

Pastoral care and counselling of families with deaf children: a Practical Theological model

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DECLARATION

I, Rineé Pretorius, hereby declare that the thesis entitled, **Pastoral care and counselling of families with deaf children: A Practical Theological model**, which I am submitting for the PhD degree at the North-West University, Potchefstroom Campus, in compliance with the set requirements, is my own work, has been language-edited and has not already been submitted to any other university.

Rineé Pretorius

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In the completion of this thesis I did not only encounter unanticipated challenges but at times also felt like I had bitten off a little more than I could chew.

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Rineé Pretorius (née Viljoen) April 2017

Declaration

This is to declare that I, Annette L Combrink, accredited language editor and translator of the South African Translators' Institute, have language-edited the thesis by

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Pastoral care and counselling of families with deaf children: A Practical Theological model



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ABSTRACT

PASTORAL CARE AND COUNSELLING OF FAMILIES WITH DEAF CHILDREN: A PRACTICAL THEOLOGICAL MODEL

The research done in preparation for this study illustrates that – although extensive research has been done worldwide on Deaf culture, sign language, mental health services to deaf people, the challenges that families with deaf children face, as well as the counselling and therapy of deaf children – research remains inadequate when it comes to pastoral care and counselling of hearing families with deaf children.

The above situation has resulted in the main research question:

What practical theological model can be formulated as a foundation for the pastoral care and counselling of families with deaf children? Further research questions arise from this research question.

Thus, this study is aimed at indicating what the pastoral care and counselling of families with deaf children ought to entail by developing a practical theological counselling model to be utilized by pastoral practitioners. The model of practical theological interpretation for Practical Theology designed by Richard Osmer is used in this study.

The **descriptive-empirical task**, asking “*What is going on?*” and aimed at gaining an understanding of the experiences of hearing families with deaf children as well as the current situation of pastoral care and counselling of families with deaf children is done in chapter 2. The results of the qualitative enquiry, derived from semi-structured interviews with parents of deaf children, indicate the challenges families with deaf children face, the lack of formal pastoral care and counselling, and the necessity for increased attention being paid to the needs and expectations of these families.

A literature study of various related sciences in chapter 3 forms part of the **interpretative task** of answering the question “*Why is this going on?*” in regard to the current situation of families with deaf children in South Africa, and it provides important information with an array of facets related to deafness and various models of deafness. The dominant view of deafness as a disability is sharply contrasted to the socio-cultural view of deafness as a cultural and linguistic matter, but an additional development in literature indicates a shift toward a more bicultural approach in which dialogue between the opposing views is made possible. The challenges in terms of Deaf ministry and the lack of readily-available, reliable

spiritual resources on deafness, and pastoral work with families with deaf children, turn out to be increasingly evident in this chapter.

An exegetical study characterises chapter 4 as an attempt to answer the question which Osmer's **normative task** asks: "*What ought to be going on?*" thus, it endeavours to determine what ethical and normative perspectives are provided by Scripture for the pastoral care and counselling of families with deaf children. The focus in this chapter is on normative principles pertaining to the process of grief, attitudes towards deafness, and ethical questions pertaining to deafness; this is approached by concentrating mainly on the book of Lamentations, 1 Corinthians 12 and a few additional passages. It is clear from studying specific parts of Scripture that relevant normative principles can indeed be derived from Scripture in terms of pastoral care and counselling of families with deaf children.

The **pragmatic task** responds to the last of the four questions connected to the four tasks of Osmer's model, namely "*How might we respond?*" Chapter 5 marks the hermeneutical integration between the findings of the descriptive-empirical, interpretative and normative tasks in order to move from theory to practice. The subsequent result of this hermeneutical interaction and transition is then the formulation of a practical theological model for the pastoral care and counselling to families with deaf children (the DEAF model). The aim of this model is to expand parents' and pastoral practitioners' understanding of and perspectives on deafness, and to facilitate a life anchored in the Triune God, which can consequently promote spiritual growth and the overall well-being of the family, and in particular that of the deaf child.

Keywords

Pastoral care and counselling, deafness, deaf children, practical theological model.

