerns and about their communities’ suspicions about their children’s deafness and there is the potential for strength and solidarity within a COP in this regard.

Caregivers in this study spoke of their limited access in communicating with powerful structures such as government departments. They cannot get the opportunity to express their concerns, challenges, and needs, nor can caregivers make suggestions for government input. Therefore, because their voices are not heard by government structures and departments, they cannot demand the necessary support and, consequently, these are not efficiently provided. COPs may offer individuals a stronger and louder voice to demand support because, through this combined voice, caregivers can potentially facilitate change in their context and situation. For example, in this study, caregivers mentioned the challenges they faced in finding schools for their deaf children and, therefore, caregivers could be empowered to call for structural improvement with regard to their children’s schooling and

> schools should be at the forefront of an advocacy agenda. Given that we are in an era of South African education where new schools and classrooms are being built, there is an ideal opportunity to influence planning to ensure better accessibility for disabled children” (Graham et al., 2013, p. 334).

This study has also demonstrated the value of communicating via the written form and illiteracy has been highlighted as a detractor of agency and a reason for the devolution of agency. COPs of practice may be able to want to voice their concerns with the government, but the mode of communication may rely on writing to government while also reading and scrutinising government documents so as to demand that which is promised in government policies. If caregivers cannot read, they cannot know to what they are entitled and therefore may be disempowered by that obfuscation of information written in policies and entitlements. Therefore, there is a need for structures to improve their communication means with people who access those structures. This study demonstrated the value of utilising the services of social workers but also of informed peers who, because of their experience, may be well positioned to share this information with caregivers who cannot access government information. Younger caregivers who may have had better schooling opportunities, through a community of practice, may be able to share the information which they glean from reading the relevant documents with older, less literate caregivers thereby contributing to ubuntu in that they can offer support for the upliftment of other caregivers.

9.3.8. Contextually attuned practice.

This thesis argues for contextually sensitive and attuned partnering of audiologists and others with caregivers of deaf children. It reinforces the call for a humanitarian stance that is respectful of human rights and context in the offering of deafness-related services (McPherson, 2008). There is a call for an increased congruence between the profession of speech-language pathology and audiology and the people of South Africa. Also, it resonates with the call to consider context and situational factors when encouraging self-efficacy so that the focus extends from concrete, task-specific self-efficacy to a broader, domain self-efficacy (Coleman & Karraker, 1997).

Therefore, “training institutions are enrolling student groups that are increasingly representative of the ethnic, linguistic, and cultural diversity of South Africa to redress a historically white Afrikaans- and English speaking profession” (Swanepoel, 2006, p. 263). However, although this suggestion is a good starting point, it does not provide South Africa with contextually sensitive and attuned speech-language therapists and audiologists because race, language, ethnicity, and culture do not suggest contextual understanding or sensitivity. Even though people may be from various ethnic, language, or culture backgrounds, they may be from different socio-economic and differently empowered backgrounds which do not match the caregivers of deaf children with whom they interact. This study shows that, by promoting contextual sensitivity as an extension of cultural sensitivity, practitioners can account for poverty and its ramifications as part of their experience.

I offer that contextual sensitivity includes an understanding of a range of contextual variables and eschews the conflation of race, culture, or language with context and reflects a “sensitivity to multiple, dynamically interactive levels of influence” (Coleman & Karraker, 1997, p. 75). For example, my fluency in Portuguese and socialisation within a Portuguese context offers me an insight into the contextual experience of other Portuguese-South Africans and I have an internalisation of the nuances, metaphors, and connotations that a deep understanding of that language provides. However, although I speak isiZulu and have Zulu friends and acquaintances and have insight into cultural aspects, I cannot claim to know what it is to be a Zulu person because identification extends beyond language ability. Notwithstanding this limitation, familiarity with the languages, cultures, and contexts of the people with whom professionals interact is necessary so that there is a genuine and respectful interaction with people.

The possession of only cultural competence or linguistic competence creates the potential for reducing interaction to a technical skill with a checklist of do’s and don’ts

(Kleinman & Benson, 2006). By advancing a cultural competence agenda, there is the risk that, in training future speech-language therapists and audiologists, stereotypes can be reinforced. It would be more appropriate and congruent to focus on contextual sensitivity because "it seems that in training clinicians, what is more important is to invite an attitude which will generalise to various intercultural situations, rather than be advised about the specifics" (Penn, 2002, p. 96). Clinicians ought to, instead, exhibit more than just a competence because the term 'competence' implies a pass or fail of technical skill whereas a contextual sensitivity or attunement implies a harmony in the interactions between hearing care personnel and their clients, families, and communities.

Therefore, there is an implication for the need to foster a fuller engagement with clients through an inclusion of their clients' ethnography (Kleinman & Benson, 2006) so that, within clinical settings, "courtesy treatment by the healthcare workers develops confidence in end users and empowers them" (Chiegil et al., 2014 p. 144). There is a need to offer services which reflect attunement and sensitivity in the use of language, appropriate information sharing strategies, attainable goal setting, considerate appointment scheduling in terms of time, distance, and accessibility, and engagement in agency and power enhancing interactions which are respectful of people. Within this ethnographic approach, there is also the need to espouse values such as "fidelity, altruism, confidentiality, integrity, empathy, and compassion" (de Andrade, 2011, p. 354) while also demonstrating "respect for persons, deference for elders, reverence for authority figures, family centeredness, compassion, empathy" (de Andrade, 2011, p. 352).

The preceding discussion, therefore, suggests that the notion of cultural competency is insufficient and that, rather, interactions ought to be contextually attuned because people consist of more than just culture. Also, culture is not an all-encompassing descriptor; the concepts of "caring, hope, empathy, social support, are complex because they are used in a myriad of ways, even within the same culture and language groups" (Williams et al., 2004, p. 944) which suggests that the same concepts mean different things to different people of the same language and culture in different contexts. Including ethnographic considerations in interactions with deaf children and their caregivers can prove fruitful in the creation of a closeness between audiologists and the people with whom they interact by "emphasizing engagement with others and with the practices that people undertake in their local worlds" (Kleinman & Benson, 2006, p. 1674) in order to foster empathy with people's lived experience. This thesis encourages the use of an ethnographic lens in order to explore people's experience in their particular contexts and suggests that people's experience reflects these contextual variables more than just cultural aspects.

9.3.9.   Internalised context within the medical model.

Throughout this thesis, I call for a shift away from a purely biomedical relationship with deafness and suggest that tenets of cultural competence can, and ought to be, extended to audiology too because audiology has been described predominantly within a quantitative and biomedical paradigm (Knudsen et al., 2012). The findings of this study suggest the need for practice which is in harmony with caregivers' contexts, including their language. By more seriously considering concepts of context, agency, structure, self-efficacy, and others raised in this study, biomedical attempts at proposing more social interventions, such as the ICF, can, indeed, offer closer, more sensitive, and more appropriate interactions. This study proposes that, by applying these ideas, concepts such as the ICF framework ought to facilitate the inclusion of these ideas so that these frameworks are all encompassing, humanist, and considerate.

Within the medical model, in trying to address the language differences between clinicians and clients, there has been a suggestion that "the ideal is for the health service to employ health professionals who are already culturally and linguistically capable. Health professionals who would be proficient in the language of their patients should be identified and recruited" (Hussey, 2013, p. 193). This suggestion would preclude the employment of people who have different languages and cultures to the settings in which they work. But, if that were the case, many South Africans would not be able to work in different parts of the country. For example, a TshiVenda speaking audiologist from Limpopo in the far north of the country is linguistically and culturally different to Xhosa people in the Eastern Cape where many people only speak isiXhosa and may encounter difficulties communicating with clients. Therefore, in this aforementioned example, the TshiVenda audiologist may be considered an immigrant within an isiXhosa context and there is, therefore, the need for a context mediator because contextual sensitivity rather than cultural competence can be more embracing since there is a sensitivity to the underlying humanist values and respect which can transcend specific languages and cultures.

Also, there are implications for consultations with people from other countries who have moved to South Africa and now call it home since the constitution offers protection to other languages of minorities in South Africa such as German, Greek, Gujarati, Hindi, Portuguese, Tamil, Telegu and Urdu (Constitution of the Republic of South Africa, 1996, p. 1245). Therefore, a contextual approach is considerate of minorities and embraces minorities in the provision of audiological services to all people.

Therefore, it means that all practitioners ought to provide services to all people and boosts the value of contextual sensitivity which can transcend specifics of culture with the contribution from a context mediator. By being able to offer a contextually attuned practice, then practitioners may be more equitably and universally able to adapt to context rather than focussing on a specific culture and language. This contextual sensitivity is not a technical competence but is, instead, nurtured and applied within the specific context while recognising the impact of that particular context while it transcends the check lists and superficial attempts at paying lip service to cultural competence and multilingual abilities within medical settings.

Additionally, this study has shown how caregivers appreciate a qualitative approach to deafness and understanding of deafness which, within a predominantly biomedical paradigm, may offer novel opportunities for hearing care personnel, including audiologists and doctors, to explore deafness within clinical settings. Therefore, qualitative approaches can be merged with biomedical ones so as to best and most fully interact with all aspects of deafness so that in its blended form,

> finding out what matters most to another person is not a technical skill. It is an elective affinity to the patient. … And its main thrust is to focus on the patient as an individual, not a stereotype; as a human being facing danger and uncertainty, not merely a case; as an opportunity for the doctor to engage in an essential moral task, not an issue in cost accounting (Kleinman & Benson, 2006, p. 1676).

This blending is crucial so that, within clinical settings where the qualitative perspective and social approach may not dominate, people can know that they matter and opportunities for people to talk about their experience is part of the consultation because people

> want an explanation about their symptoms, treatment or investigations. Many have ideas about what is wrong and what may have caused it, but they do not always articulate these. … Failure to engage with end-users’ agenda can lead to misunderstandings, dissatisfaction and poor outcomes (Chiegil et al., 2014 pp. 139-140).

9.3.10. Language and culture mediators need to facilitate as context mediators.

In light of this study's findings, it appears necessary to include context mediators in deafness-related interactions, amongst others. Through the valuable inclusion of context mediators, contextual factors can be sensitively accommodated in interactions with caregivers and other people. Not all audiologists can and will be familiar with every official language of South Africa as well as the various cultures and ethnicities of the country which, therefore, implies the need for the formalisation of the language and culture mediators' role within clinical and other interactions with practitioners of all races and languages in South Africa. The inclusion of a formal context mediator within medical settings appears prudent to grow caregivers' agency by providing them with accurate deafness information such as the diagnosis of the deafness so as to demystify the deafness for caregivers which may happen when, for example, caregivers and audiologists speak different languages.

The structural limitations imposed by South Africa's language policy history and its oppressive use during apartheid means that there exists power differentials between people who provide services and those who seek those services. Furthermore, caregivers' agency is reduced because the information about their children's deafness diagnosis and subsequent options is not available to them when hearing care personnel do not engage with them in a way that is respectful or accommodating of their language variation. Consequently, from the results of this study, it became apparent that caregivers do not have access to the audiological, medical, diagnostic, and hearing aid amplification terminology associated with their deaf children which suggests that they may have limited agency in talking to other hearing care personnel about their children's deafness and it also suggests a heightened risk of miscommunication between caregivers and hearing care personnel when the caregivers consult with different hearing care personnel. Therefore, it suggests the need for contextually sensitive interactions with caregivers where that contextual sensitivity includes respect for and inclusion of the caregivers' language within consultations.

However, this contextual sensitivity does not mean that hearing care personnel perpetuate the use of vague and non-specific terminology about the diagnosis of deafness, the hearing amplification options, the therapeutic avenues, amongst others. It reinforces the suggestion that the hearing care personnel may not always empower the caregivers with the necessary language and terminology and the hearing care personnel which may perpetuate the communication difficulties when they do not communicate effectively with the deaf children's caregivers. By providing caregivers with the appropriate and distinctive terminology, caregivers can be empowered to communicate about their children's deafness and, as a result, can enact greater agency in collaborative decision making and discussions about their children's deafness without maintaining power over people through their "disciplinary grip of experts on citizens" (Bloor, 2011, p. 410).

The cooperation between the context mediators may bolster the number and quality of collaborative consultations within clinics, hospitals, schools, and any other such occasion for consultation between hearing care personnel and deaf people and their families. As has been highlighted earlier, interpreting between languages involves more than a literal transposition of one language into another but rather an assimilation of the language, context, and meaning. There has been a call to increase the number of interpreters within clinical settings because "interpreter services have been shown to lower costs by decreasing the use of diagnostic testing" (Hussey, 2013, p. 192). However, this qualitative project has demonstrated that cost, although a factor which cannot be ignored, ought not be the driving factor behind the inclusion of interpreters and that, instead, they ought to be seen as people who can offer more personal and collaborative interactions between clinicians and caregivers. Also, context mediators, in their "redistribution of power and resources to the individual or group that has demonstrated a need" (Andrews et al., 2010, p. 129) can empower caregivers by more fully and congruently reflecting their experience.

9.3.11. Psycho-emotional support for caregivers is necessary at various levels.

This study calls for the psycho-emotional support of caregivers of deaf children. The results suggest that caregivers need and value the potential support from different structures which means that therapeutic goals ought to be respectful of caregivers' specific concerns which include their priorities, hopes, needs, goals, and wishes while attentive to the need to "work with adults to enhance their confidence and competence in fostering their children's development" in ways which are contextually sensitive so that interactions "are flexible, individualized, and responsive to changing needs, preferences" (Moeller et al., 2013, p. 432). This support, especially from similar others, can alleviate some of the pressure caregivers experience because caregivers can become aware of existing services and facilities within their vicinity while cognizant of caregivers work and family obligations (Ahlert & Greeff, 2012) so as to empower the caregivers in their attempts to fulfil their caregiver role most completely. The support offered by groups of people with similar experiences can empower the members of the group through the sharing of information and the development of social consciousness (Mundell et al., 2012).

However, this study has demonstrated that psycho-emotional support is interlinked with material support because the absence of material resources within a resource-poor context manifests itself in caregivers' psycho-emotional distress. Therefore, in order to address the psycho-emotional aspects, due consideration needs to be given to the caregivers' contextual needs and requirements so as to reduce the third-party disability that may arise from their children's deafness, for example, the inability to engage in employment seeking due to their caregiver responsibilities for their deaf children in particular. Therefore, there is the suggestion that collective capabilities ought to be enhanced to maximise caregivers' potential for engagement in employment (Graham et al., 2013). Therefore, it appears insufficient to offer specific psycho-emotional support without offering support in the other domains too. By having appropriate structures in place to accordingly support caregivers, they may be able to experience buffers to the stress, even if the stress itself is not removed.

Moreover, in fostering COPs in which caregivers can interact with similar others, caregivers ought to be empowered to recognise the value of the support of similar others who are contextually and experientially similar to each other and who can offer horizontal support between caregivers rather than being disappointed by the poor structural support offered by vertical engagement at, for example, government institutions. Having said that, COPs should include a variety of stakeholders who can maintain the necessary checks and balances so that the COP does not become another instrument to exert power over caregivers by hearing care personnel. Similarly, the composition ought to be diverse including a range of people from caregivers of deaf people, teachers of deaf children, social workers, audiologists, deaf people themselves, family members of deaf children, and community members who show a particular interest in deafness.

Also, this study affirms the need for the involvement of male caregivers and father figures in the COP so as to support the female caregivers who tend to carry the caregiver burden. However, it does not suggest that women can only become empowered through and by men because that only perpetuates the erroneous notion that women are actualised through men. Instead, in the finding that the caregiver role is gendered towards female caregivers, it suggests that they could benefit from sharing the roles and responsibilities in being caregivers to deaf children. The COPs offer occasions for the male caregivers who are involved to interact with each other. There are opportunities to learn SASL in instances when “fathers are unwilling to display their lack of signing skill in public” and so the inclusion of male caregivers within the COPs is essential because the “presence of other men with the same ability level might help fathers to practice signing without feeling self-conscious” (Meadow-Orlans & Sass-Lehrer, 1995, p. 319). Therefore, there is a safety within the social network and COP where people can learn from each other and become empowered through that interaction and through a sense of belonging.

COPs can fit with the recognition of the different people’s contributions, value, and resources from which all members can benefit in which “the importance of a consulting and supporting strategy using a resource-oriented approach aimed at empowerment is confirmed” (Hintermair, 2006, p. 508) while keeping within their natural networks so that the COP does not appear as stifled, contrived, and regulated. Instead, the caregivers’ natural networks of family and friends, among others, ought to interact with the artificial networks that have developed after the deafness so that these artificial networks overlap with the naturalness of the natural networks to encourage caregivers’ comfort in engaging with the COP and to develop their personal and social resources in their caregiver role, especially because the caregivers in this study seemed to experience material poverty as well as resource poverty, both of the personal and social kinds. Also, within rural settings such as the one where this study was conducted there appears to be a need to extend social networks so as to “communicate and share information with isolated and uninvolved families” (Ahlert & Greeff, 2012, p. 403).

Despite the strengths and benefits of COP, there is a caveat: COPs need to ensure that they do not become vehicles for perpetuating ineffective or poor practice amongst caregivers and hearing care personnel alike. People can learn from each other and they ought to take strength from each other, but their practices also need to be interrogated so that effective practices can be encouraged and less effective ones can be modified and that this modification can be driven by the people themselves but backed up with literature, research, and theory thereby reinforcing the need for evaluation of a COP so as to avoid the learning of bad habits or ineffective practices from other caregivers and from other hearing care personnel.

In this study it was observed that caregivers' poverty of agency and structure meant that they had to devolve agency to others which caused them unease. By expanding the COP and social networks, caregivers may be able to devolve or even share agency with people inside of their networks rather than having to devolve to unfamiliar and impersonal sources of support. A COP may offer a more intimate, familiar, and personal support base, the features of which caregivers identified in this study as the benefits of family support. Therefore, in this study, it appears as though the values usually ascribed to families are sought in wider networks and this desire has echoes of the notion of ubuntu which people may seek in the broader community.

This study suggested that due to family intimacy, family support is especially valued. However, as this study also demonstrated, families can contribute to the weakening of caregivers' agency and so, especially within a context which understands the value of ubuntu, the concept of family could be extended to include the community members and similar others with whom caregivers can share similar intimacy and with whom they can identify. Therefore, in the same way that in the context where this study was conducted and in South Africa in general, the notion of caregivers extend to beyond biological parents, the notion of family may need to be extended too so that other people can be identified as family through their similarity with caregivers. This particular recognition of the contextual variations of established and formal notions of family and of family-type support is in line with the suggestion that practice be contextually attuned so that "innovative, grassroots-located programmes that recognise and enhance the assets of all household members might lead to these households being able to enhance their outcomes" (Graham et al., 2013).