OPSOMMING

PASTORALE SORG EN BERADING VAN GESINNE MET DOWE KINDERS: 'N PRAKTIES-TEOLOGIESE MODEL

Navorsing gedoen ter voorbereiding van hierdie studie toon dat – hoewel uitgebreide navorsing wêreldwyd alreeds gedoen is oor Dowe kultuur, gebaretaal, geestesgesondheidsdienste aan dowe mense, die uitdagings wat gesinne met dowe kinders in die gesig staar, asook die berading en terapie van dowe kinders – studies met betrekking tot pastorale sorg en berading van horende gesinne met dowe kinders, steeds onvoldoende is.

Die bogenoemde situasie lei tot die oorkoepelende navorsingsvraag:

Watter praktiese teologiese model kan geformuleer word vir die pastorale sorg en berading van gesinne met dowe kinders? Verdere navorsingsvrae vloei uit die navorsingsvraag voort.

Hierdie studie is dus daarop gemik om aan te dui wat die pastorale sorg en berading van gesinne met dowe kinders behoort te behels deur die daarstel van 'n prakties-teologiese beradingsmodel vir gebruik deur pastorale praktisyns. Die model van prakties-teologiese interpretasie vir Praktiese Teologie ontwerp deur Richard Osmer word in hierdie studie gebruik.

Die **beskrywend-empiriese taak**, wat vra "*Wat is aan die gebeur?*" en wat daarop gemik is om sowel 'n begrip van horende gesinne met dowe kinders se ervarings, as die huidige situasie van pastorale sorg en berading van gesinne met dowe kinders te ontwikkel word in hoofstuk 2 gedoen. Die resultate van die kwalitatiewe ondersoek bestaande uit semi-gestruktureerde onderhoude met ouers van dowe kinders, dui op die uitdagings wat gesinne met dowe kinders in die gesig staar, asook die gebrek aan formele pastorale sorg en berading van hierdie families, en beklemtoon die noodsaaklikheid vir 'n verhoogde bewustheid van die behoeftes en verwagtinge van hierdie families.

'n Literatuurstudie van verskeie verwante wetenskappe in hoofstuk 3 maak deel uit van die **interpretatiewe taak** van die beantwoording van die vraag: "*Hoekom is dit aan die gebeur?*", met betrekking tot die huidige situasie van families met dowe kinders in Suid-Afrika, en bied belangrike inligting ten opsigte van 'n verskeidenheid fasette wat verband hou met doofheid en verskeie modelle van doofheid. Die dominante siening van doofheid as 'n gestremdheid is in skerp kontras met die sosio-kulturele siening van doofheid as 'n kulturele

en taalkundige kwessie, maar 'n bykomende ontwikkeling in die literatuur toon 'n verskuiwing in die rigting van 'n meer bikulturele benadering waarin dialoog tussen die teenstellende standpunte moontlik gemaak word. Uitdagings in terme van Dowe-bediening en die gebrek aan geredelik beskikbare, betroubare geestelike hulpbronne oor doofheid, en pastorale werk met gesinne met dowe kinders, word toenemend duidelik in hierdie hoofstuk.

'n Eksegetiese studie kenmerk hoofstuk 4 as 'n poging om die vraag wat Osmer se **normatiewe taak** vra, te beantwoord, nl: "*Wat behoort te gebeur?*" en dus om te bepaal watter etiese en normatiewe perspektiewe die Skrif bied vir die pastorale sorg en berading van gesinne met dowe kinders. Die fokus in hierdie hoofstuk is op normatiewe beginsels met betrekking tot die rouproses, houdings teenoor doofheid, en etiese vrae met betrekking tot doofheid deur hoofsaaklik te konsentreer op die boek Klaagliedere, 1 Korinthiërs 12 en 'n paar bykomende Skrifgedeeltes. Dit is duidelik uit die bestudering van spesifieke Skrifgedeeltes dat relevante normatiewe beginsels wel vanuit die Bybel afgelei kan word ten opsigte van pastorale sorg en berading van gesinne met dowe kinders.

Die **pragmatiese taak** reageer op die laaste van die vier vrae in verband met die vier take van Osmer se model, naamlik "*Hoe kan ons reageer?*". Hoofstuk 5 merk die hermeneutiese integrasie tussen die bevindinge van die beskrywend-empiriese, interpretatiewe en normatiewe take vir die oorgang van teorie na praktyk. Die gevolg van hierdie hermeneutiese interaksie en oorgang kulmineer in die formulering van 'n prakties-teologiese model vir die pastorale sorg en berading aan gesinne met dowe kinders (die DEAF model). Die doel van hierdie model is om begrip van ouers en pastorale praktisyns se verstaan van en perspektiewe oor doofheid uit te brei, 'n lewe geanker in die Drie-enige God te fasiliteer, wat gevolglik geestelike groei en die algehele welstand van die gesin en in die besonder van die dowe kind, kan bevorder.