More specifically, cognisant of contextually specific needs and caregivers' specific contextual knowledge, true agency means "the capacity to transpose and extend schemas to new contexts" (Sewell, 1992, p. 18) which means that caregivers, especially within a COP, can share and mould the support accordingly so that it is pertinent and relevant to specific contexts. In being able to support other caregivers, in even the smallest way, caregivers are building their own personal resources psychologically, even if not materially, because there is "mutuality and a common focus regarding the key issues among members and inspires them to contribute their knowledge and ideas" (Moodie et al., 2011, p. 14) especially when the structures which are meant to offer that opportunity for agency are inefficient or unavailable as is the case in this rural context.

9.3.12. Respect for caregivers ought to be shown in every interaction.

This study also demonstrated the need for continued respect for caregivers and the need for respectful, mindful, and considered interactions with caregivers in every instance. The ascription of the caregivers' value onto their participation in the project highlights the importance of every interaction that audiologists, other hearing care professionals, and researchers have with caregivers and other people. It highlights the significance which caregivers may place on activities which audiologists and researchers consider routine and perfunctory. There appears to be a lot more value ascribed to these interactions than professionals may realise and so it reinforces the importance of the need for respect, consideration, and attention during all interactions, regardless of whether they are within a clinical setting or otherwise.

This thesis calls for the respect of caregivers as people while also calling for respect for the role which they fulfil with regard to deaf children, a role which is often devolved to them and which they assume. However, that respect for caregivers ought to be based on their worth in themselves, not only in relation to their caregiver role in relation to deaf children and how that role impacts on deaf children. Caregivers have the right to be cared for and are important in themselves. This respect ought not be used with ulterior motives in order to ‘get them on side’ and to garner cooperation with the caregivers: the respect ought to be for respect’s sake. The caregivers may appreciate the respect and the value shown to them especially because they may not necessarily always get this due respect and validation as revealed in their interviews. Also, as audiologists, this respect ought not be hollow or shallow, nor should it be used as a way of demanding reciprocal respect from the caregivers because the respect given to the caregivers is unconditional.

In interactions with caregivers of deaf children, there must be an avoidance of obsequious and even insincere demonstrations of respect that do not show the depth of consideration for the caregivers themselves. It means acquiring and using contextual knowledge from the caregivers’ contexts about the appropriate use of signs of respect, which in the context where this study included: greeting people with a respectful handshake where one hand holds the other forearm; greeting people respectfully, for example, the use of ‘*sanibonani*’ rather than ‘*sawubona*’ when greeting people who are older or people of higher social standing because the former suggests the magnitude of people’s status based on age and social standing; and using appropriate terms of respect and deference by, for example, avoiding the trite use of the title ‘*gogo*’ (granny) when it does not apply. People recognise these acts and it shows that they are valued. Similarly, the transformative effect of the interview cannot be limited to the participants of research projects but to the researchers too, especially because qualitative research is a collaborative exercise which suggests that the researchers have the potential for change too that comes from the exploration of the participants’ meaning and experience. From the qualitative research, researchers can transform their own preconceptions and anecdotal ideas into a personalised understanding of people and their experience.

9.3.13. Implications for future research.

This study has highlighted the need to further explore the caregiver dimensions of deafness in the five domains which were identified in relation to childhood deafness. It suggests that there is a need for further study into the following aspects:

- Third-party disability is an under researched phenomenon which suggests the need to more widely explore this concept as it relates to other family members of deaf children and the social dynamics around this phenomenon. This study revealed that siblings of deaf children may not experience the same level of third-party disability as the caregivers do and so there is the need to look at the buffers to third-party disability in younger children so as to build on those, in addition to the components of structure and agency which were identified in this current study. Also, with regard to communication difficulties, there is a need to broaden the topics of research in which the notion of third-party disability is experienced and to publish these so that it extends beyond the pioneering works on adult deafness and aphasia (Grawburg et al., 2013; Scarinci et al., 2009, 2012).
- Caregivers in this study referred to the impact of their children’s deafness on their siblings. It appears necessary to more fully explore the experience of siblings with regard to their siblings’ deafness, especially with regard to non-parental siblings such as cousins when caregivers of deaf children are aunts or grandmothers and not biological parents. The situation in South Africa where deaf children may live with non-fraternal siblings requires interrogation to look at how the different familial relationships may mediate the experience of deafness.

- The role of fathers and male father figures requires particular attention, especially in light of the historical position of fathers in relation to migrant labour and the homeland system under apartheid. Fathers' experiences of deafness requires exploration because of the potential for the support for mothers and female caregivers of deaf children which comes from the shared responsibility and reduced sense of loneliness in their experience as caregivers of deaf children. I am not suggesting that the inclusion of male caregivers into the caregiving equation is the panacea to female caregivers' difficulties; I am suggesting that, as expressed by the caregivers in this study, the sense of spousal support is important and beneficial and that it could transcend gender, notwithstanding the power dynamics of gender relations.
- There is a need for research into research itself with regard to deafness. The contribution and value of qualitative research needs further exploration, especially with regard to the strengths and weaknesses of the different approaches and to study, specifically, the value of the ethnographic interviews from the participants' point of view where the focus would be on the specific points which caregivers find beneficial and which they find distressing (Funk & Stajduhar, 2009). There is also the need to explore the long term outcomes of participation in qualitative interviews where the focus would look at enquiring from the caregivers whether participation in collaborative qualitative research empowered them and to consider the specifics of that possible empowerment. Specifically, the Framework method offers opportunities for the detailed analysis of the participants' interview transcriptions so as to further explore these and other aspects of qualitative research.
- Self-efficacy, and especially parental self-efficacy (T. L. Jones & Prinz, 2005) ought to further explored with regard to caregivers in South Africa. The domains in this study identified barriers to self-efficacy and it appears to be necessary to explore the

underlying psycho-emotional processes which apply specifically to South Africa in light of the country's oppressive history and context of vulnerability. Furthermore, there is the need to expand on the concept of parental self-efficacy to include caregivers who fulfil parental roles because their self-efficacy may be challenged by processes which are different to those of biological parents.

- Considering the historical educational disadvantage which many South Africans experienced under apartheid, it is important to study the specifics around literacy and communication capabilities and power exercised by caregivers in different interactions with regard to their different children in the different domains. That is, explore the strategies they use with regard to literacy and language difference when they have to interact with formal structures where they may exert less influence and power. Specific attention can be directed at their feelings and frustrations specifically as well as the strategies they employ in different situations. This information could be useful to use as a platform for capacity building for other caregivers by sharing that information with them through, for example, support groups and other opportunities for community of practice. There is a need to look at the literacy and communication congruence of caregivers and service providers. Additionally, the literacy and communication competence of deaf people themselves in their attempts at interacting with structures of power such as government.
- Community of practice was identified as a potential empowerment tool for caregivers in this study. However, long term research is required in this under-researched aspect of audiology (Moodie et al., 2011), especially as it relates to caregivers of deaf children but also with regard to significant others of deaf adolescents and deaf adults. Longitudinal studies in this regard could be useful to explore the timeframe and lifespan of community of practice as well as the different types of support and benefit

which different age groups of caregivers and significant others require and receive. Moreover, there is the need to look at the different configurations and participants in the community of practice and how power differentials within the community may play out so as to establish the most effective constitution of the community of practice and the mix of participants. There is the need to look at the formal establishment of community of practice as well as the sustainability of that community while also considering the specific topics of support and the value of that support within the community of practice.

- This study was conducted in a rural setting which has a particular characteristic of poverty which is flavoured with the specific rural considerations such as scarcity of resources, large geographical distance to resources, and the rural terrain, amongst others. Additionally, this particularly vulnerable rural community is characterised by food vulnerability, limited access to services, and communicable diseases (Goudge et al., 2009) but peri-urban and urban communities experience similar challenges, especially in light of newer and more all-encompassing interpretations of rurality (Watermeyer & Barratt, 2013). Therefore, in order to get a fuller picture of the caregiver experience in South Africa, there is the need to look at the experience of urban caregivers of deaf children too.
- Research is necessary to explore the experience of caregivers who themselves have a disability, not third-party disability, and those who are deaf or Deaf so as to understand specifically the intricacies of how their disabilities impact on their caregiver experience, not to mention the identification with their children. Caregivers may have different disabilities to their children and it would be important to study the impact of those disabilities on their caregiver experience while also looking at the facilitation strategies employed by the deaf children around their disabled caregivers.

9.4. In Closing, For Now …

This study calls for a renewed curiosity into the exploration of deafness and the experience of deafness. It is crucial that audiologists and others consider context in order to engage in ethical interactions with deafness. The participants in this study revealed that there is a need for audiologists and deafness personnel to co-construct meaning with regard to the experience of deafness. Caregivers of deaf children want and need to be heard. A humanitarian approach to audiology does not imply a missionary stance where audiologists prescribe what they feel is best for caregivers and to deaf. Instead, a humanist and contextually attuned approach enhances caregivers' self-efficacy and agency within the five domains identified in this study. Audiologists need to be aware of the domains in which deafness is experienced so that the focus is not limited to ears and hearing; the focus ought to be a collaborative interaction with children who are deaf and their caregivers too.

There is also an ethical and human rights imperative to be more than audiologists and to understand barriers to agency, to reveal those barriers, and to take steps to address them by enhancing self-efficacy. The only way to understand these structural barriers to agency is to ask the people who experience them and qualitative methods are invaluable in discovering the essential and often unasked. People want and need to be heard. Audiologists, ironically, are called upon to listen to people's experience and to recognise the challenges in their life domains while remaining conscious of the contexts of that experience. By doing so, audiology can collaborate more fully and respectfully with people to provide opportunities for the realisation of potential which would otherwise have remained unearthed. In doing so within a community of practice, there is an opportunity for collective effort and action. Considering South Africa's history, in our interaction with deafness, we can do well to remember:

> As a society we enjoy the benefits left by those before us, who collectively resisted inhumanities and worked for social reforms that permit a better life. Our own collective efficacy will shape, in turn, how future generations will live their lives. The times call for a commitment of collective effort, rather than litanies of powerlessness that instil in people beliefs of inefficacy to influence conditions that shape the course of their lives (Bandura, 1982, p. 145).

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Appendices

Appendix A: Information about Kamagugu Inclusive School

As was detailed in Chapter 6, Kamagugu Inclusive School in Kabokweni, Ehlanzeni District, Mpumalanga, served as a source for participant recruitment and snowball sampling. According to the school's 2013 prospectus, the school's vision is to "provide programmes supporting learner and staff development and growth, preparing them for participation in formal schooling, skills development and lifelong learning" while its mission encourages "working together with parents, community and staff to create a network of support to all stakeholders of the school whilst focusing on inclusive strategies" (Erasmus, 2013, p. n.p.)

In my meeting with the occupational therapist, I asked her for more background information on the school and she explained that the school accommodates learners with special needs, including those with physical, cognitive, learning, hearing and visual difficulties, although not blind children because they do not offer Braille facilities. She went on to say that the school had been started about 10 years previously and its catchment area was the Ehlanzeni District.

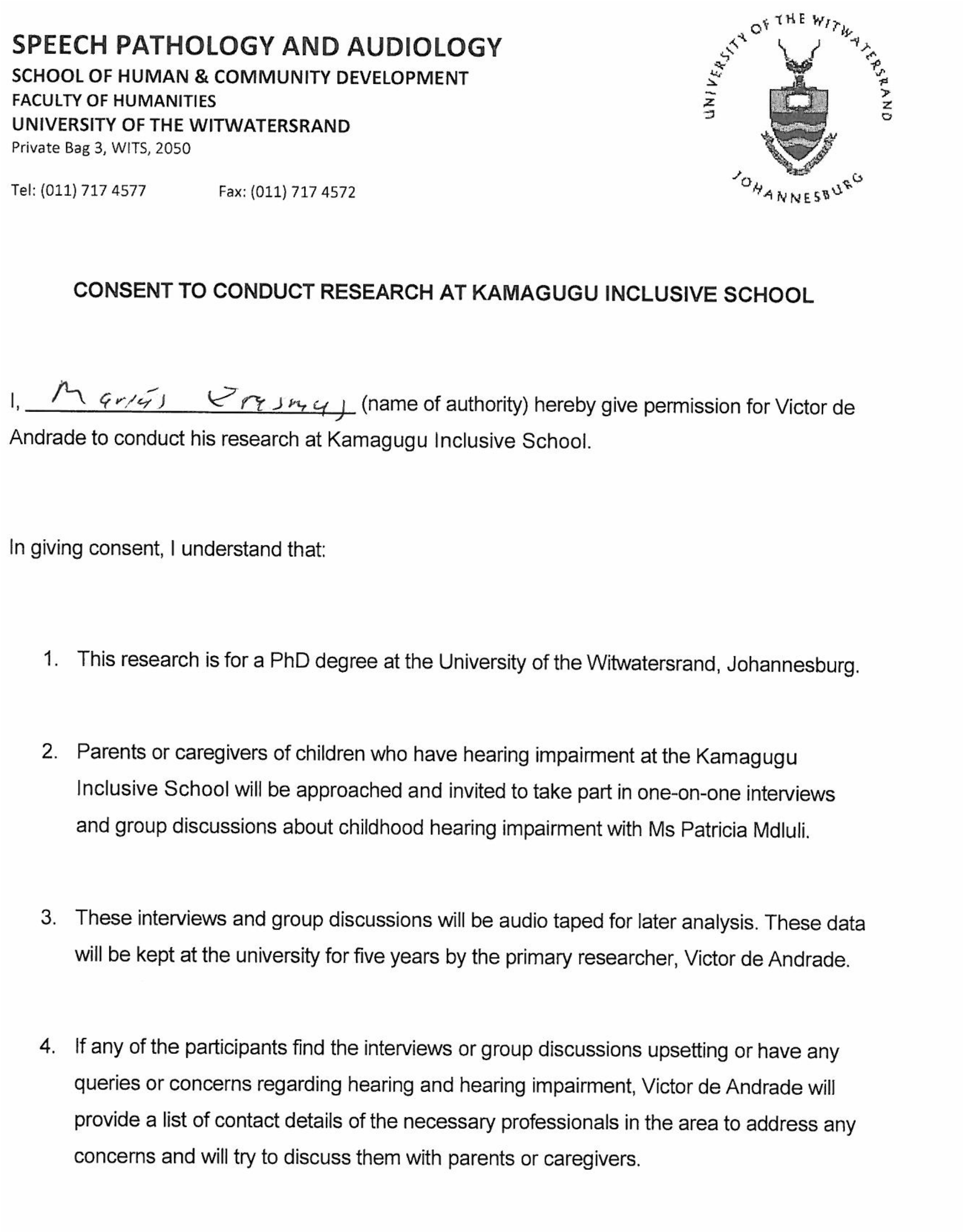
The 2013 prospectus reports on the race of the learners at the school and says that 96% of the learners at the school are classified as black, 2% as coloured and 2% white (Erasmus, 2013). The language of instruction is English and siSwati for hearing learners and South African Sign Language for deaf learners. It is a day school which does not have students who board at the school. Because it is a day school, there are transport arrangements to get the children to school and back to their homes. It was reported that the children travel by bus and kombi taxis to school and that there is a public and private sector partnership where the government pays for the children to travel to and from the school on these buses and taxis. She pointed out that the same drivers are used all the time and that assistants travel on the buses with the children to supervise and accompany the children.

The occupational therapist said that the school falls under the auspices of the Mpumalanga province's Department of Education and therefore receives a government subsidy. It is also a Section 21 school which she said means that the learners are required to make a financial contribution to the school in terms of school development fees which amount to R490.00 per year. She did say that there were bursaries available to students in financial need. When I asked her about the admission policy to the school, she reported that applicants fill in an application form and the children are assessed by the therapist at the school whereupon, if they are accepted into the school, they are placed with children of the same age in age grouped classes. According to the prospectus, there are a maximum of 15 learners per class (Erasmus, 2013). The school is described as a primary school which tries to get the learners to reach the equivalent of grade 9 but can accommodate learners up to the age of 18 years through a modified curriculum. Vocational training is offered to the learners in terms of "computer classes, garment making, nail and beauty, arts and craft, beadwork, car wash, woodwork, housekeeping, office practice and communication skills" (Erasmus, 2013, p. n.p.) at the school. There are also workplace practice opportunities through some businesses in Nelspruit (Erasmus, 2013).

The occupational therapist said that the school employs 50 members of staff where 28 are paid for through the Department of Education while 10 are paid through the school's governing body. In terms of support services at the school, it was reported that there is occupational therapy and a social work support at the school and that a post for a speech therapist had just become open and that they would be advertising for that post.

During my meeting with the occupational therapist, she told me that, at the time of my data collection phase, the school had approximately 200 learners, of whom 35 are deaf. The school has three classes for the deaf learners: the 6 years of age to 9 years of age class, the 10 years of age to 13 years of age class and the 14 to 18 years of age class. These classes had 14 learners, 11 learners and 10 learners respectively. The children who are deaf are grouped according to age and are in classes with other deaf children where they are taught in South African Sign Language. The two teachers' assistants are deaf themselves and support the teaching offered by the hearing teachers who provide instruction in South African Sign Language. The teachers' assistants have a Grade 10 qualification and have completed courses and workshops to prepare them for their roles as teachers' assistants. The occupational therapist pointed out that all the children and teachers in the school attend South African Sign Language classes. South African Sign Language classes are also offered free of charge to the general public and to caregivers. When I asked her about hearing aid provision, she said that the children who have hearing aids get their hearing aids from different hospitals.

Appendix B: Permission from Kamagugu School to conduct research.



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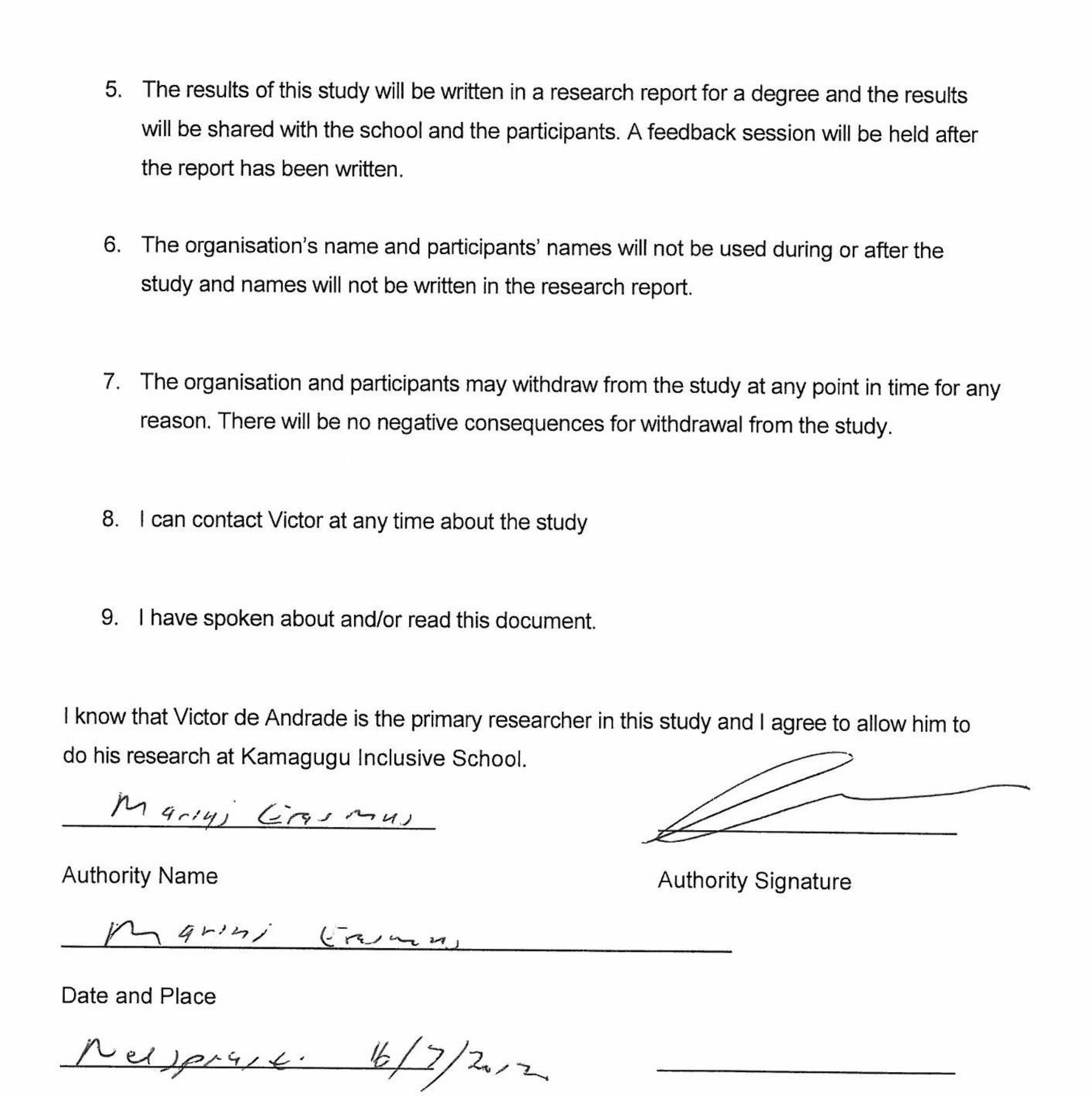
CONSENT TO CONDUCT RESEARCH AT KAMAGUGU INCLUSIVE SCHOOL

I, Marius Erasmus (name of authority) hereby give permission for Victor de Andrade to conduct his research at Kamagugu Inclusive School.

In giving consent, I understand that:

1. This research is for a PhD degree at the University of the Witwatersrand, Johannesburg.
2. Parents or caregivers of children who have hearing impairment at the Kamagugu Inclusive School will be approached and invited to take part in one-on-one interviews and group discussions about childhood hearing impairment with Ms Patricia Mdluli.
3. These interviews and group discussions will be audio taped for later analysis. These data will be kept at the university for five years by the primary researcher, Victor de Andrade.
4. If any of the participants find the interviews or group discussions upsetting or have any queries or concerns regarding hearing and hearing impairment, Victor de Andrade will provide a list of contact details of the necessary professionals in the area to address any concerns and will try to discuss them with parents or caregivers.



5. The results of this study will be written in a research report for a degree and the results will be shared with the school and the participants. A feedback session will be held after the report has been written.

6. The organisation's name and participants' names will not be used during or after the study and names will not be written in the research report.

7. The organisation and participants may withdraw from the study at any point in time for any reason. There will be no negative consequences for withdrawal from the study.

8. I can contact Victor at any time about the study

9. I have spoken about and/or read this document.

I know that Victor de Andrade is the primary researcher in this study and I agree to allow him to do his research at Kamagugu Inclusive School.

Marinus Erasmus

Authority Name

Authority Signature

Marinus Erasmus

Date and Place

Nelspruit. 16/7/2012

Appendix C: Contextual considerations during the data collection phase

Navigation of the Particular Context

This study has provided numerous opportunities to appreciate the importance and the necessity for research, and invariably practice, to be contextually sensitive but also contextually aware. The data collection phase, in particular, required particular consideration due to the dynamics of the participants and of the setting. Although I have worked in that district of Mpumalanga before, through this study, I was afforded the opportunity to look at the setting and the people from a different, more analytical perspective. I knew that there were deaf people in the area, yet people in the community did not seem to know about deaf people or about the services offered to them. It appeared necessary to explore this hidden population (Singer, 1999) within their setting. I was invigorated by the excitement of studying facets of deafness within a context in which deafness does appear to receive the prominence it merits, albeit from the perspective of an audiologist. Before the data collection phases, I had foreseen challenges in physically getting to meet with caregivers because of the rural terrain as well as the need to consider participants' language, culture and socio-economic status when exploring the experience of caregivers' of deaf children in the Ehlanzeni District of Mpumalanga. Hereafter I have provided some examples of the considerations which had to be given with regard to the participants and to the context while conducting this study.

Navigating the Physical Terrain: The Examples of Little Rose and Ventures

The physical context and setting in which the research was conducted required particular consideration, not only to me as the researcher, but also to participants. Even though P lived in this district, she did not know the location of the participants' homes in every village we visited and the satellite navigation systems were not very helpful either because the villages were not well represented there either. P asked for directions to the participants' venue choices, and often when these were at their homes, the landmarks used to direct us to the homes were not always very noticeable.

For example, for Participant 8's interview, we travelled along a tar road and as P was on the phone with the participant's sister, the participant's sister said that we must turn onto a sand road at a shop called Little Rose. We drove down the road until it ended and we could not find Little Rose. We drove around looking for this shop but to no avail and when P called back, the participant's sister said that we'd probably passed Little Rose. P explained where we were and that we were outside another shop named Kasadosol on that same street. The participant's sister replied that we were at the correct shop. P replied that the shop was not called Little Rose to which the participant's sister responded that Little Rose was the old name for that shop and that we ought to turn onto the sand road there.

Another example was when a participant, Participant 12, said that we ought to drive to the KFC in Barberton and that we were to phone her when we were in town so that she could direct us from there. When we got there, P phoned the participant whom we were due to meet and asked for directions to her village. She replied, "*Just follow the Ventures*." In other words, we were to follow the Venture kombi taxis. When P then asked her for more specific details, the participant said that it was easy and gave the same reply as earlier, "*Just follow the Ventures*."

These examples illustrate how the people from the villages where the interviews were conducted had their known system of navigating around and between the villages because of their knowledge of the area with which we were unfamiliar. We were often given landmarks of transient structures, for example, a make shift car wash. The absence of street names and house numbers made it difficult to find participants' houses. More than once we drove into dead-end sand roads and up steep, overgrown embankments looking for people's houses.

The situation was made more difficult when it rained since the car could often not travel up the sand roads as they often had big chunks which had been washed away. When we made the appointments with caregivers for the individual interviews, we set aside about an hour for each individual interview since the pilots had suggested that the interviews could take about half an hour to three quarters of an hour each but we also had to set aside extra time to account for the difficult terrain we had to cross to get to the interviews. Sometimes we encountered obstructions in the road over which we had no control such as the herd of cows which blocked the one road for a time and we could not pass. All of these factors made timekeeping difficult. Never the less, I tried as much as I could to keep to time because I was concerned that my apparent tardiness could be misconstrued as rudeness, when that was not my intention at all.

The physical setting in which the research is conducted may pose particular challenges to participants to which researchers need to be sensitive and considerate. For example, when P phoned Participant 13 to schedule the second group interview, this participant asked to be collected from her home for the group interview because she said she could not take public transport to the community centre. Upon our arrival by car at her house, it became obvious to me why she could not take a kombi taxi to the community centre. She really appeared to be struggling to walk and she was using a wooden rod to steady herself as she walked. During the individual interview with her the year before, she had been walking independently. However, there appeared to have been a dramatic change in her mobility since the year before. When we arrived at her house, it was raining quite heavily. P and I approached her and P thanked her in siSwati for her willingness to participate in the group interview but she also explained that in light of the rain and her apparent mobility difficulties, she did not have to feel obliged to participate in the group interview. Participant 13, however, said that she wanted to come to the group interview and that she would make the effort. Her difficulties were very obvious and again we reminded her that there was no obligation, yet she reiterated her desire to take part in the group interview. We, therefore, assisted her to the car while holding an umbrella over her head due to the rain. P, Participant 13 and I drove to the community centre. This lady's determination to participate in the group interview seemed to reflect the value she placed on participation and reminded me about the considerable effort which many participants have to exert to be involved in research projects. It was a humbling reminder to me that it is not only the researcher who experiences challenges but that participants are also susceptible to challenges which we need to consider.

The Participants' Choice of Venue for Participating in Research

Within the interpretivist approach, participants' choice of venue for the interviews appeared interesting. I offered participants the choice of venue for the interview so that they could feel comfortable during the interviews. The majority of the participants, despite my attempt at giving them a choice of setting, defaulted to their home settings since they did not have other options available to them due to unemployment and limited financial means. The people who were employed chose to meet at their workplace or at a neutral setting. Those participants who were employed could choose to meet somewhere outside of the house, thereby apparently creating some personal distance between the research and the intimate space of the home. This use of a public space rather than a private space may have been chosen to protect these personal boundaries (Hesse-Biber & Leavy, 2011) of their family lives. For those who were employed and who chose to meet at their place of employment, the settings included in the car in an avocado plantation car park, an office boardroom, a crèche playroom, and a spaza (informal) shop, while, for those who were employed and chose to meet elsewhere, two chose to meet at the KFC in Nelspruit while we met with another in the car in the car park of the hospital where her husband was receiving treatment.

The choice of venue seemed to reflect class structures too since when the appointment was made with Participant 6, when the fieldworker asked her how we should identify her when we met at the KFC in Nelspruit, she replied that she would be driving a white BMW and that we should then know that it is her. The freedom of choice of venue did not seem to be there for the unemployed or financially challenged participants and the interviews were conducted in participants' courtyards, kitchens, sitting rooms, and even bedrooms. I often felt a mix of emotions with regard to the venue for the interview. It could be perceived as a welcoming gesture where I, as the researcher, was in the participants' personal spaces. However, despite being welcomed in to people's homes and despite no apparent hostility to my being there, part of me also felt as though I was intruding in that very personal space: the personal physical space as well as the emotional space.

Temporal Considerations in Conducting Research

It was noticed that, especially for the participants who were not employed, there was less expectation of me to be time bound or punctual and I found that a common time arrangement with participants was a vague description. Interview times were designated generally and not specifically, for example, late morning, early afternoon, after lunch. Again, the participants who were not employed did not seem to be as constrained or dictated to by time.

Having worked in similar settings before, I was not surprised by the less rigid keeping to clock time. However, I did not like it when we, P and I, did not keep to time, especially because I was aware of the effect it would have on the next interview. However, participants did not appear to be too disturbed if we had run late from the previous interview, which does not excuse our tardiness, but I was taken by people's acceptance of it. When we were running late or when we were lost, P phoned the participants and advised them of such. I made every effort to make sure that we arrived on time for appointments but it was not always possible because of the poor road infrastructure and the poorly marked roads that did not have street names or house numbers.

Distance Communication with Participants – Reliance on Cellular Telephone Communication

Most of the distance communication with potential participants and participants was conducted via spoken cellular telephone communication. The reliance on cellular telephone communication reflects the need for verbal communication in light of many participants' literacy limitations. The participants' reliance on the use of cellular telephones instead of landline telephones reflects the underdeveloped resource infrastructure provided by the government in this rural context with regard to communication and people's reliance on other methods and structures. The distance communication with the two deaf participants was also conducted via cellular telephone but via text message or WhatsApp because their deafness precluded them from hearing spoken conversation over the cellular telephone.

This underdeveloped government support and infrastructure with regard to telecommunications mirrors the underdevelopment of its infrastructure and support of the caregiver and the deafness needs. Cellular telephone provision can be considered a metaphor for the support of deaf children and their caregivers where caregivers cannot use government support because it is not available or insufficient and, because of this unavailability and insufficiency, caregivers need to explore alternative options and methods. Similarly, notwithstanding cultural choices and practices, caregivers may seek traditional healing practices to supplement the inaccessible screening, diagnostic, and support services for deafness in their rural setting. Relatedly, because of the poor landline telephone infrastructure to people's houses in this rural district, people do not have choice in their use of cellular telephone communication. Even if caregivers prefer to use an alternative method of communicating telephonically, their options are limited in terms of the telecommunication infrastructure in the very rural areas where they live and by their limited financial means. The caregivers’ need to use what is available is representative of their lack of choice when it comes to deafness related services where they can only utilise what is available to them and that they do not have alternatives. In the same way that the caregivers’ use of cellular telephone communication incurs high call costs, caregivers also incur high costs in their attempts at sourcing support for their deaf children. The caregivers to whom we spoke, due to their financial limitations and consequent difficulty to access cellular network contracts, tended to have pay-as-you-go cellular phone packages and this inability to access a contract is a metaphor for the lack of power and recognition that caregivers of deaf children have. Due to caregivers’ limited financial resources, participants often mentioned that they had run out of credit on their cellular telephones and so they could not make telephone calls. This running out of credit could serve as a metaphor for their running out or exhaustion of options when it comes to their children’s deafness and their need for support. It was observed that participants appeared to use other people’s phones or ask other people to call on their behalf when their credit ran out which may serve as a metaphor for the caregivers’ need to ask other people to support them and for other people to fulfil tasks on their behalf because they do not have the resources to do so themselves.

Cellular telephones are also symbolic of the duality of South Africa where it represents a very technologically advanced service which is being used in a context where many people in this rural district do not have access to running water in their houses and use outside, long-drop toilets. It appears to be a metaphor for the pockets of development and infrastructure which is available in some contexts and settings in South Africa but wholly absent in others; a reflection of the contradictory South African landscape where some people have all the access and resources they require while others may not.

The Need for Flexibility When Conducting Research in a Context Where People's Survival Needs are the Priority

A particular consideration which researchers need to keep in mind is the exploration of phenomena in contexts where research does not hold immediate and tangible rewards, especially in contexts of limited resources and where people have more immediate survival needs and, therefore, although participants voiced their satisfaction with having participated in the research project, research may not be a priority in light of people's vulnerability and survival needs.

The manager of a centre for children with disabilities withdrew from recruiting participants because she did not see a material and immediate benefit to participation in the study. Originally I had approached her and then met with her and I asked if she could invite caregivers of deaf children to participate in my study because of her work at the day centre for children with special needs. During our initial meeting she appeared interested in inviting participants to be interviewed for my study and said that some children who attended the centre were deaf and that she could ask their caregivers whether they would be interested in participating in the project. I thanked her for her willingness to assist in this study and she said that I would need to get permission from the relevant government departments to include the centre as a point of contact for the study. I, subsequently, went through quite a difficult bureaucratic application process characterised by the continuous handing over of the application from one person at the department to another to source that permission where the application went through seven different people before it was eventually signed off because at each stage the person said that it was not his or her responsibility and passed it on to another person. However, in the weeks which followed, the director of the disability centre withdrew from the project and the centre fell away as a possible recruitment site because she said she had not contacted any of the caregivers and that she was no longer interested in participating in the study. After that, she stopped taking my calls and answering my messages. Even though I did not want to base my thesis within purely a disability studies framework, this centre for children with disabilities appeared to be a viable recruitment point but it was not to be.

The second group interview serves as another example of withdrawal from the research process. This group interview was to be held in a community centre in Matsulu village but, instead, it was held in the garage of someone's house in the same village. This community centre had been proposed by Participant 10 since she had attended at the centre various times and was agreed upon by the caregivers who had agreed to participate in this second group interview. Participant 10 gave P the centre manager's number to arrange for the date and time. The field worker, P, phoned him and after she had introduced herself and explained the project, she asked permission to hold the interview there. The centre manager agreed and also agreed on the date and the time for the group interview. A follow up call was made to the centre manager on the morning of the interview to confirm the availability of the centre for the group interview and the centre manager again confirmed it. On our way to the community centre for the interview, P phoned the centre manager to confirm the directions which he gave to her and to confirm our attendance. However, upon our arrival at the centre and upon approaching the centre manager to whom P had spoken to before, we were declined access to use the community centre. The centre manager asked us how the community centre would benefit from the group interviews and when we reminded him that it was for research purposes as per the earlier telephonic conversation, he declined the use of the centre for the interviews.

By this stage, the participants, except for one, had arrived at the centre. I was very disheartened and angry at his decision. This discussion took close on an hour which delayed the start of our interviews. As it was raining and we were standing in the porch of the centre, I knew that an alternative venue had to be found especially because I was aware of the effort people had made to attend for the group interview so I could not, at this stage, tell them that the interview was not going to proceed. Fortunately for me, one of the employees at the centre, who lived nearby, offered the use of her garage for the interviews and this offer was accepted by the participants. It was now closer to 3.30pm and the one participant who had agreed to join the group interviews at the specified time of 2pm did not arrive for the interview and P phoned her to advise her of the change of venue but her phone just rang unanswered. I then drove the participants to the lady's garage so that the participants would not have to walk in the rain.