Sleutelterme

Pastorale sorg en berading, doofheid, dowe kinders, prakties-teologiese model.

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CHAPTER 1

INTRODUCTION AND PROBLEM STATEMENT

1.1 TITLE AND KEY TERMS: DEFINING THE FOCUS

The title of this study is *Pastoral care and counselling of families with deaf children: a Practical Theological model*. The key terms that drive the study are *Pastoral care and counselling; deafness; deaf children; practical theological model* (the Afrikaans terms are: *Pastorale sorg en berading; doofheid; dowe kinders; prakties-teologiese model*).

1.2 DEFINITION OF TERMS

1.2.1 Pastoral care and counselling

Pastoral care, also referred to as the 'cure of souls', refers to caregiving, including healing, support, guidance and reconciliation provided to troubled people during times of crisis, when life has become difficult and seemingly impossible, when relationships have been distorted or destroyed and when the tragic contravenes common sense and even faith fails (Anderson, 2001:218; Collins, 2005:4).

Pastoral counselling is a more specialized aspect of pastoral care and involves helping people to heal, to learn and to grow personally and spiritually by bringing their woundedness, struggles, problems and anxieties into dynamic healing contact with God, the Wonderful Counsellor (Benner, 2002:32; Collins, 2005:4).

1.2.2 Deafness

The term "deaf" is an audiological category used when referring to physiological deafness from a medical point of view. In broad terms, deafness is used to refer to all levels of deafness, differentiating between hard-of-hearing (deafness of between 10-90 decibels) and profoundly deaf (deafness of 91 decibels or more) only when it is necessary to do so (Störbeck, 2011:383). Although different degrees of deafness can be measured, the same measure of deafness can be experienced differently by different individuals (DeafSA [Deaf Federation of South Africa], 2006:1–39).

When referring to people who are deaf or are hard of hearing, a clear distinction is made between deaf persons and Deaf persons. Generally deafness as a pathology is indicated

using lower case “d”, whereas capital “D” is used to describe deafness as a culture (Jones, 2002:2). Where the former denotes a hearing impairment, the latter indicates the cultural identity of a Deaf person who uses sign language as a first language, just in the same way others define themselves as belonging to the Zulu or Afrikaans culture (cf. Morgan, 2008:6).

Broesterhuizen (2005:304; 2007:2) illustrates what it means to be Deaf by stating that Deaf people do not view themselves as impaired, disabled or challenged, but would rather be defined by the positive aspects of their language and culture. “Deaf culture” in these terms refers to the way of life of Deaf communities and includes characteristics such as a strong orientation towards sign language, rejection of the medical (pathological) model of deafness and a strong sense of community (Broesterhuizen, 2007:2; Broesterhuizen, 2005:304; Butler, McNamee, Skelton & Valentine, 2001:80).

It is important to highlight the fact that sign languages are natural and fully-fledged languages with its own distinct lexicon, phonetics, syntax and grammar and are independent of any spoken language (Lombaard & Naudé, 2007:141; Theunissen, 2011:4) and not merely a gestural mode of communication, as it is often referred to. sign language is a visual-manual language in contrast to oral-auditory languages, seeing that hands, facial expressions and movements of the body are used to communicate (De Jong, 2010:2; DeafSA, 2006:6).

1.2.3 Deaf children

The United Nations Convention on the Rights of the Child (1989:1) defines a child as “a young human being under the age of 18, unless under the law applicable to the child, majority is attained earlier”. Generally the term child is used when referring to persons of either sex and below puberty (Oxford Dictionaries, 2014).

As touched on in the previous definition, the term *deafness* can be used when referring to hard-of-hearing individuals, profoundly deaf individuals as well as individuals who are culturally Deaf. For the purposes of this study the term deaf children will be used as an overarching concept to refer to children up to the age of 18 years with varying degrees of deafness¹.

¹ Although not explicitly stated every time, this study focuses specifically on newly-diagnosed deaf children and their hearing families.