When we arrived at this lady's garage, the owner of the garage arranged for 4 chairs and two large reed mats on which we could sit for the group interviews. Her garage was separate from her house and so there was no risk of her or her family sitting in or overhearing the interviews since they were inside the main house. It was raining quite hard at this stage and it was quite noisy on the roof of the garage. Also, the back of the garage was open to the yard and the chickens had made their way into the garage to shelter from the rain and, despite me taking them out, they often returned but the participants did not seem to be perturbed or disturbed by their presence. It may be because in many of the houses we visited, chickens were seen to roam around freely and so the participants did not appear to be bothered by them.

These examples highlight the need for flexibility during the research process because the process does not always go according to plan. They suggest the need to improvise and alter plans, while also showing a reliance on the unexpected assistance offered by people who may not be directly involved in the research.

Reflection upon Culture and Language Mediation

One of the most important considerations in conducting this qualitative study with participants of another language and another culture was my need to conduct the study in such a way that was contextually sensitive. Although I am familiar with working with culture and language mediators during consultations with clients and in my previous research endeavours, in conducting this study I was particularly aware and attentive to the need for the inclusion of the mediation of meaning provided by people familiar with the culture and the language of the participants. Without the language and culture mediator, meaning would have been obscured. P helped me to differentiate between the different actors in the participants' accounts since sometimes the participants would use a pronoun to refer to a person and I could not follow to whom the pronoun referred, especially because siSwati has a single pronoun '*yena*' for 'he' and for 'she' and so P helped clarify that for me too. She also helped me understand some of the metaphorical expressions and idioms which, on their own I did not understand. For example, Participant 17 said in line 200, "*They talked alone and ended up speaking to my husband. And they did not understand him too saying if the baby died, he is going to eat him*" which suggests some form of cannibalism. However, P explained that it is an expression in siSwati which means that the child's uncles were critical and suspicious of the aunt and spoke to the husband and the uncles said that if the child died, the husband would have to take responsibility for the child's death. In other words, to use the English expression, the blood would be on the husband's hands or the blame would be laid at the father's door.

It was particularly challenging for me to delegate the role of fieldworker to others in order to more accurately capture participants' experience. In delegating the role of primary fieldworker to P for the siSwati interviews and to the teachers' assistant for the SASL interviews, I found that I had to be comfortable with the reassurance that their familiarity with the language and culture of the participants as well as their familiarity with the research study and research process, added to this study. When we arrived anywhere, people tended to speak to P first and spoke to her in siSwati translations. For example, at the provincial government buildings, the security desk where we had to sign in to enter the building, the staff spoke to P first in siSwati and directed her in siSwati to where we needed to go. I thanked the security guards in isiZulu which appeared to surprise them as it seems as though they did not expect me to speak isiZulu. Although isiZulu and siSwati are not the same language, they share similarities in their syntax, semantics, phonology and morphology and I therefore found it to be a useful language with which to interact with people when they spoke in siSwati with P. Because of my race, people may not have expected me to speak a language which was like siSwati which seemed to be a way of reflecting my genuine interest in engaging with people rather than absolving the responsibility to P. After a while I learnt the siSwati versions of some of the isiZulu terms, for example, '*akezwa*' (which in English means 'does not hear') in isiZulu was '*akeva*' in siSwati and I found that this knowledge of isiZulu facilitated my ability to follow the interviews to an extent and facilitated my communication with people in the provincial government departments. While setting up the interviews, people would start speaking to P instead of speaking to me. P served a vital function in asking for directions in siSwati as we were driving to the different interview venues. Because of the poorly demarcated streets and house numbers, it proved very useful for P to ask for directions based on local landmarks. She was also the person who made first contact with the participants after they'd given us permission to contact them.

Three participants chose to have their interviews conducted in English and not in siSwati. These three participants had attended school in English and had higher qualifications which suggests a proficiency in English. The choice to speak about their children's deafness in English could have been a way of maintaining the distance between me, their children and the children's deafness by using a more personally distant language to the participants' home language. It could be that the choice of language in which they interview was conducted is in itself a tool to keep the research at a distance from the children by speaking about caregivers' children's deafness in another language.

When the all the individual and group data collection, interview transcription and interview translation had been completed by the end of April 2013, I met with P and asked her to reflect on her role as the fieldworker and the culture and language mediator in this study. She reflected that, in her role as fieldworker in this project, she'd had a "*great opportunity*" and that she felt "*honoured*" to be part of the study. P also said that she learnt a great deal during this project, especially because initially she "*had no idea that other people are facing such challenges*." Additionally, she said that she was fortunate to have met people such as the sister of the two deaf participants because she had learnt great deal about deafness from her which I felt showed her openness to learning through the project in that she did not appear to approach the interviews in a haughty manner, but in a manner that was open to the participants and the people around them providing insight. P did say that, at first, she felt that she was not quite sure what the interviews could contribute to the participants' needs but she felt that the interviews had been "*very helpful*" in that people had had an opportunity to discuss the topic of their children's deafness. None the less, she also said that it was very emotional listening to the caregivers' accounts and that she was "*deeply touched by the different stories she heard, the background of the families and what is happening currently.*" With regard to her conducting the interviews in siSwati, she said that it meant that she "*could* *relate to what they* (participants) *were talking about. I* (P) *understood and they could open up with their family issues and the kids.*" These reflections on her role within the study reinforce the idea that she was not just there as a technician collecting data but that, together, we were involved in the attempt at understanding caregivers' lived experience.

Bureaucratic Aspects

The process of obtaining permission to conduct the study proved to be a major challenge in conducting this study. Before I was able to conduct the study, I had to get permission from the relevant government departments. I submitted applications to the Department of Social Development and to the Department of Education in Mpumalanga. This process was extremely taxing and time consuming since I was often referred from one person to the other, was left holding on the phone, left messages and was promised calls which never came, and sent e-mails which were not answered. The bureaucratic chain of command also resulted in major delays, not to mention the apparent passing of my request from one person to another. Eventually the applications seemed to get through to the correct people but a final decision was still pending about whether I had permission to conduct the study in the district.

The school was very helpful and willing to be involved in the study and the principal of the school granted me permission to recruit caregivers of children attending at the school, pending authorisation from the Department of Education. Although I had applied for permission from the Mpumalanga Province Department of Education and the Mpumalanga Department of Health in advance, due to bureaucratic delays, I only obtained permission from the Department of Education the month before my arrival in Mpumalanga but had not yet received permission from the Department of Health. I informed the school that I had received government permission from the Department of Health to conduct the study and the school confirmed its earlier agreement to serve as a base from where to recruit participants. Dates were set for the fieldwork during which the interviews would be conducted although the specific dates for the interviews could not be set because I was still awaiting permission from the Department of Health. Therefore, I did not yet request the contact details for the potential participants because of the pending government department permission. Nonetheless, I kept the occupational therapist at Kamagugu Inclusive School updated about my application status. I arrived in Mpumalanga without yet having the official permission from the Mpumalanga provincial government’s Department of Health, despite the application having been submitted earlier in the year. I had to go to the Mpumalanga government buildings in Nelspruit on two occasions to follow up on my application and to collect the permission documentation. Therefore, I learnt that, despite the delays and the bureaucratic challenges, it was essential that I kept following up on the matter with the relevant departments, even though on numerous occasions there was no reply to my queries. I also learnt that it is very necessary to maintain the lines of communication open between the different potential sources of participant recruitment, firstly as a sign of respect and also to accommodate their schedules.

Ethical Considerations and Responsibilities

All aspects of research have ethical considerations and therefore there are associated ethical responsibilities. Even the choice of topic has ethical implications as we are reminded that “Research topics rarely come out of the blue… (and) personal biography will be involved in topic selection” (Silverman, 2011, p. 101) and that choice of topic can have ethical implications. Is my choice of topic informed by the real and judicious enquiry for the benefit of the people I’m interviewing or is the choice less altruistic and mediated by the intention of obtaining the PhD degree? I should like to think that in trying to obtain the PhD, the enquiry into caregivers' experience can provide insight into that phenomenon and vice versa. Which takes priority? The socially desirable answer would be that the caregivers are at the forefront of the interest. And, they are. But, in a utilitarian way, the PhD is one way of enquiring into that which I found interesting and needing exploration.

I also recognise that there is a broader ethical responsibility. In a country of scarce resources, it could be seen as irresponsible to be spending research time and funding on projects which may not have direct social merit. Although this study is not a grounded theory study, Charmaz, in discussing grounded theory, highlights a valid point with regard to the social justice responsibility of research which may relate to my project when she says that, "the very process of witnessing their participants' lives…may elicit concerns about social justice that they had not understood earlier or anticipated" (Charmaz, 2011, p. 360). I have tried to rationalise the need for this study and although there were no direct interventions offered in the form of hearing assessments, hearing aids, aural rehabilitation, South African Sign Language classes, formal counselling services, or workshops, I anticipate indirect networking benefits from participation in the project, although it could be argued that this anticipated benefit is insufficient.

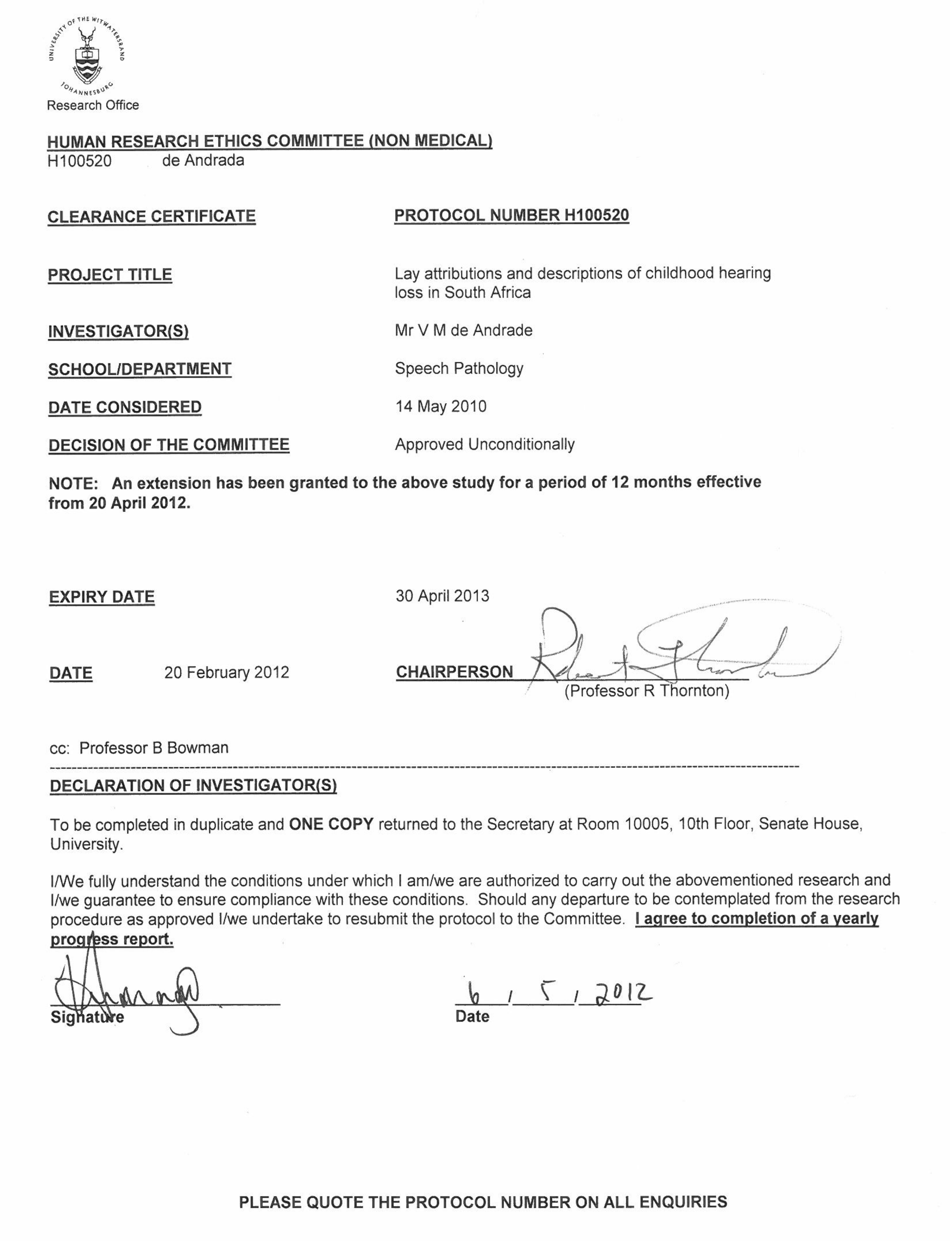
Through this exploratory study, it is hoped that the results can be used to offer contextually synchronous services in relation to children's deafness. For example, and only as an example, one of the conditions upon which the permission was granted by the Mpumalanga Department of Education was that the results of the study would be fed back to the department which holds promise for the possible use of the results of the study by the provincial government. I am, humbly, aware that there is some evidence which shows that research does not always translate into policy but that ought not detract us from conducting research which could have an influence (Bloor, 2011). I may have to be satisfied with the suggestion that "the process by which research informs policy is a subtle one involving ‘incremental nudges’ rather than immediate translation” (Spencer, Ritchie, Lewis, et al., 2003, p. 81). By no means am I obligated to find results in support of the government’s policies. I am not a government employee nor am I tasked by the government to research the topic and so I do not have a particular social policy agenda, but, as discussed earlier, it is important to be conducting research which has some real world value. I hoped that the networking opportunities created by the group interviews and the snowball sampling would transfer to beyond the research project, although that was something I did not directly study. By participating in interviews, participants experienced no direct benefit for their children. However, the networking and sharing of information which I observed occur after the interviews could suggest that there may be some benefit for their children.

Universities are also called upon to consider the research which they choose to support and it is suggested that there is the risk that

> academic social scientists’ engagement in autopoetic theoretical and methodological efforts disconnects them from society at large. Research and teaching agendas are motivated more by what is fashionable … than by the aim of addressing pertinent societal problems (Levin & Greenwood, 2011, p. 27).

Therefore, there is an ethical responsibility to look at socially meaningful research and to “analyse actual social science behaviour in concrete contexts” (Levin & Greenwood, 2011, p. 27). None the less, the same authors also caution that action research on its own is insufficient and that there is a need to marry the exploration of the concepts with the implementation of action (Levin & Greenwood, 2011). There is also a call for an ethical responsibility to advance notions of advocacy (Ramos, 1989). By no means am I supercilious in suggesting that my study will be ground breaking or the final word in this field. Instead, I’m saying that I’m aware of the need for the different types of research and the ethical responsibility which research, my research included, has towards making an impact.

Appendix D: Permission from the University of the Witwatersrand's Human Research Ethics Committee (Non medical) to conduct the study.



Research Office

HUMAN RESEARCH ETHICS COMMITTEE (NON MEDICAL)
H100520 de Andrada

CLEARANCE CERTIFICATE	**PROTOCOL NUMBER H100520**
PROJECT TITLE	Lay attributions and descriptions of childhood hearing loss in South Africa
INVESTIGATOR(S)	Mr V M de Andrade
SCHOOL/DEPARTMENT	Speech Pathology
DATE CONSIDERED	14 May 2010
DECISION OF THE COMMITTEE	Approved Unconditionally

NOTE: An extension has been granted to the above study for a period of 12 months effective from 20 April 2012.

EXPIRY DATE 30 April 2013

DATE 20 February 2012 **CHAIRPERSON** ______________________
(Professor R Thornton)

cc: Professor B Bowman

DECLARATION OF INVESTIGATOR(S)

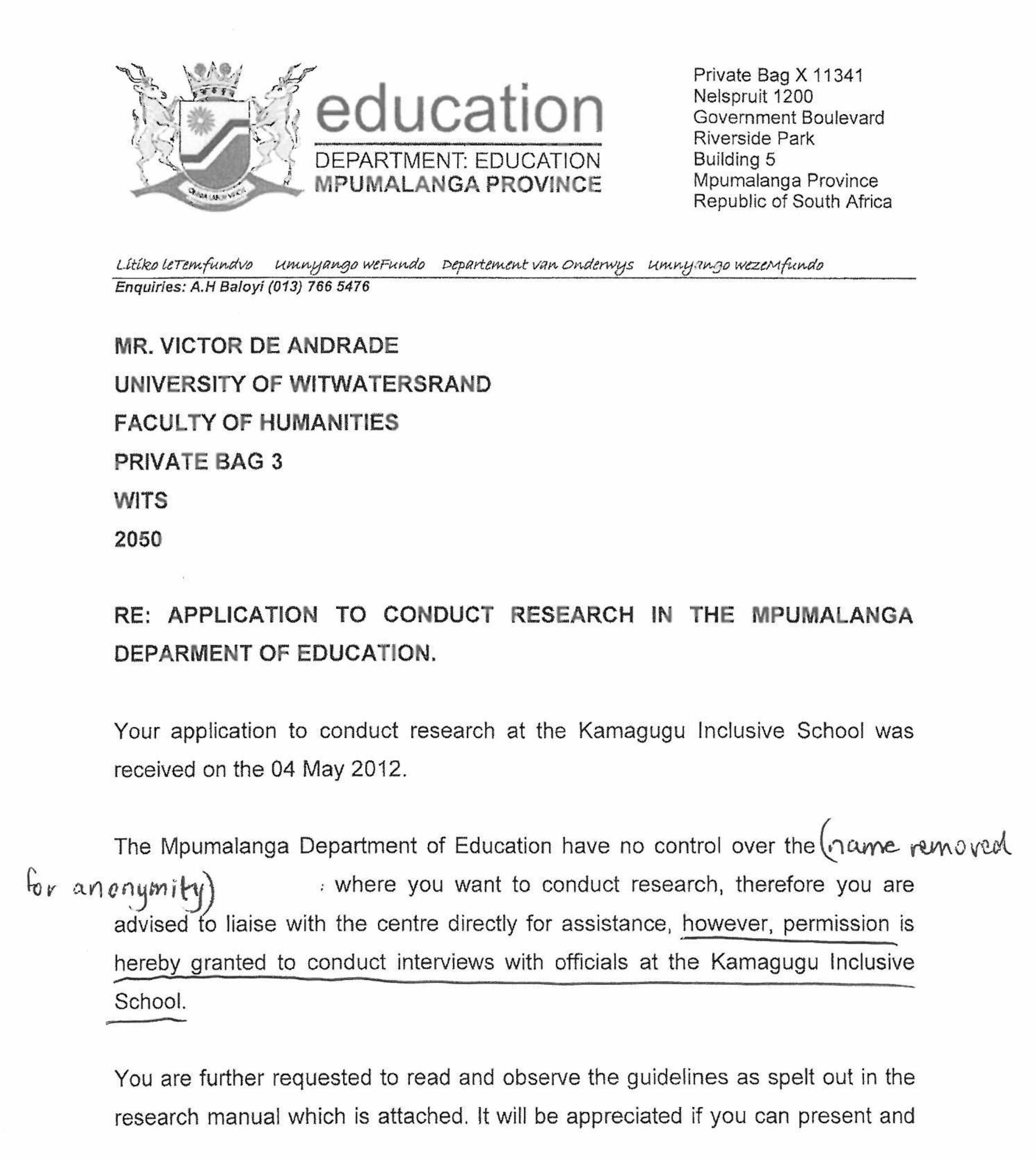
To be completed in duplicate and **ONE COPY** returned to the Secretary at Room 10005, 10th Floor, Senate House, University.