1.2.4 Practical Theological model

A model refers to the way or the procedure by which certain aims and objectives are attained (Van Wyk, 1995:85–101), and practical theology indicates the dynamic process of critical and constructive theological reflection on the praxis of the church in the world, carried out in the light of Christian Scripture and tradition. It entails critical dialogue with other sources of knowledge in response to their interpretations of the challenges and situations they face. This dialogue leads to ongoing modifications and transformations of the church's practices in order to be more adequately responsive to their interpretations of the shape of God's call to partnership. The primary purpose of a practical theological model would therefore be to propose a way to ensure that the church's public proclamations and praxis in the world authentically address the contemporary contexts into which the church seeks to minister by faithfully reflecting the nature and purpose of God's continuing mission to the world (Anderson, 2001:22; Fowler, 1999:75).

1.3 ORIENTATION AND PROBLEM STATEMENT

1.3.1 Orientation

Around the world, an estimated ninety per cent of all deaf children are born to hearing parents (Marschark, Lang & Albertini, 2002:91; Theunissen, 2011:7) and according to the Deaf Federation of South Africa (2006:14) the situation in South Africa is no different. For most of these hearing parents of deaf children, having a child with permanent deafness is their first encounter with a deaf person (Klein, 2008:54; Theunissen, 2011:7; THRIVE, 2016:1). This unfamiliar journey hearing parents of deaf children embark on holds a variety of challenges, primarily due to the barrier in communication, of which a rollercoaster of a range of emotions is only the beginning.

According to Kurtzer-White and Luterman (2003:235) parents are very early on expected to make decisions regarding the mode of communication for their deaf child. These decisions are life-altering as they directly impact on the holistic development of the child. For various reasons, including age of diagnosis and mode of communication selected, the deaf child may miss out on most of the interaction and communication that take place in his/her family by which family members normally build relationships and feelings of closeness with each other (Gentzel, 2007:14). It is therefore a common occurrence that ineffective communication between hearing families and the deaf child leads to impaired family relationships. The deaf child can experience feelings of being left out and this exclusion is similarly experienced by the deaf child in the greater hearing community (Gentzel, 2007:19–

22; Maloney, 2010:5). From a covenantal perspective, God uses the family as a very important vehicle in the transference of the covenantal promises and demands (Larney, 2009:15) and therefore effective communication in the family is indispensable.

Being deaf also has an influence on the culture the deaf child identifies with. In hearing families the language, culture and religion of the parents are naturally passed down to their children as a matter of course, whereas most deaf children are likely to become part of a Deaf culture to which no other members of their family belong (Calderon & Greenberg, 2003:180; Chapel, 2005:133; John, 2009:362). As mentioned earlier, this identification with Deaf culture would mean that deaf children will use sign language as their first language and identify with the Deaf community, which, for all practical reasons, would imply that the deaf child's hearing parents are raising a foreign child (Singleton & Tittle, 2000:227).

The fact that the average deaf child might not be fully immersed in his/her hearing parents' culture consequently has an effect on the extent to which the deaf child will share his/her parents' religion. This may be one of the reasons an estimated less than two per cent of the world's deaf population have been reached by the Gospel (Anonymous, 2012; Newell, 2009).

According to Wilson (2011:2) the inaccessibility of the written Bible is another contributing factor to the low percentage of deaf people reached by the Gospel. Sign language as the first language of most deaf people (Lombaard & Naudé, 2007:151) is a visual language with no written equivalent. Because it is not presented in their first language, information in written text is not the most effective way to convey religious information to deaf persons, in the same way that a native English speaker would understand an English Bible far better than an Afrikaans or Setswana Bible.

It therefore seems clear to Newport and Meier (as quoted by Burke, Kushalnagar, Mathur, Napoli, Rathmann & Vangilder, 2011:275) that when the language needs of deaf children are not met, it can profoundly harm their psychosocial health and spiritual development.

1.3.2 Status of research

Before work on this research proposal commenced, the following search engines were consulted (using the keywords from 1.1): NEXUS, North-West University library catalogue, SACat, EBSCOhost, Sae Publications and Sabinet Online. The search yielded the following results:

- Much research attention has been paid to Deaf culture, Deaf identity and sign language as central to the Deaf communities around the world (Burke *et al.*, 2011; Butler *et al.*, 2001; Jones, 2002).
- Several studies exist that focus on the counselling and therapy services provided to deaf people (Theunissen, 2011; Vernon & Leigh, 2007).
- In addition, there are numerous studies on the challenges faced by deaf children as well as counselling and therapy of deaf children in particular (Chapel, 2005; Kasza, 2013; Lim & Simser, 2005; Oualline, 1975 & Zieziula, 1979).