I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee. **I agree to completion of a yearly progress report.**

______________________ 6 / 5 / 2012
Signature **Date**

PLEASE QUOTE THE PROTOCOL NUMBER ON ALL ENQUIRIES

Appendix E: Permission from the Department of Education, Mpumalanga Province to conduct research.



education
DEPARTMENT: EDUCATION
MPUMALANGA PROVINCE

Private Bag X 11341
Nelspruit 1200
Government Boulevard
Riverside Park
Building 5
Mpumalanga Province
Republic of South Africa

Litiko leTemfundvo Umnyango weFundo Departement van Onderwys Umnyango wezeMfundo

Enquiries: A.H Baloyi (013) 766 5476

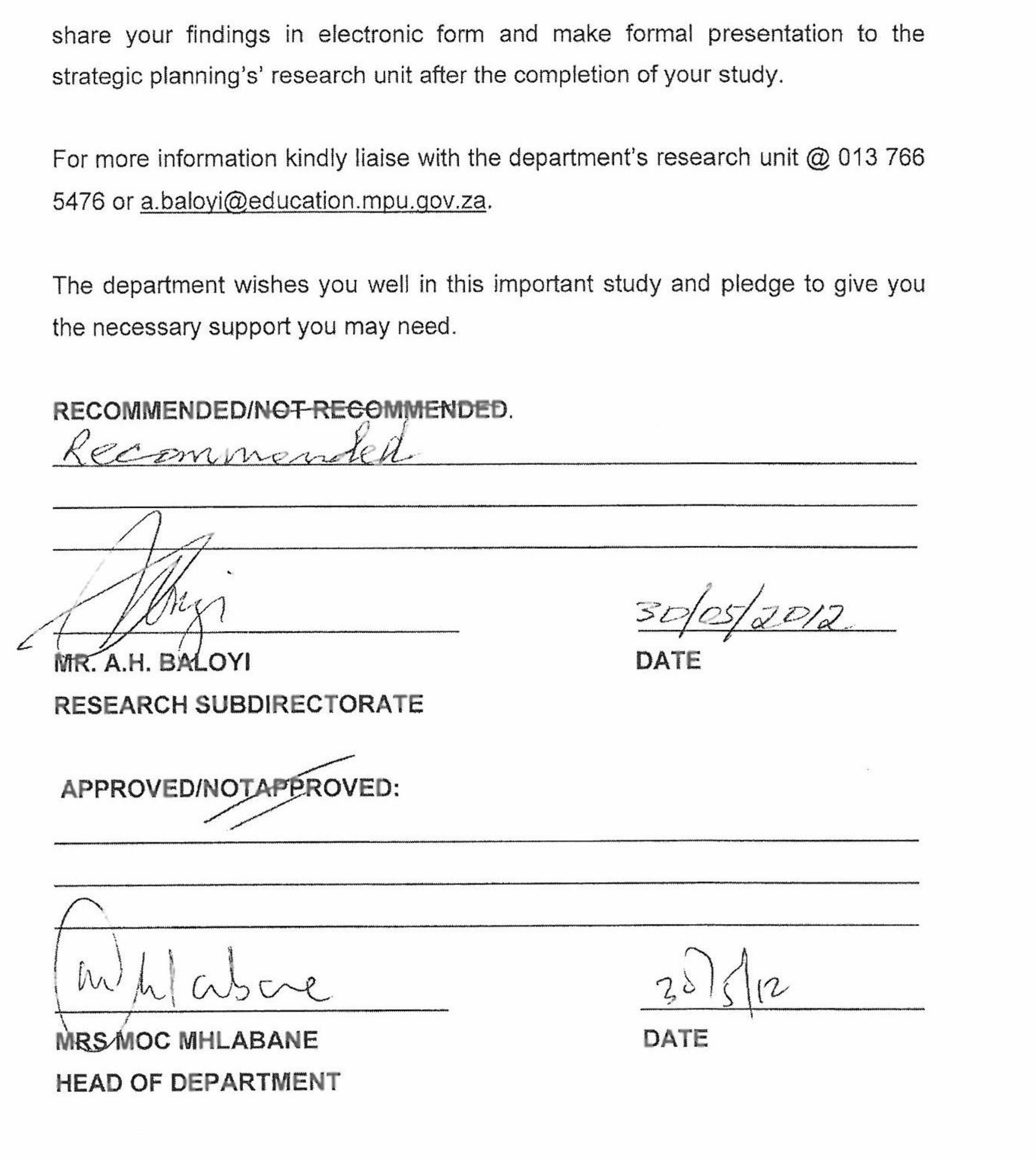
MR. VICTOR DE ANDRADE
UNIVERSITY OF WITWATERSRAND
FACULTY OF HUMANITIES
PRIVATE BAG 3
WITS
2050

RE: APPLICATION TO CONDUCT RESEARCH IN THE MPUMALANGA DEPARMENT OF EDUCATION.

Your application to conduct research at the Kamagugu Inclusive School was received on the 04 May 2012.

The Mpumalanga Department of Education have no control over the (name removed for anonymity) where you want to conduct research, therefore you are advised to liaise with the centre directly for assistance, however, permission is hereby granted to conduct interviews with officials at the Kamagugu Inclusive School.

You are further requested to read and observe the guidelines as spelt out in the research manual which is attached. It will be appreciated if you can present and



share your findings in electronic form and make formal presentation to the strategic planning's' research unit after the completion of your study.

For more information kindly liaise with the department's research unit @ 013 766 5476 or a.baloyi@education.mpu.gov.za.

The department wishes you well in this important study and pledge to give you the necessary support you may need.

RECOMMENDED/~~NOT RECOMMENDED~~.

Recommended

30/05/2012

MR. A.H. BALOYI **DATE**

RESEARCH SUBDIRECTORATE

APPROVED/~~NOTAPPROVED~~:

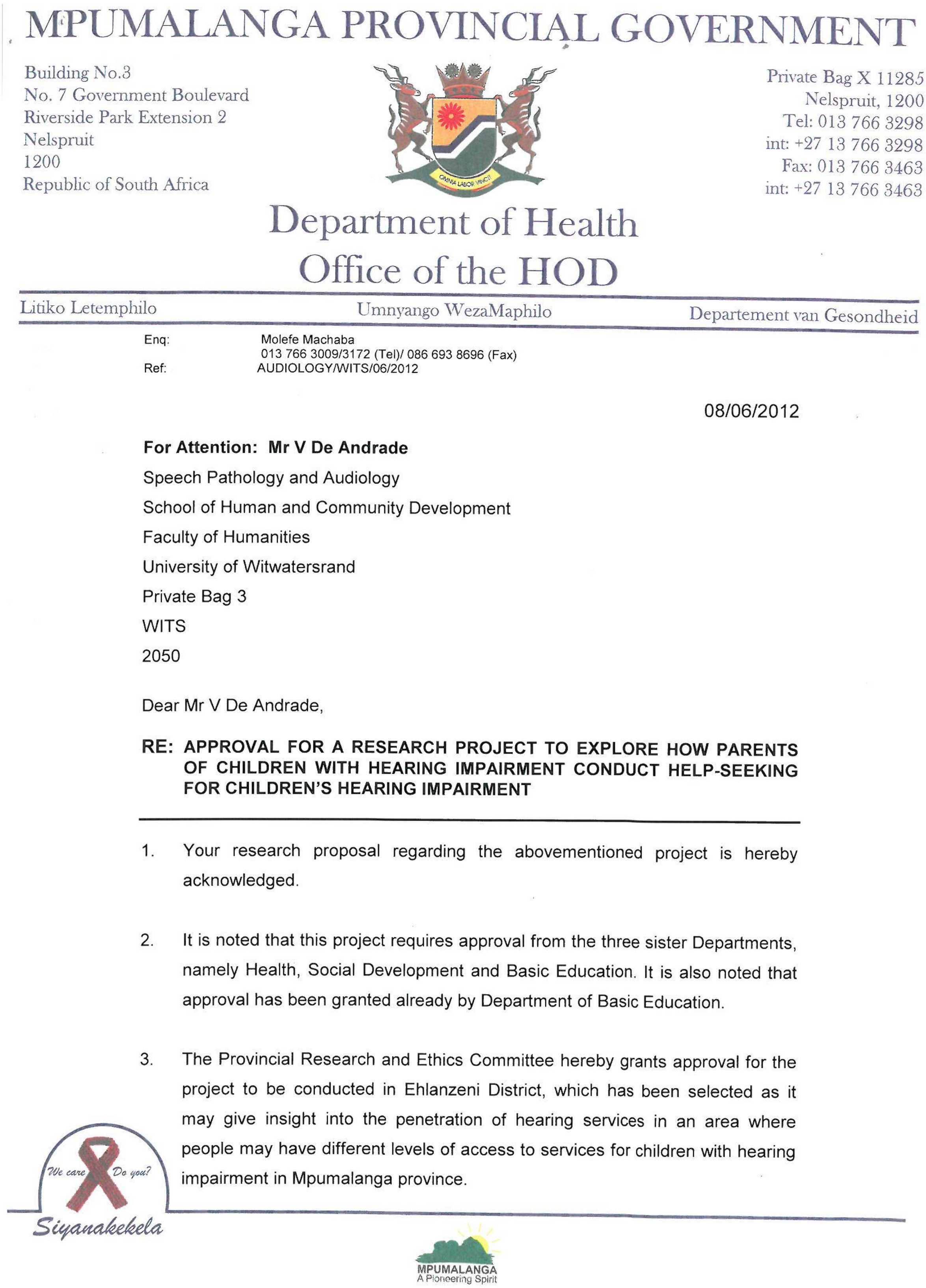
Mhlabane

30/5/12

MRS MOC MHLABANE **DATE**

HEAD OF DEPARTMENT

Appendix F: Permission from the Mpumalanga Provincial Government Department of Health to conduct research.



MPUMALANGA PROVINCIAL GOVERNMENT

Building No.3
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Republic of South Africa

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Department of Health
Office of the HOD

Litiko Letemphilo | Umnyango WezaMaphilo | Departement van Gesondheid

Enq: Molefe Machaba
013 766 3009/3172 (Tel)/ 086 693 8696 (Fax)
Ref: AUDIOLOGY/WITS/06/2012

08/06/2012

For Attention: Mr V De Andrade
Speech Pathology and Audiology
School of Human and Community Development
Faculty of Humanities
University of Witwatersrand
Private Bag 3
WITS
2050

Dear Mr V De Andrade,

RE: APPROVAL FOR A RESEARCH PROJECT TO EXPLORE HOW PARENTS OF CHILDREN WITH HEARING IMPAIRMENT CONDUCT HELP-SEEKING FOR CHILDREN'S HEARING IMPAIRMENT

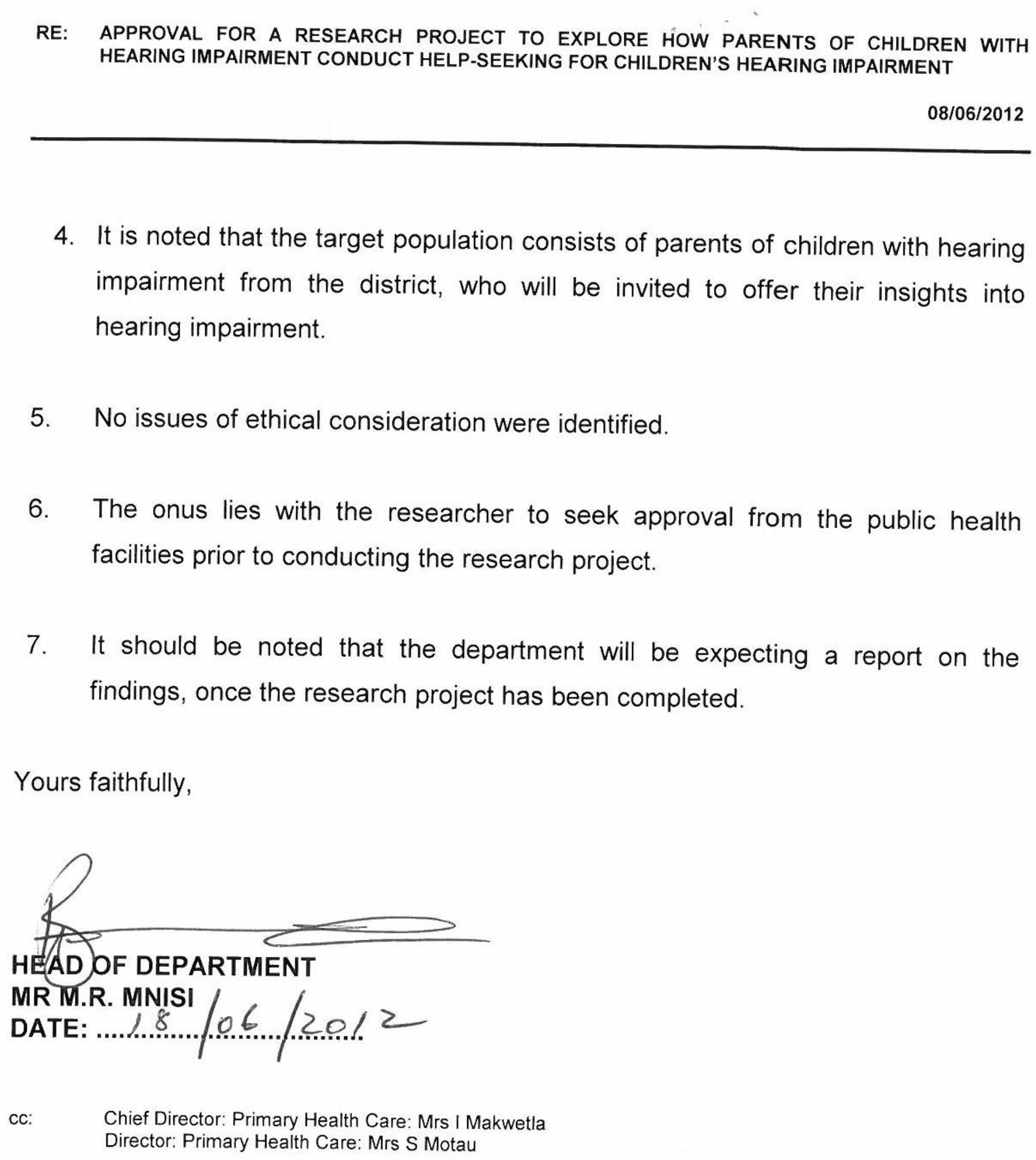
1. Your research proposal regarding the abovementioned project is hereby acknowledged.

2. It is noted that this project requires approval from the three sister Departments, namely Health, Social Development and Basic Education. It is also noted that approval has been granted already by Department of Basic Education.

3. The Provincial Research and Ethics Committee hereby grants approval for the project to be conducted in Ehlanzeni District, which has been selected as it may give insight into the penetration of hearing services in an area where people may have different levels of access to services for children with hearing impairment in Mpumalanga province.

We care Do you?
Siyanakekela

MPUMALANGA
A Pioneering Spirit



RE: APPROVAL FOR A RESEARCH PROJECT TO EXPLORE HOW PARENTS OF CHILDREN WITH HEARING IMPAIRMENT CONDUCT HELP-SEEKING FOR CHILDREN'S HEARING IMPAIRMENT

08/06/2012

4. It is noted that the target population consists of parents of children with hearing impairment from the district, who will be invited to offer their insights into hearing impairment.

5. No issues of ethical consideration were identified.

6. The onus lies with the researcher to seek approval from the public health facilities prior to conducting the research project.

7. It should be noted that the department will be expecting a report on the findings, once the research project has been completed.

Yours faithfully,

HEAD OF DEPARTMENT
MR M.R. MNISI
DATE: 18/06/2012

cc: Chief Director: Primary Health Care: Mrs I Makwetla
Director: Primary Health Care: Mrs S Motau

Appendix G: The individual and group interview guides

The individual interview guide which was used in the interviews while still allowing for exploration of topics not covered in the guide but raised by the participants.

1. Please tell me about your child.
2. What do other people around here say about your child?
3. What do you think caused your child's deafness?
4. What do other people say caused the child's deafness?
5. What did you do about what other people said about the cause of the deafness?
6. What made you think your child couldn't hear?
7. What did you do when you thought your child had deafness?
8. Now that you have more experience of deafness in children, what would have been helpful for your child's deafness which you didn't know about or couldn't access?
9. How do you communicate with your child?
10. What happens to a child if he or she can't hear?
11. What do you think people here need to know about deafness in children?
12. Who has a very strong influence on the decisions parents make about a child with hearing difficulties?
13. When and to whom do you get to talk to other people about your child's deafness?
14. What does it do for you to be able to talk about your child's deafness?

The group interview guide which was used in the interviews while still allowing for exploration of topics not covered in the guide but raised by the participants.

A. Introduction

1) Please tell me about deaf children in your community, where you live.

B. Hearing aids

1) We saw that many children don't wear or weren't wearing hearing aids. Why do you think it is so?

C. Sign Language

1) We see that many children are using sign language. What does sign language do for deaf children?
2) How was it decided for your children to learn sign language?
3) Besides sign language, what other options are available for the child to be able to communicate?
4) How come those other options were not chosen?

D. Communication

1) Communication between caregivers and children, how successful is it?
2) Communication between caregivers and health care personnel, teachers, social workers, how is it?

E. Disability

1) Some people say deaf children are disabled. Some say they are not. What do you say?
2) We've heard of some caregivers locking up their deaf children. What do you think about that? Why is it done?