The above results show that considerable research has been done worldwide on Deaf culture, sign language, mental health services to deaf people, the challenges families with deaf children face as well as the counselling and therapy of deaf children. However, research regarding the situation of deaf people in South Africa, Deaf culture in South Africa and pastoral care of deaf people in South Africa is basically non-existent. It appears from this exploratory research that there is a notable absence in research regarding pastoral care and counselling of families with deaf children. This study attempts to address this void.

1.3.3 Problem statement

Accurate statistics about the deaf population in South Africa have proven difficult to obtain, but researchers estimate the number of deaf people in South Africa to be around 500 000 with a further 1–1.5 million people with varying degrees of deafness (DeafSA, 2010:1; John, 2009:39; Klein, 2008:1; Maloney, 2010:1). Estimates of Ganiso (2012:26), Pieterse, (2012:2), Lombaard and Naudé (2007:14) and Theunissen (2011:94) indicate that between 500 000 and one million of all South Africans use South African Sign Language (SASL).

Deaf children who are born to hearing parents and who are not provided with the opportunity to attend pre-schools for deaf children might spend the first six years of their life without exposure to the language that comes to them most naturally – sign language. These first six years of life are crucial years for language and cognitive development. As mentioned earlier, this greatly impacts on family relationships and may leave the deaf child isolated (Burke *et al.*, 2011:283).

As children progress through the normal developmental stages of childhood, they are faced with numerous challenges, and these challenges could be even more pronounced in deaf children (John, 2009:58; Rennie, 2000:10; Smith, 2002:59). All levels of deafness can have a detrimental impact on a child's development, one of which could be the delay in effective

communication (THRIVE, 2016:1), which in turn hampers the mastery of expected levels of performance at an earlier stage and also impacts on reading, emotional adjustment, social interaction, social maturity, problem-solving and learning strategies (Barker *et al.*, 2009:375; Chapel, 2005:56; John, 2009:59).

Since deaf children are mostly born to hearing parents and as such do not necessarily understand or identify with their parents' culture and language, a spiritual dilemma arises. The Great Commission (Matt. 28:16-18; Mark 16:15-18; Luke 24:44-49; John 20:19-23) is to reach and preach the Good News to all people, deaf people included. Imagine the following scenario: a family in a congregation in the reformed tradition in South Africa learns that their child is deaf. The family shows up on their minister's doorstep – how would a pastor respond? Would the pastor and the congregation recognise that they have a responsibility towards this family? What would the minister's plan of action be? How would the congregation assist this family? How would the pastor or pastoral practitioner ensure that the spiritual and emotional needs of the whole family are met? Informal preliminary correspondence (in the form of questionnaires) with practising pastoral practitioners indicated pastoral practitioners' lack of awareness related to deafness and the consequent lack of competence in terms of pastoral care and counselling of families with deaf children (cf. Appendix 6).

From the information the researcher has been able to gather, it is clear that wonderful initiatives are being taken by some organisations (Centre for Deaf Studies at the University of the Witwatersrand, the Deaf Federation of South Africa, the National Institute for the Deaf) and churches (DeLaBat Dutch Reformed Church; Germiston Deaf New Life Church East) in the South African context. Some of these initiatives include a home intervention programme for children who are Deaf and hard-of-hearing, advocating for deaf South African citizens, training of Deaf ministers, accommodating Deaf church members and ministering to the Deaf. However, the researcher found little literature published indicating churches in South Africa pastorally assisting families with deaf children, educating communities about the deaf, Deaf culture and South African Sign Language, bringing the Gospel to the deaf, accommodating deaf brothers and sisters, and pastorally caring for and guiding deaf children on their spiritual journey.

The above situation may be due to various reasons, among which the most probable would be ignorance, the challenge in terms of the unfamiliar territory of working with families with deaf children and the lack of resources in terms of available guidance, expertise and information in most churches in South Africa. Extensive research is needed regarding the

situation, language and pastoral care of deaf people in the South African context. Research into the pastoral care and counselling of specifically hearing families with deaf children is vital. As many members of a congregation might turn to pastoral practitioners for spiritual guidance during challenging times in their lives, pastoral practitioners should be equipped to have informed responses to issues they may be faced with such as:

How can a pastoral practitioner assist a hearing family with a deaf child? What are the cultural and linguistic aspects a hearing pastoral practitioner needs to be aware of when working with the deaf children and their families? How does deafness influence a child's spiritual development? How can a deaf child understand and find their identity in Christ? What are effective ways of bringing the Gospel to the deaf child? Which strategies can assist the hearing pastoral practitioner in his pastoral care and guidance of the family with the deaf child?