F. Traditional practices.

1) Please tell us about what traditional healers do when caregivers take their deaf children to them?
2) What do you think of taking deaf children to traditional healers (probe about diagnosis and treatment)

G. Change

1) If you could do whatever you liked, what would you like to see happen/change for children who are deaf in your community?

H. Caregiver support

1) Who do you talk to when you need to talk to someone about the child's deafness or about something to do with the deaf child?
2) What does talking to other people do for you?
3) What caregiver support is available?
4) What support do you feel you need, emotionally, personally?
5) How can caregivers support each other?

Appendix H: Piloting of the interview guide

The method of data collection for this project needed to be well considered and therefore it had to be piloted to ensure that it sensitively but accurately gauged information about the experience of caregivers of deaf children. This appendix provides a little more detail with regard to the piloting of the interview guide.

While piloting the interview guide, the aim was to look at the instrument in general and to get a feel for it in terms of the duration, the flow of the questions, the order of the questions in the guide, the way these questions were interpreted and understood, their wording, especially in relation to the translation of certain ideas into another language. The first pilot study was conducted in a peri-urban township in Alexandra, Johannesburg, and not in a rural township. Despite Alexandra's more peri-urban character compared to the quite rural Ehlanzeni District, it is an informal settlement characterised by poverty as approximately 43% of the inhabitants are reportedly unemployed and 31% of its inhabitants live in informal housing (Department of Provincial and Local Government & The Business Trust, 2007) and, on average, the monthly household income is approximately R2467.00 per month which is less than the national average (Department of Provincial and Local Government & The Business Trust, 2007). Therefore, even though Alexandra does not fully represent the geographical setting where the study was conducted and is approximately 400km from the Ehlanzeni District in Mpumalanga (Google Maps, 2014), it offered a good starting point for piloting the interview guide due to the aforementioned reasons.

The pilot study was conducted in isiZulu, the predominant language of Alexandra township (Wilson, 2002). IsiZulu is very closely related to siSwati as it forms part of the same family of Bantu languages but more specifically the South Eastern Bantu group and particularly the Nguni sub-group (Olivier, 2009) thereby sharing a very close similarity in syntax, morphology and phonology despite some semantic variations. Although the instrument was piloted in another language during the first phase, I was looking at aspects related to the translation of the instrument into another language and the words which may not have been so readily translated rather than the specific use of siSwati which enabled me to conduct the first pilot in isiZulu.

The first pilot interview was not conducted by the fieldworker who eventually conducted the interviews in the final data collection phase of this study. Instead, because this first pilot was conducted in Alexandra and not in the Ehlanzeni District of Mpumalanga, a university student who was completing her master of arts dissertation and who is fluent in isiZulu conducted the pilot after she had been briefed about the study and about the interview process. Although she was not the fieldworker who conducted the interviews during the data collection phase of the study and had a different cultural, educational and language background, at this stage of the piloting, she was an appropriate choice because at this stage I was interested in the process of the translation, for example, the words which retained their English form as discussed earlier, so that I could prepare for that during the siSwati interviews. From this pilot, it transpired that there were some words which would probably be used in English, for example: hearing aid, deaf, test, earphone, disability.

Additionally, from the first pilot, it became apparent that potential participants could be unsure about the level of their contribution to this study. This feeling came across when a grandmother, the person on whom the first interview guide was piloted, when invited to share experiences of being a caregiver of deaf children, said that she probably could not be of much assistance because she had not been to university. She did not seem to recognise her valuable contribution to the research and that it is not only university graduates who contribute to knowledge. This lady did not appear confident in responding to the questions and I was concerned that the participants in the study could feel the same way and could therefore be reticent to speak freely about the topic. Therefore, I opted for a semi-structured format, which is a method regularly used in ethnographic interviewing (Davies, 2001). The topic guide can “ensure that relevant issues are covered systematically and with some uniformity, while still allowing flexibility to pursue the detail that is salient to each individual participant” (Arthur & Nazroo, 2003), p. 115) when interviewing different participants with their particular characteristics.

From this pilot, it seemed as though the probes were eliciting information relevant to the study and were also broad enough to open the way for participants to provide further information, not just based on the question. I also found it necessary to employ a more general introduction, that is, “Tell me about your child” so that it allowed for a contextualisation to the conversation. The pilot revealed that I did not need to video record the interviews and that audio recording would be sufficient. I had originally been wary that the audio recording would not capture the clarity of the interviews and that the extraneous noise, for example, from the cars in the street just outside the room where the pilot interview was conducted, would affect the integrity of the recording. I thought that by video recording the interviews, then the visual cues could supplement where the noise had interrupted the interview. However, it appeared unnecessary since the audio recording equipment, if set up quite close to the person speaking, would be sufficient, since it is very sensitive at picking up the participants’ voices. Since audio recording would be sufficient, it would address a concern I had about people being reluctant to be video recorded and I felt that people may be more amenable to audio recording. The pilot showed that the audio recording would suffice and that people could feel more comfortable during the interviews if they were not video recorded and it also sat more comfortably with the ethics committee in terms of protecting the participants’ anonymity.

The second pilot was conducted within the Ehlanzeni District in Mpumalanga by P, the fieldworker and language and culture broker for the main study. The pilot interview which had been conducted in Alexandra and which had appeared to yield information pertinent to the study was now piloted in the geographical area in which the study would be based. A father was recruited from a local clinic and interviewed at the local clinic. Despite my endeavours to not stay fixed within the medical framework, for the pilot, this setting and recruitment appeared and was the most viable to pilot the interview guide before moving out into the field. From this pilot, it appeared as though, compared to the first pilot, that the pilot participant stuck quite closely to the interview probes and did not seem to elucidate on his responses as the grandmother from Alexandra had done. The fieldworker responded by using some of the strategies we had discussed during our briefing sessions. She waited for an expansion on the response without dragging it out too long and making it uncomfortable. Also, she used affirmation markers such as “Mmm” and “OK” to show that she was listening and following the conversation. When she was uncertain of something or felt that a point needed clarification, she would seek clarification from him by asking him what he meant by what he had said or she would repeat what he had said as a question if she had not understood what he meant. These techniques she employed without trying to sound as though the participant had not expressed himself clearly. Instead, she framed her requests for clarification by stating from the outset that because she did not have a deaf child, there could be some things about which she would need more information from him and would ask him to clarify. Interestingly, the same code switching occurred in the siSwati interview as it had in the isiZulu interview, even though the fieldworkers were different people, and the same words came up as in the isiZulu interview, including words such as ‘government,’ ‘transport,’ and ‘bus.’

The suitability of the ethnographic interview was also confirmed in the pilot studies in that I was able to account for the expected limitations which may be associated with the interview method. This type of interview is a means of getting to hear about the way people think, feel and act because the participants can mediate between what they are thinking and feeling with the re-presentation of these thoughts and feelings in the interviews. Furthermore, it is recognised that the interview provides testimony and not evidence, per se, of the participants' lived experience and so "interviews do not tell us directly about people's experiences but instead offer indirect representations of those experiences" (Silverman, 2011, p. 168), in other words, accounts of their experiences. The piloting of the interview guide revealed that participants could re-present and re-package their experiences in ways which they think are more accessible to the audience and thereby provide a neater, more contained expression of the real experience. Therefore, by using the interview, I tried to ensure that participants did not feel threatened by the data collection because participants could choose how to reply to the probes in the interview guide. Furthermore, I went into the interviews with the expectation that by creating an opportunity for an open-ended discussion, conversation even, between the caregivers and the fieldworker, participants would feel less threatened and less inclined to offer socially desirable responses, a recognised limitation of interview methods (Guest et al., 2006). I recognised this risk and addressed it by creating a space, as best I could, of non-judgement and comfort to discuss the matter. The inclusion of the fieldworker was also an attempt to engage more completely with the participants in their preferred language to reduce the risk of the short-comings of the interview method.

Therefore, attempts were made at checking that the interview guide was tailored to meet the requirements of the study and to anticipate any special considerations during the data collection phase of this project.

Appendix I: Identifying initial themes

1. Relationship to the child
2. Factors which have brought the child into the caregivers’ care
3. A sense that they have a should be looking after the child/their gift to look after the child
4. Caregivers’ concerns that the child is restricted/jailed because of disability
5. Caregivers’ mediation of their child and the wider community
6. Caregiver employment
7. Searching
8. The child as a gift
9. The child as perceived by the caregiver
10. Description of children as being ‘owned’
11. Caregivers’ description of feelings/emotions
12. Caregivers’ sense of being alone
13. The child as perceived by others
14. How child spends time
15. The child’s friends
16. Schooling
17. Perceptions and descriptions of disability
18. Deaf child’s contribution, place in the community and family
19. Caregiver role reversal/absolution
20. Imbalance between what the child teaches the caregiver and the caregiver teaches the child
21. Caregiver not able to completely be there for the child

22. Spousal rejection of responsibility for deaf child when child has moved in to the family/rejection of responsibility for child that is not biologically his
23. Contradiction: caregivers saying that they understand the child and the child understand them but still feel that they wish they could communicate better.
24. The father – presence, absence, involvement
25. A sense of giving up on the child
26. Caregivers’ appear to even be aware of their emotional load, don’t even realise that these things are hard/when asked about talking about heavy things, they don’t even seem to realise that it’s worth talking about/offloading. Don’t even know what there is to offload.
27. Caregiver confidence/ability to care for the child
28. Caregiver has disability too
29. Caregiver decision making
30. Ways of describing the deafness
31. Relationship between speech and hearing
32. Safety
33. Psycho-emotional-physical manifestations of stress of looking after deaf child
34. Caregiver reports about delays in care for the child e.g. only going back when 15 or 18
35. Traditional healing
36. Caregiver responsibilities
37. Caregivers’ split responsibilities
38. Financial aspects of being a caregiver to deaf children
39. Financial issues in general
40. Geographical aspects of being a caregiver to a deaf child

41. Reported feelings towards the child
42. Child’s communication
43. Caregiver’s communication
44. Sign language
45. Sense of family support
46. Value of spousal support
47. Value of the interview, this interview, in addressing caregiver concerns?
48. Race
49. Diagnosis of deafness
50. Hospital and clinic distances
51. ‘Treatment’ of deafness
52. Do whatever if you love your kid
53. Audiological/ontological support
54. Hearing amplification
55. Caregivers reported reasons for children not wearing aids
56. Terminology for hearing aids
57. Caregivers’ need for a home of their own/a place to call their own
58. Social grant
59. Sources of advice for caregivers
60. Types of support for caregivers and support missing
61. Caregivers’ psycho-emotional offloading
62. Services for the child
63. Besides deafness, other concerns about the child
64. Child’s concomitant problems

65. Legacy of their own parents not having opportunities has lessened the caregivers’ opportunities
66. Family dynamics
67. Caregivers’ total absorption/assumption of the caregiver’s role
68. Sense that the child is condemned
69. Sense of the child being neglected/overlooked/ignored
70. Caregiver resistance to traditional healing despite others’ insistence
71. Sense of isolation despite large families and lots of people living in the same house
72. Sense of responsibility for the cause of deafness
73. Government role
74. Useful advice caregivers received
75. Advice caregivers wished they had received
76. Advice for the community
77. Support from others not necessarily a given
78. Engagement with emotional aspects of child’s deafness
79. Constant sense of unease
80. Child is different/incomparable to others
81. A sense of waiting
82. Spousal violence
83. Anxiety about separation from the child
84. Caregivers’ sense that the home is the best place for the child
85. Caregiver sense of responsibility to the people looking after their children/their obligations to people who are looking after their children
86. Caregiver role in maintaining harmony in family

87. HIV/AIDS
88. Death
89. Reward for looking after the deaf child
90. Caregivers are being made to feel responsible/blamed for the child’s deafness, even if they have taken over the care of the child
91. Presence of logistical/grant/school support but not psycho-emotional for the caregiver
92. Gender
93. Concerns about the child’s future
94. Faith
95. Hope
96. Constant sense of being there, constant hypervigilance
97. Conflating of hearing with understanding
98. Caregivers’ sense of not being able to contribute to the child’s development
99. “Growth” in the caregivers that’s come from having a deaf child
100. Violence – deaf child
101. Caregivers’ sense that if others were involved with the child it would be better for the child and for the caregiver
102. Caregivers’ sense of wanting to assist other caregivers with deaf children
103. Caregivers’ sense of trepidation that the child pays for his/her doings
104. Caregivers’ sense of having to restrain him/herself in interactions with community in order to protect child
105. Sense of forever
106. Violence – caregiver
107. Age of the medical interventionist

108. Caregiver questioning of why them

109. Defeatist feeling

110. Caregivers’ sense of being lost/opaque/overlooked

111. Caregivers being berated for their caregiving

112. Caregiver uncertainty about what to do with the child

113. Uses of the grant

Appendix J: Construction of the initial index

1. Help-seeking by caregivers for their children's deafness.
    1.1. Assumption of the caregiver role/responsibility
    1.2. Comparison of child with others
    1.3. Children's concomitant problems/ Besides deafness, other concerns about the child
    1.4. Decision making dynamics
    1.5. Females as caregivers but males as power holders
    1.6. Employment aspects
    1.7. Geographical, distance, location and relocation aspects
    1.8. Cause of the deafness
    1.9. Diagnosis of deafness
    1.10. 'Treatment' of deafness
    1.11. Caregivers' interaction with traditional healing aspects
    1.12. Audiological/otological support
    1.13. Hearing aids/amplification
    1.14. Financial aspects of actions taken/help-seeking
    1.15. Services for deaf children (e.g. audio, speech, physio, OT, medical, social work etc.)
    1.16. Deafness was not the main/first/noticeable concern
    1.17. Suspicion/clue that children are deaf
2. Caregivers' interactions with the educational aspect of being caregivers to deaf children.
    2.1. Deaf children's specific educational needs
    2.2. Caregivers' striving for education and the subsequent sense of accomplishment of their responsibility

- 2.3. Considerations in the choice of school for their deaf children
- 2.4. Caregivers’ satisfaction with their deaf children’s schooling
- 2.5. Deaf children’s post school considerations
- 2.6. School as a vehicle for getting government grants
- 2.7. Geographical aspects of schooling
- 2.8. Children’s education outside of school
- 2.9. Financial aspects of education
- 2.10. Schools which cater for deaf children as socialisation and disability awareness tools

3. Communicative aspects of being caregivers to their deaf children.
    - 3.1. Modes of communication between children and caregivers
    - 3.2. Communication efficacy between deaf children and caregivers and other adults
    - 3.3. Communication efficacy between deaf children and hearing children
    - 3.4. Means of facilitating communication
    - 3.5. Challenges to communication
    - 3.6. Communication as a tool for socialisation
    - 3.7. Sign language for communication
    - 3.8. Sign language as a tool for learning
    - 3.9. Contradictions and ironies with regard to communication (who teaching whom, “you see,” I cannot hear the child when the child is using sign language, speaking sign language)
    - 3.10. Children as teachers of language
    - 3.11. Caregivers’ communication with other people about their deaf children
    - 3.12. Emotions around communication
    - 3.13. Communication efficacy between deaf children and other adults

4. Caregivers’ internalisation of their children’s deafness.
    - 4.1. Caregivers’ characterisation of their deaf children
    - 4.2. Caregivers’ interactions with the ways of describing deafness (Conflating of hearing with understanding)
    - 4.3. Caregivers’ interactions with the notion of their children’s deafness as a disability
    - 4.4. The function/benefit of the description of the child as disabled
    - 4.5. Caregivers’ efforts to point out that the children are deaf and not cognitively impaired
    - 4.6. Contradictions of disability and ability in the same children
    - 4.7. Reported feelings towards the child and the child’s deafness
    - 4.8. Sense that the child is condemned
    - 4.9. Sense of the child being neglected/overlooked/ignored
    - 4.10. Sense of responsibility for the cause of deafness
    - 4.11. Constant sense of unease
    - 4.12. A sense of waiting
    - 4.13. Reward for looking after the deaf child
    - 4.14. Concerns about the child’s future
    - 4.15. Constant sense of hyper vigilance
    - 4.16. “Growth” in the caregivers that’s come from having a deaf child
    - 4.17. Sense of forever
    - 4.18. Caregiver questioning of why them
    - 4.19. Defeatist feeling
    - 4.20. The child as a gift/the child as owned

  - 4.21. The deaf children as unfulfilled/not met their full potential/not been given opportunities

5. Caregivers' mediation between their deaf children and the family and community.
  - 5.1. Caregivers' perception of others' interactions with their deaf children
  - 5.2. Caregivers' mediation of deaf children and the community
  - 5.3. Caregivers' mediation of deaf children and the family
  - 5.4. Caregivers are being made to feel responsible/blamed for the child's deafness, even if they have taken over the care of the child
  - 5.5. Caregivers being berated for their caregiving
  - 5.6. Caregivers' sense of trepidation that the child pays for caregivers' actions/behaviour
  - 5.7. Caregivers' sense of having to restrain themselves in interactions with community in order to protect child
  - 5.8. Caregivers' split responsibility between their deaf children and their other children
  - 5.9. Financial considerations in terms of family and community
  - 5.10. The child's ability to fulfil familial and societal expectations
6. Caregivers' internalisation of their role as caregivers of deaf children.
  - 6.1. Caregivers' responsibilities to deaf children
  - 6.2. Caregivers' expression of the need to appear to be good/competent caregivers of their deaf children
  - 6.3. Caregivers' identification with their deaf children
  - 6.4. Caregiver uncertainty about what to do with the deaf children
  - 6.5. Caregivers' sense of constant searching
  - 6.6. The sense of being alone

- 6.7. Caregivers’ role reversal and absolution/transfer of the caregiver responsibilities
- 6.8. Caregivers’ sense of confidence/ability in being caregivers to deaf children
- 6.9. A sense of giving up on the child
- 6.10. Caregivers’ sense of helplessness
- 6.11. Anxiety about separation from the child
- 6.12. Caregivers’ sense of responsibility to the people looking after their children/their obligations to people who are looking after their children
- 6.13. Caregivers’ disability