1.4 RESEARCH QUESTION

The question to be answered by this research is:

What practical theological model can be formulated for the pastoral care and counselling of families with deaf children?

Further questions that arise from the research question are:

- To which perspectives does empirical research contribute in the creation of a clear depiction of the current situation of pastoral care and counselling of families with deaf children in South Africa?
- What elucidation do other related sciences provide to the understanding and explanation of the current situation of pastoral care and counselling of families with deaf children in South Africa?
- What are the normative and ethical perspectives that Scripture provides for the pastoral care and counselling of families with deaf children?
- What perspectives and guidelines can be given to pastoral practitioners regarding a practical theological model for the pastoral care and counselling of families with deaf children?

1.5 AIM AND OBJECTIVES

Aim

The overall aim of this study is to indicate what the pastoral care and counselling of families with deaf children ought to entail by developing a practical theological counselling model to be utilized by pastoral practitioners.

Objectives

This research aims to address the above-mentioned questions by pursuing the following objectives:

- To gain a clear picture of the current situation of pastoral care and counselling of families with deaf children in South Africa through empirical research;
- To conduct a literature study of various related sciences in order to provide understanding and explanation of the current situation of families with deaf children in South Africa;
- To determine the normative and ethical perspectives Scripture provides for the pastoral care and counselling of families with deaf children; and
- To propose perspectives and guidelines for a counselling model for pastoral practitioners in the pastoral care and counselling of families with deaf children.

1.6 CENTRAL THEORETICAL ARGUMENT

The central theoretical argument is that families with deaf children could greatly benefit from a much-needed pastoral practical theological counselling model for pastoral care and counselling.

1.7 METHODOLOGY

This practical theological study is done from the perspective of the Reformed tradition. This includes the inspired Word of God as the primary source for spiritual direction and normative foundation (2 Tim. 3:16-17).

In answering the different research questions of this study, Richard Osmer's (Osmer, 2008:4) model of practical theological interpretation for Practical Theology is used. Osmer mentions a "reflective equilibrium" which provides a helpful way members of a particular field

can talk to each other instead of past each other, by finding the points of convergence in their work (Osmer, 2008:241). The model of Osmer comprises four questions that guide the researcher to concentrate on the four interrelated, intellectual tasks of practical theological research (Osmer, 2008:4).

These four core tasks of practical theological research, guided by the four questions, are to be explored in this research:

- The *descriptive-empirical task* examines the current situation ("What is going on? / What happened?").
- The *interpretative task* tries to understand from a literature study of various related sciences what causes gave rise to the current situation ("Why is it going on? / Why is this happening?").
- The *normative task* consists of normative and ethical perspectives Scripture provides to describe the desired situation ("What ought to be going on? / What should happen?").
- The *pragmatic task* entails the formulation and implementation of a strategy or action plan for the solution of the problem formulated in the empirical-descriptive task ("How might we respond? / How should we act?").