7. Caregivers’ emotional responses/dimension of being caregivers to deaf children
   - 7.1. Emotions described by caregivers associated with being a caregiver
   - 7.2. Psycho-emotional-physical manifestations of stress of looking after deaf child
   - 7.3. Caregivers’ personal responses to being caregivers to deaf children
   - 7.4. Caregivers’ appear to not even be aware of their emotional load, don’t even realise that these things are hard/when asked about talking about heavy things, they don’t even seem to realise that it’s worth talking about/offloading. Don’t even know what there is to offload.
   - 7.5. Caregivers’ psycho-emotional offloading
   - 7.6. The value of talking about children’s deafness and the effects of talking about it.
   - 7.7. Caregivers’ total absorption/assumption of the caregiver’s role
   - 7.8. Caregivers’ sense of being lost/opaque/overlooked
8. Support of the caregivers in relation to their caregiving of their deaf children.
   - 8.1. Sense of family support
   - 8.2. Sense of spousal support

- 8.3. Sense of support from other caregivers of deaf children
- 8.4. Sense of other forms of support
- 8.5. Social grant and other financial support
- 8.6. Sources of advice and support for caregivers
- 8.7. Sense of the presence and absence of community support, neighbourliness (?ubuntu?)
- 8.8. Sense of isolation despite large families and lots of people living in the same house
- 8.9. Advice caregivers wished they had received
- 8.10. Caregivers’ advice for the community
- 8.11. Support from others not necessarily a given
- 8.12. Caregivers’ sense that the home is the best place for the child
- 8.13. Caregiver role in maintaining harmony in family
- 8.14. Presence of logistical/grant/school support for the child but not psycho-emotional for the caregiver
- 8.15. Caregivers’ focus on financial/logistical/physical support or assistance for the child over psycho-emotional support for themselves
- 8.16. Caregivers’ sense that if others were involved with the child it would be better for the child and for the caregiver

9. Other themes
   - 9.1. Race
   - 9.2. Legacy of their own parents not having opportunities has lessened the caregivers’ opportunities
   - 9.3. Government
   - 9.4. Violence

9.5. HIV/AIDS

9.6. Death

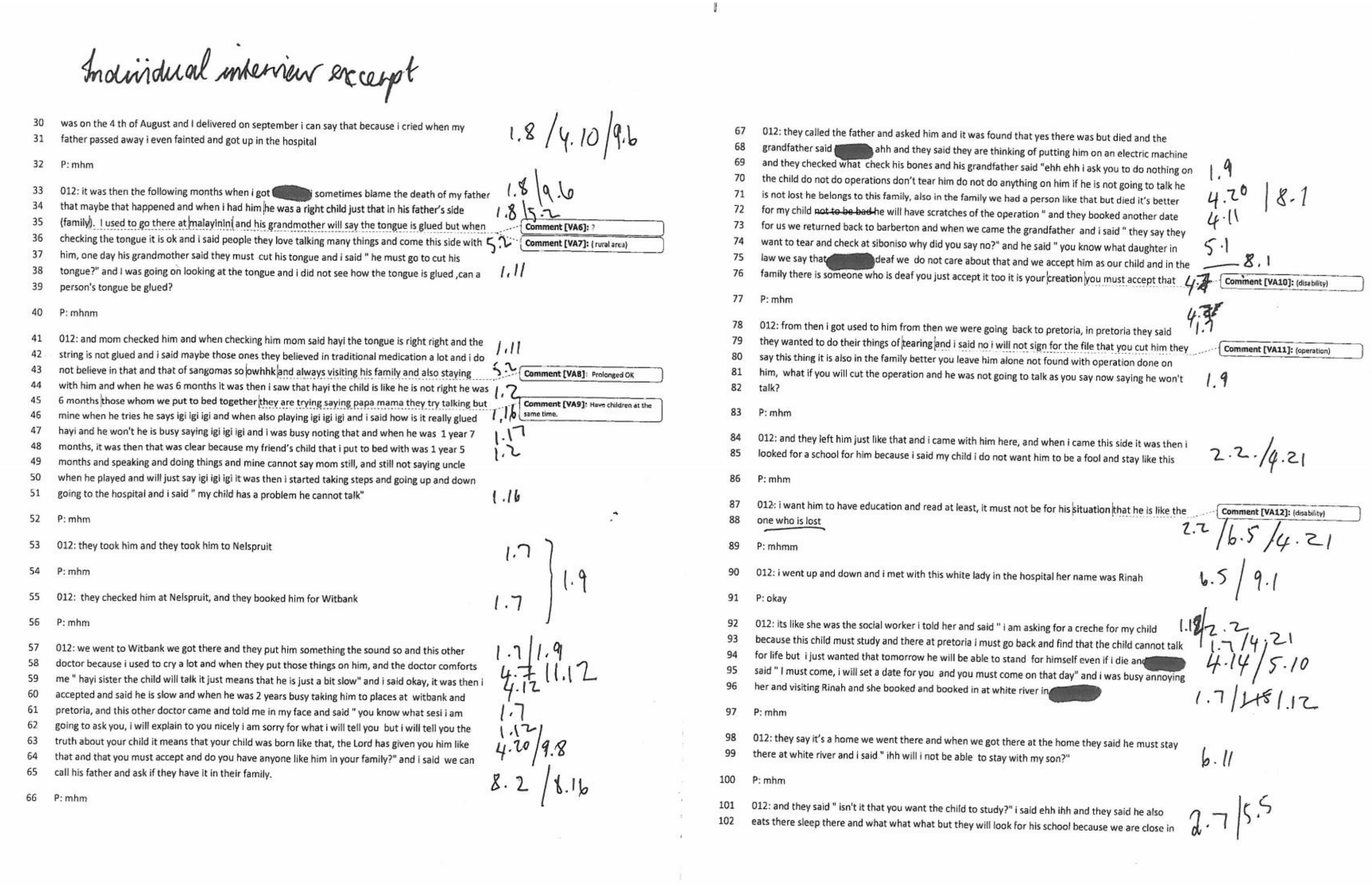
9.7. Gender

9.8. Faith

9.9. Hope

9.10. Age

Appendix K: Examples of the process of labelling the data



Individual interview excerpt

was on the 4 th of August and I delivered on september i can say that because i cried when my father passed away i even fainted and got up in the hospital
1.8 /4.10/9.6

P: mhm

012: it was then the following months when i got [redacted] i sometimes blame the death of my father that maybe that happened and when i had him he was a right child just that in his father's side (family). I used to go there at malayinini and his grandmother will say the tongue is glued but when checking the tongue it is ok and i said people they love talking many things and come this side with him, one day his grandmother said they must cut his tongue and i said " he must go to cut his tongue?" and I was going on looking at the tongue and i did not see how the tongue is glued ,can a person's tongue be glued?
1.8/9.6 1.8/5.2 5.2 1.11

Comment [VA6]: ?

Comment [VA7]: (rural area)

P: mhnm

012: and mom checked him and when checking him mom said hayi the tongue is right right and the string is not glued and i said maybe those ones they believed in traditional medication a lot and i do not believe in that and that of sangomas so owhhk and always visiting his family and also staying with him and when he was 6 months it was then i saw that hayi the child is like he is not right he was 6 months those whom we put to bed together they are trying saying papa mama they try talking but mine when he tries he says igi igi igi and when also playing igi igi igi and i said how is it really glued hayi and he won't he is busy saying igi igi igi and i was busy noting that and when he was 1 year 7 months, it was then that was clear because my friend's child that i put to bed with was 1 year 5 months and speaking and doing things and mine cannot say mom still, and still not saying uncle when he played and will just say igi igi igi it was then i started taking steps and going up and down going to the hospital and i said " my child has a problem he cannot talk"
1.11 5.2 1.2 1.16 1.17 1.2 1.16

Comment [VA8]: Prolonged OK

Comment [VA9]: Have children at the same time.

P: mhm

012: they took him and they took him to Nelspruit
1.7

P: mhm

012: they checked him at Nelspruit, and they booked him for Witbank
1.7 } 1.9

P: mhm

012: we went to Witbank we got there and they put him something the sound so and this other doctor because i used to cry a lot and when they put those things on him, and the doctor comforts me " hayi sister the child will talk it just means that he is just a bit slow" and i said okay, it was then i accepted and said he is slow and when he was 2 years busy taking him to places at witbank and pretoria, and this other doctor came and told me in my face and said " you know what sesi i am going to ask you, i will explain to you nicely i am sorry for what i will tell you but i will tell you the truth about your child it means that your child was born like that, the Lord has given you him like that and that you must accept and do you have anyone like him in your family?" and i said we can call his father and ask if they have it in their family.
1.7/1.9 4.7 4.12/11.12 1.7 1.12 4.20/9.8 8.2 /8.16

P: mhm

012: they called the father and asked him and it was found that yes there was but died and the grandfather said [redacted] ahh and they said they are thinking of putting him on an electric machine and they checked what check his bones and his grandfather said "ehh ehh i ask you to do nothing on the child do not do operations don't tear him do not do anything on him if he is not going to talk he is not lost he belongs to this family, also in the family we had a person like that but died it's better for my child ~~not to be bad~~ he will have scratches of the operation " and they booked another date for us we returned back to barberton and when we came the grandfather and i said " they say they want to tear and check at siboniso why did you say no?" and he said " you know what daughter in law we say that [redacted] deaf we do not care about that and we accept him as our child and in the family there is someone who is deaf you just accept it too it is your creation you must accept that
1.9 4.20 | 8.1 4.11 5.1 8.1 4.7

Comment [VA10]: (disability)

P: mhm

012: from then i got used to him from then we were going back to pretoria, in pretoria they said they wanted to do their things of tearing and i said no i will not sign for the file that you cut him they say this thing it is also in the family better you leave him alone not found with operation done on him, what if you will cut the operation and he was not going to talk as you say now saying he won't talk?
4.3 1.7 1.9

Comment [VA11]: (operation)

P: mhm

012: and they left him just like that and i came with him here, and when i came this side it was then i looked for a school for him because i said my child i do not want him to be a fool and stay like this
2.2./4.21

P: mhm

012: i want him to have education and read at least, it must not be for his situation that he is like the one who is lost
2.2 /6.5 /4.21

Comment [VA12]: (disability)

P: mhmm

012: i went up and down and i met with this white lady in the hospital her name was Rinah
6.5 / 9.1

P: okay

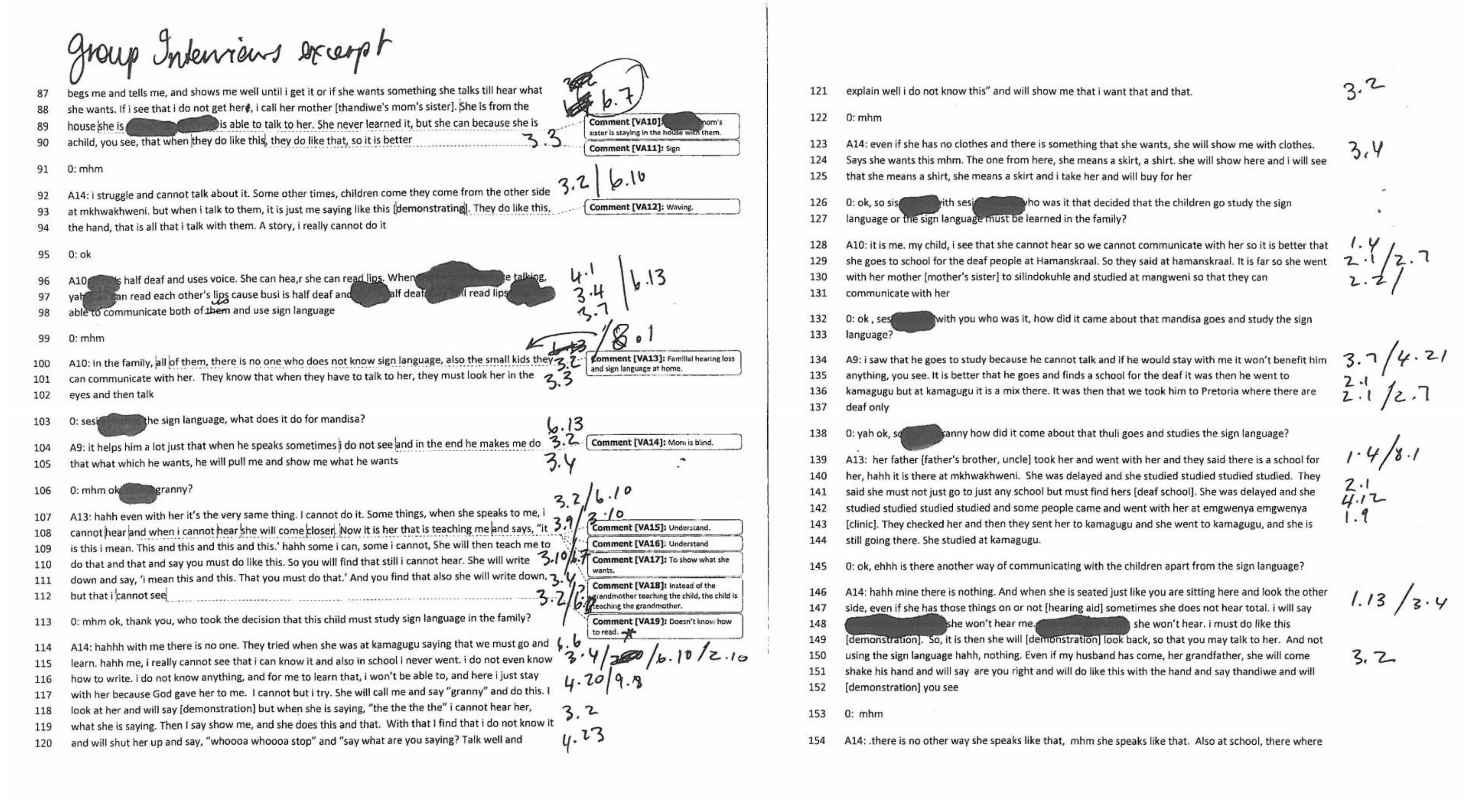
012: its like she was the social worker i told her and said " i am asking for a creche for my child because this child must study and there at pretoria i must go back and find that the child cannot talk for life but i just wanted that tomorrow he will be able to stand for himself even if i die and [redacted] said " I must come, i will set a date for you and you must come on that day" and i was busy annoying her and visiting Rinah and she booked and booked in at white river in [redacted]
1.18/2.2 1.7/4.21 4.14/5.10 1.7/~~1.15~~/1.12

P: mhm

012: they say it's a home we went there and when we got there at the home they said he must stay there at white river and i said " ihh will i not be able to stay with my son?"
6.11

P: mhm

012: and they said " isn't it that you want the child to study?" i said ehh ihh and they said he also eats there sleep there and what what what but they will look for his school because we are close in
2.7/5.5



Group Interviews excerpt

begs me and tells me, and shows me well until i get it or if she wants something she talks till hear what she wants. If i see that i do not get her~~e~~, i call her mother [thandiwe's mom's sister]. She is from the house she is [redacted] is able to talk to her. She never learned it, but she can because she is achild, you see, that when they do like this, they do like that, so it is better

~~3.2~~ ~~6.2~~ 6.7
3.3

Comment [VA10]: [redacted] mom's sister is staying in the house with them.

Comment [VA11]: Sign

0: mhm

A14: i struggle and cannot talk about it. Some other times, children come they come from the other side at mkhwakhweni. but when i talk to them, it is just me saying like this [demonstrating]. They do like this, the hand, that is all that i talk with them. A story, i really cannot do it

3.2 | 6.10

Comment [VA12]: Waving.

0: ok

A10[redacted]s half deaf and uses voice. She can hea,r she can read lips. When [redacted]e talking, yah[redacted]an read each other's lips cause busi is half deaf and [redacted]alf deaf[redacted]l read lips[redacted] able to communicate both of ~~them~~ us and use sign language

4.1
3.4 | 6.13
3.7

0: mhm

A10: in the family, all of them, there is no one who does not know sign language, also the small kids they can communicate with her. They know that when they have to talk to her, they must look her in the eyes and then talk

~~6.13~~ / 8.1
3.2
3.3

Comment [VA13]: Familial hearing loss and sign language at home.

0: sesi[redacted]he sign language, what does it do for mandisa?

A9: it helps him a lot just that when he speaks sometimes i do not see and in the end he makes me do that what which he wants, he will pull me and show me what he wants

6.13
3.2
3.4

Comment [VA14]: Mom is blind.

0: mhm ok[redacted]granny?

A13: hahh even with her it's the very same thing. I cannot do it. Some things, when she speaks to me, i cannot hear and when i cannot hear she will come closer. Now it is her that is teaching me and says, "it is this i mean. This and this and this and this.' hahh some i can, some i cannot, She will then teach me to do that and that and say you must do like this. So you will find that still i cannot hear. She will write down and say, 'i mean this and this. That you must do that.' And you find that also she will write down, but that i cannot see

3.2 / 6.10
3.9 / 3.10
3.10 / 6.7
3.4 / 2
3.2 / 6.12

Comment [VA15]: Understand.

Comment [VA16]: Understand

Comment [VA17]: To show what she wants.

Comment [VA18]: Instead of the grandmother teaching the child, the child is teaching the grandmother.

Comment [VA19]: Doesn't know how to read. *

0: mhm ok, thank you, who took the decision that this child must study sign language in the family?

A14: hahhh with me there is no one. They tried when she was at kamagugu saying that we must go and learn. hahh me, i really cannot see that i can know it and also in school i never went. i do not even know how to write. i do not know anything, and for me to learn that, i won't be able to, and here i just stay with her because God gave her to me. I cannot but i try. She will call me and say "granny" and do this. I look at her and will say [demonstration] but when she is saying, "the the the the" i cannot hear her, what she is saying. Then I say show me, and she does this and that. With that I find that i do not know it and will shut her up and say, "whoooa whoooa stop" and "say what are you saying? Talk well and explain well i do not know this" and will show me that i want that and that.

6.6
3.4 / ~~2.0~~ / 6.10 / 2.10
4.20 / 9.8
3.2
4.23
3.2

0: mhm

A14: even if she has no clothes and there is something that she wants, she will show me with clothes. Says she wants this mhm. The one from here, she means a skirt, a shirt. she will show here and i will see that she means a shirt, she means a skirt and i take her and will buy for her

3.4

0: ok, so sis[redacted]ith sesi[redacted]ho was it that decided that the children go study the sign language or the sign language must be learned in the family?

A10: it is me. my child, i see that she cannot hear so we cannot communicate with her so it is better that she goes to school for the deaf people at Hamanskraal. So they said at hamanskraal. It is far so she went with her mother [mother's sister] to silindokuhle and studied at mangweni so that they can communicate with her

1.4
2.1 / 2.7
2.2

0: ok , ses[redacted]with you who was it, how did it came about that mandisa goes and study the sign language?