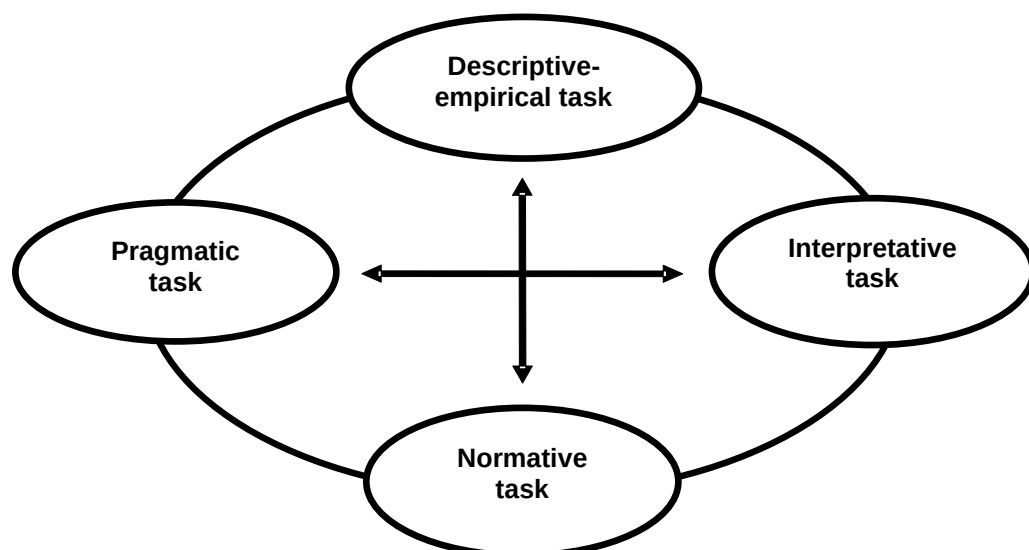


Figure 1-1: Osmer's model (Osmer, 2008:11)

The community's participation in Christ's priestly, royal and prophetic mediation of salvation is facilitated by the leader, pastoral counsellor or minister in the carrying out of the four tasks of practical theological interpretation (Osmer, 2008:28).

Since these four tasks form the core structural and procedural guidelines for this study the tasks will now be briefly outlined.

1.7.1 Descriptive-empirical task

In order to attain the first objective postulated for this study, which is to gain a clear depiction of the current situation of pastoral care and counselling of families with deaf children in South Africa, a qualitative empirical study, grounded in a spirituality of presence and priestly listening (Osmer, 2008:33–35) was embarked on by means of data collection with interviews and analysis being the methods of research.

1.7.1.1 Data collection

As the research is about the pastoral care of families of deaf children, interviews were necessary in order to explore experiences of families with deaf children. The qualitative data was generated through semi-structured interviews with a core group consisting of five families with deaf children in order to provide insight into and determine, explore and describe the meanings, experiences, challenges and perceptions of families with deaf children. The respondents were identified in Potchefstroom, other areas of the North West Province based on the expectation that they could make a meaningful contribution in the answering of the research questions.

The respondents were all asked the same question: *"What is your experience of being part of a family with a deaf child?"* Further probing questions emanate from the above question:

The questions posed to families with deaf children were phrased as follows:

- *"How and when did you learn about your child's deafness?"*
- *"What was, up to that point, your knowledge about and attitude towards deafness?"*
- *"What was your response and what emotions did you have to deal with?"*
- *"What was the response of your extended family and friends?"*
- *"What was the response of your religious community?"*
- *"What were your family's greatest challenges?"*
- *"Did learning about your child's deafness have an impact on your spiritual life?"*

- *“Did you and if so to whom did you turn for guidance and advice in learning to live with deafness?”*
- *“What were your needs and expectations in terms of your religious community?”*

The collected data from the interviews was analysed by examining the raw data, then marking different sections of the data as being relevant to one or more of the themes (coding) in order to finally identify relationships among the different themes (Forman, Creswell, Damschroder, Kowalski & Krein, 2008:767).

1.7.1.2 Specific ethical implications of the data-collection process

1.7.1.2.1 Role of respondents in data collection

Participants were asked to fill in a short questionnaire which was followed up by an in-depth interview. Participants recalled their experiences of the period of learning that their child is deaf and well as the period of adjustment to deafness.

1.7.1.2.2 Benefits of participation for respondents

The benefits of participating in this study were that participants had the opportunity to express and share their experiences and to contribute to improving the pastoral care and counselling provided to families with deaf children.

1.7.1.2.3 Criteria for respondent selection and recruitment

The criteria for selecting respondents were that they should be self-declared Christian parents of deaf children. The theme of this study made random recruitment inappropriate to this study and therefore serves as the justification of the inclusion criteria.

1.7.1.2.4 Setting of data-collection

For their own convenience and to eliminate any financial expenditure to participate in this research, all interviews were conducted in the comfort of participants' own homes or other appropriate places they preferred.

1.7.1.2.5 Incentives of respondents

No form of incentive or financial remuneration was offered to any respondents for participation in this research.

1.7.1.2.6 Availability of research results to respondents

The research results of the current study will be made available online to all respondents on the completion thereof. The researcher will be available for any follow-up questions or discussion of the results.

1.7.1.2.7 Management, storage and destruction of data

The interviews were audio-recorded with a digital recorder in order to ensure the accurate reproduction and processing of the data. Confidentiality was achieved by storing the audio-recordings in a safe place where no one but the researcher and her promotor would have access to the recordings.