A9: i saw that he goes to study because he cannot talk and if he would stay with me it won't benefit him anything, you see. It is better that he goes and finds a school for the deaf it was then he went to kamagugu but at kamagugu it is a mix there. It was then that we took him to Pretoria where there are deaf only

3.7 / 4.21
2.1
2.1 / 2.7

0: yah ok, s[redacted]ranny how did it come about that thuli goes and studies the sign language?

A13: her father [father's brother, uncle] took her and went with her and they said there is a school for her, hahh it is there at mkhwakhweni. She was delayed and she studied studied studied studied. They said she must not just go to just any school but must find hers [deaf school]. She was delayed and she studied studied studied studied and some people came and went with her at emgwenya emgwenya [clinic]. They checked her and then they sent her to kamagugu and she went to kamagugu, and she is still going there. She studied at kamagugu.

1.4 / 8.1
2.1
4.12
1.9

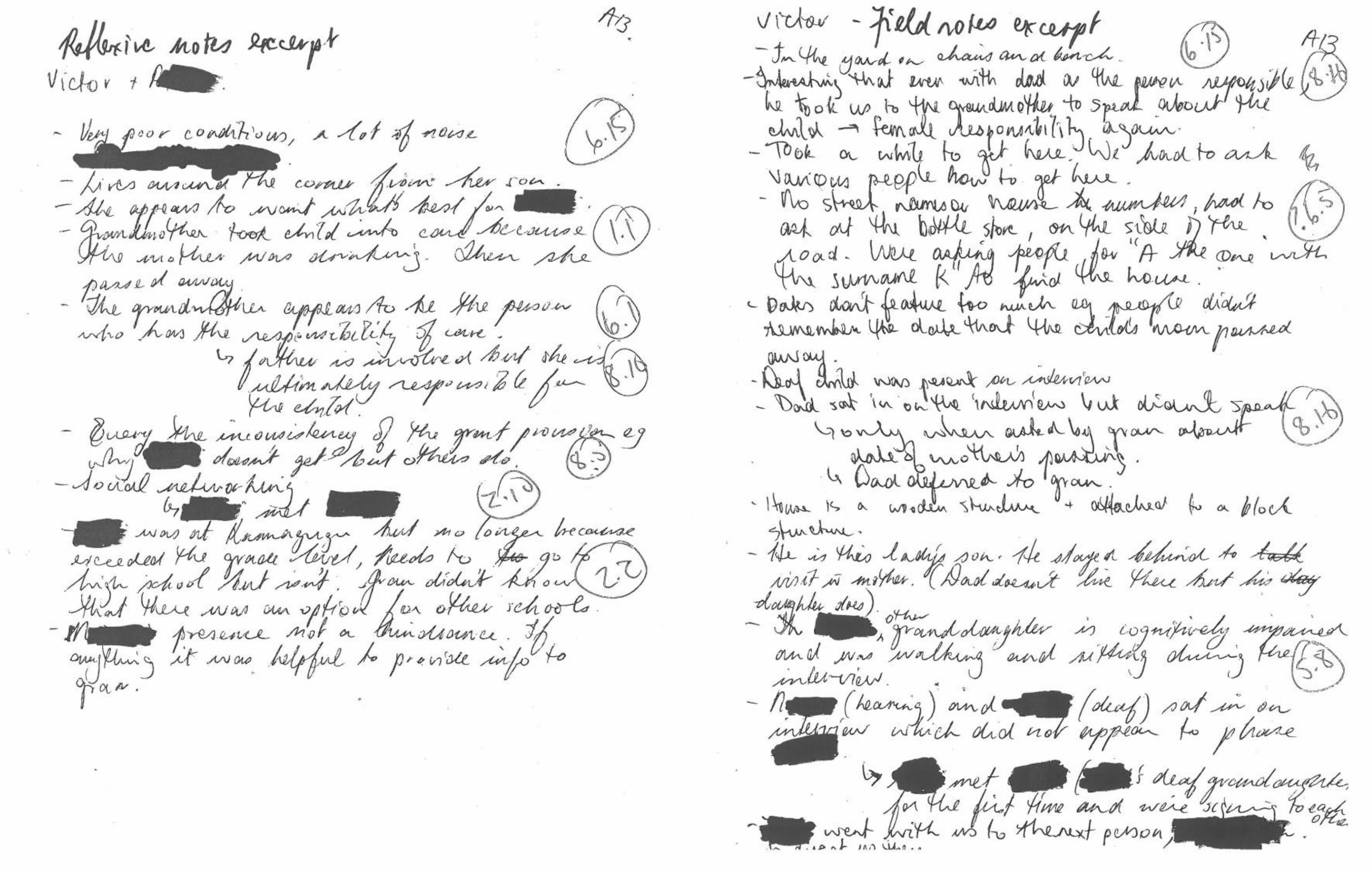
0: ok, ehhh is there another way of communicating with the children apart from the sign language?

A14: hahh mine there is nothing. And when she is seated just like you are sitting here and look the other side, even if she has those things on or not [hearing aid] sometimes she does not hear total. i will say [redacted]she won't hear me.[redacted] she won't hear. i must do like this [demonstration]. So, it is then she will [demonstration] look back, so that you may talk to her. And not using the sign language hahh, nothing. Even if my husband has come, her grandfather, she will come shake his hand and will say are you right and will do like this with the hand and say thandiwe and will [demonstration] you see

1.13 / 3.4
3.2

0: mhm

A14: .there is no other way she speaks like that, mhm she speaks like that. Also at school, there where



A13.

Reflexive notes excerpt

Victor + [redacted].

- Very poor conditions, a lot of noise (6.15)

[redacted]

- Lives around the corner from her son.
- She appears to want what's best for [redacted].
- Grandmother took child into care because the mother was drinking. Then she passed away (1.7)
- The grandmother appears to be the person who has the responsibility of care. (6.1)
  - ↳ father is involved but she is ultimately responsible for the child. (8.16)
- Query the inconsistency of the grant provision eg why [redacted] doesn't get but others do. (8.3)
- Social networking (2.10)
  - ↳ [redacted] met [redacted]
- [redacted] was at Kamagugu but no longer because exceeded the grade level, needs to ~~to~~ go to high school but isn't. Gran didn't know that there was an option for other schools. (2.2)
- [redacted] presence not a hindrance. If anything it was helpful to provide info to gran.

Victor - Field notes excerpt (6.15) A13

- In the yard on chairs and a bench.
- Interesting that even with dad as the person responsible he took us to the grandmother to speak about the child → female responsibility again. (8.16)
- Took a while to get here. We had to ask various people how to get here.
- No street names or house ~~to~~ numbers, had to ask at the bottle store, on the side of the road. Were asking people for "A the one with the surname K" to find the house. (7.6.5)
- Dates don't feature too much eg people didn't remember the date that the child's mom passed away.
- Deaf child was present on interview
- Dad sat in on the interview but didn't speak (8.16)
  - ↳ only when asked by gran about date of mother's passing.
  - ↳ Dad deferred to gran.
- House is a wooden structure + attached to a block structure.
- He is this lady's son. He stayed behind to ~~talk~~ visit w mother. (Dad doesn't live there but his ~~dau~~ daughter does).
- The [redacted], other granddaughter is cognitively impaired and was walking and sitting during the interview. (5.8)
- [redacted] (hearing) and [redacted] (deaf) sat in on interview which did not appear to phase [redacted]
  - ↳ [redacted] met [redacted] ([redacted]'s deaf granddaughter) for the first time and were signing to each other.
- [redacted] went with us to the next person, [redacted].

Appendix L: Example of the process of sorting the data by theme

3. Communicative aspects of being caregivers to their deaf children (**bold = group interview**, *Italics = clarification notes,* underlined = fieldnotes).

Participant number	Index									
	3.2. Communication efficacy between deaf children and caregivers and other adults	3.3. Communication efficacy between deaf children and hearing children	3.4. Means of facilitating communication	3.6. Communication as a tool for socialisation	3.7. Sign language for communication	3.8. Sign language as a tool for learning	3.9. Contradictions and ironies with regard to communication	3.10. Children as teachers of language	3.11. Caregivers’ communication with other people about their deaf children	3.12. Emotions around communication
A9	3.2. *The caregiver/mom is blind which adds another dimension to the communication dynamics with her child who uses SL.* “I sometimes think that I am sick, you see I cannot see clearly and (Child’s name) to be	3.3. “Ahi. The ones from here they know him. They are used to him and the small ones they know that if they want to talk to him. Even if they cannot, they do not have a problem they are right” L141-6. **“The friends are**	3.4. *Before he started attending school, they improvised and made up their own signs* L153. “other things we mad up, water we just say like this (demonstrating with her hands), when we want to writ, we tell	3.6. **“The friends are happy when they see him, even if he is not talking. They do also sign even” L45-6. Ref 3.3**	3.7. He is learning SL at school L155. ***However, in this case SL has an extra dimension in light of mom’s blindness. She acknowledges its benefit but also the limitation in her case*** *“***It helps him a lot.**	3.8. **“I saw that he goes to study because he cannot talk… It is better he finds a school for the deaf… he went to Kamagugu but at Kamagugu it is a mix there. It was then that we took him to Pretoria**	3.9. *During the interview kept saying, “wubona” translated to “you see” which appeared out of place because she is blind.*	3.10. *Now that he is learning SL at school, they don’t need to improvise on the signs because now he teaches them the signs* “And now he is studying, you see, and he comes and teaches us” L155. “but now we are	3.11. *Mom needed a report from the physio to say that he is attending therapy before she could enrol him at school* “they said they need a report and I went to the physio to look for a letter just to state that he is attending	3.12. *The child finds it funny when he sees that the adults are struggling to learn SL* “but now we are better, but when we cannot, he laughs at us” L161. *He also gets frustrated when people do not understand*

	like this also (deaf).” L219	**happy when they see him, even if he is not talking. They do also sign even” L45-6. Ref 3.6**	him to take a ball pen to write” L157 and 159. The child uses SL with the aunt because the mom is blind. So the aunt is an intermediary between him and his mom. A9: He can attend to me. Isn’t it that he can see? He comes and makes me hold his hands as like water, so he will hold my fingers and does it on me, and not be fast” L162-168.		**Just that when he speaks (signs) sometimes I do not see and in the end he makes me do that what he wants. He will pull me and show me what he wants” L104-5**	**where there are deaf only” L134-7** ***So mom wanted him to learn in SL only as she saw that he is predominantly a signer.***		better, but when we cannot, he laughs at us” L161	(at the hospital). They know him.” L41-4	*what he is trying to communicate to them and mom gets angry when they don’t understand each other* “(Child’s name) can make me angry. He is stubborn and can easily get angry and he will want me to hear from him.” L176-8

Appendix M: Example of the creation of descriptive accounts of the data

Participant	3.10. Children as teachers of language (**bold = group interview**, *Italics = clarification notes*, underlined = fieldnotes).
A2	3.10. *He is teaching language* “Eish, he is teaching us… sometimes he corrects us, but no, is not like that. When you talk about TV you do like this, when you talk about mama you do this, when you talk gogo, is this. He is actually helping us, teaching us” L129-133
A3	3.10. **“She comes back and teaches me ‘sorry.’ I now know that. OK, also because granny has not gone to school, when she says ‘sorry’ she means so” L157-160** ***suggesting that the child is teaching more than one generation: teaching her mother and her grandmother.***
A4	3.10. “also, the children try to make some things easy so that we can communicate with them” L156-7. *The child/niece teaches people in the house how to sign* “Yes, we learn from her” L167.
A6	3.10. *The child is teaching the family at home* “He is also helping at home. Now he knows if you say this, is mom, this is dad, brother and all that” L9-10.
A7	3.10. “We have learned from him as we stay with him” L56
A9	3.10. *Now that he is learning SL at school, they don’t need to improvise on the signs because now he teaches them the signs* “And now he is studying, you see, and he comes and teaches us” L155. “but now we are better, but when we cannot, he laughs at us” L161
A13	3.10. “We learn from her” L182 **“I cannot do it…Now it is her that is teaching me… Ahhh, some I can, some I cannot. She will then teach me to do that and that and that.” L107-111 “until I get it. She will say it is that one and this one and this on. You are closed. Do like so so so so. She never stops until I get it and I will say, ‘Woooa, I thank you. I have heard (understood) you.’ And she will say, ‘Sharp’ (thumbs up gesture)” L219-221 “She will insist until we get each other. Mmmm. Until we get each other” L224**
A14	3.10. ***The granddaughter tries to teach the*** **gran “She sometimes says, ‘Hah, Granny, Hah, you do not know anything’ But she can see that this one, I cannot sign. She begs me and tells me, and shows me well until I get it” L85-7**
A18	3.10. *But now* “like mine, the older one, they understand each other well. He knows how to sign but the way he is easy. They have a gift, these children” L154-155. *Also suggesting the ease in which other children learn SL and that they have the aptitude for learning SL. Ref 3.3*
A19	3.10 *The daughter teaches the mother the signs* “We use signs. Learning from her”L152.

Appendix N: Example of the abstraction of the descriptive accounts

(**bold = group interview**, *Italics = clarification notes,* underlined = fieldnotes).

Caregivers' agency in communicating with their deaf children Index = 3.2 and 3.3

Hearing children are better communicators with deaf children than the caregivers themselves are which may reduce their sense of self-efficacy and agency

A3	3.3. "So the sign language is the better way of communicating with them because the small children she plays with. Plus the sign language. You see that they are trying, like talking (signing)" L160-164. *So she plays with the children and tries to communicate with SL and the other children are learning from her.*
A4	3.3. *Facilitation of communication between her and other children by demonstrating what she wants:* "they communicate well. She is able to use things as examples for them… she will communicate in a way that she shows you and the kids are used to her in that way" L159-165. When we arrived, we saw the caregiver use signs (not necessarily South African Sign Language but South African Sign Language signs) with her niece.
A7	3.3. "and they do the same, and he can see that they also should know, and they see what he is saying. They are used by now and they know" L60-1
A8	3.3. "They (other deaf children) are playing or visiting each other…They also communicate in sign language" L161-3
A9	3.3. "Ahi. The ones from here they know him. They are used to him and the small ones they know that if they want to talk to him. Even if they cannot, they do not have a problem they are right" L141-6. "The friends are happy when they see him, even if he is not talking. They do also sign even" L45-6. Ref 3.6
A11	3.3. He talks as he is talking (signs/gestures). Even them, they are used to that (child's name) does not talk" L189

Caregivers' agency appears to be mediated by their ability to communicate in a spoken language other than their home language = Index 3.11

Caregivers' agency in communicating with hearing care personnel compromised because of differences in the languages spoken by caregivers and hearing care personnel

A3	3.11. *Poor communication between the diagnosticians and the mother* "then they look on the sonar or what. I do not know what it is" L163. *The diagnosticians were vague about the child's deafness, only when she got to Witbank* "the doctors never said she does not hear" L56. *So there was insufficient communication about the diagnosis. Doctor gave mom referral letters to the different hospitals but she was getting insufficient information about the child's hearing.* "They can see I do not what what is happening" L159. *Only when she got to Witbank was it definitive when they confirmed the deafness:* "they (Robs) ended up writing a letter saying I must go to Witbank. At Witbank is where they told me straight that the ears are closed" L138-142.
A5	3.11. *Some communication concerns between hearing care practitioners and the caregiver because the aunt was told to bring him back for hearing aids when he is 15???* "Only to find that they say I must bring him when he is 15 years and he is not yet 15. So, it was then. I just sat and I'm waiting for the 15 years." 131-2
A11	3.11. *Gran seems to have difficulty communicating with the diagnosticians* "They say it is called, I cannot explain what is it, but it said he is not right. They said there is something in his head. Ehi, I do not know what is it" L81-83.
A12	3.11. "in the hospital they did not explain to me about the thing they gave him" L368.

Caregivers’ unease about the exclusion of their deaf children because their deaf children use a different communication modality = Index 3.6; 3.7; 3.2; 3.11

Caregivers’ unease that the communication difference excludes the deaf children from interacting in society

A1	3.12. *The difference in communication between her deaf child and hearing children in the community was concerning because the other children beat up her child* “I was scared and thought she will play with the other kids and they will beat her” L47. *Also, when that happened, she got angry with the daughter asking why she was there in the first place* “’What do you want from there outside? Stay inside the house. Do not play with the other children” L50-1.
A2	3.6. *Socialisation affected when the family and others are engaged in activities from which he is excluded because he can’t communicate e.g. church and camp* “I go to church with him. Sometimes he doesn’t enjoy the church because he is not hearing. He gets bored. Like now, all the new generation kids are supposed to go to a big conference in my church. They enjoy it there. They are going to sing there. Dance. Enjoy all those things. But I’m still deciding should I take him or not because after few minutes he starts to do funny things. He is bored. He doesn’t hear anything.” LL221-225. *People whom the child meets for the first time think he is very rude because they speak to him and he doesn’t reply* “When he is in the community. As he meets new people. They don’t know that this child can’t speak, can’t hear. So, they. Like when we started staying there, another man was saying, ‘You, you don’t have manners. Every time you don’t even greet me… Why is your child? You don’t teach your child to greet elders? What’s wrong with him?’ So now he was giving him an attitude every day.” L183-7.
A6	3.6. “Sometimes we laugh at home and he doesn’t understand why this guys are laughing” L11-12. “Like when we went to, last year we went to Durban to take them, we took them to Durban. We wanted to explain it to him, ‘This is Moses Madiba (sic) Stadium. This is what it’s not nice” L245-247. *Social exclusion because of communication differences between family members and the child has a different language from the rest of the family which was born into a spoken language and he was not.* “We are not born as know Sign Language”L193 *Language into which the family is born is different for the deaf child and for the rest of the hearing family.*
A17	3.6. *Very complex family dynamics because his uncles wanted him to have trad med etc. and the communication differences probably confused him and may have also added to complexity of his relation to family. Also, his mother had other children who are cared for by other family members, but this child, because he is deaf, was left with this aunt and uncle* “and isn’t it that they can see that he cannot talk and cannot hear. If you take him, if you take him, what are they going to do with him?” L218-9 *Also may have resulted in distrust of the family because he was taken by them and nothing was explained to him* “It is difficult outside, and when I say to him he must go visit, he does not want to. He can tell the difference. Even the sister. Where she stays he does not want to go. Even if she comes, he will get inside the house and sit there” L329-333.