1.7.1.2.8 Privacy and confidentiality

The personal information disclosed by respondents was treated anonymously and confidentially. Further, anonymity and privacy of the participants and their children were ensured by the use of pseudonyms. The data was and still is treated with respect and integrity.

1.7.1.3 Ethical aspects

The researcher received the required ethical approval from the Research Ethics Committee of Theology, the NWU Institutional Research Ethics Regulatory Committee (NWU-IRERC) for this empirical research. The ethics number awarded to the present research is NWU-00122-15-A6.

The following prescribed ethical norms as stipulated by the guidelines and policy of the Research Ethics Committee of the North-West University (North-West University, 2013:32:26) and reiterated by Hopf (2004:335) and Wassenaar (2006:72) underpinned this research:

- ensuring voluntary participation,
- gaining informed consent (appendix 2),
- effecting confidentiality and trust.

1.7.2 Interpretative task

A literature study of various related sciences was conducted in order to reach the second objective of this study, viz. to provide an understanding and explanation of the current situation of families with deaf children in South Africa, thereby creating the interpretative perspective. This literature from review drew on theories in psychology, sociology and social work in the search for insight and sagely wisdom into the current situation of families with deaf children in South Africa (cf. Osmer, 2008:8; 2008:85).

1.7.3 Normative task

The study primarily rests on a normative foundation. Osmer (2008:138) describes the normative task's spiritual and practical discernment as firstly entailing the admission that we do not know what to say and do and in humility, putting aside our self-confidence. Secondly, discernment involves actively seeking God's guidance and sorting out what ought to be done in certain episodes, situations and contexts (Osmer, 2008:138). Therefore, the third objective of this study, determining the normative and ethical perspectives Scripture, provides for the pastoral care and counselling of families with deaf children, and it was attained by conducting exegetical studies of applicable passages in Scripture. The book of Lamentations was focused on for guidelines in working through the process of grief and 1 Corinthians 12 in search for biblical principles for an attitude towards deafness. The method of exegesis followed for this study is the grammatical historical approach recommended by De Klerk and van Rensburg (2005). The normative perspectives gained from the exegesis of above passages in Scripture were compared to the interpretative perspectives gained from research, thereby determining how worldly wisdom appropriately relates to and interacts with the Wisdom of God (Osmer, 2008:162).

1.7.4 Pragmatic task

The pragmatic task of Osmer (2008:176) involves the formulation of a model or strategy for solving the problem formulated in the descriptive-empirical task. This pragmatic task further implies change towards desired goals. Therefore, a synthesis established by a hermeneutical interaction between the research results of the descriptive, interpretative and normative tasks was utilized in order to propose perspectives and guidelines for a model for pastoral practitioners in the pastoral care and counselling of families with deaf children.

1.8 PROPOSED CHAPTER OUTLINE

The various chapters of this study are arranged on the basis of the four tasks of practical theological interpretation as emphasized by Osmer (2008:4):

Chapter 1: Introduction, problem statement and research method.

Chapter 2: Descriptive-empirical task: Gaining a clear outline of the current situation of pastoral care and counselling of families with deaf children in South Africa through empirical research.

Chapter 3: Interpretative task: Conducting a literature study of various related sciences in order to provide understanding and explanation of the current situation of families with deaf children in South Africa.

Chapter 4: Normative task: Determining the normative and ethical perspectives Scripture provides for the pastoral care and counselling of families with deaf children.

Chapter 5: Pragmatic task: Proposing perspectives and guidelines for a model for pastoral practitioners in the pastoral care and counselling of families with deaf children.

Chapter 6: Concluding inferences and recommendations.

1.9 SCHEMATIC REPRESENTATION OF RESEARCH PROCEDURES

Title: Pastoral care and counselling of families with deaf children: a Practical Theological model.		
1.4 Research question	1.5 Aim and objectives	1.7. Methodology
What practical theological model can be formulated for the pastoral care and counselling of families with deaf children?	The overall aim of this study is to indicate what the pastoral care and counselling of families with deaf children ought to entail by developing a counselling model to be utilized by pastoral practitioners.	The study uses Osmer's (2008:4) model of the four tasks of Practical Theology to come to new insights about pastoral care and counselling of families with deaf children.
Further question 1: To which perspectives does empirical research contribute in the creation of a clear depiction of the current situation of pastoral care and counselling of families with deaf children in South Africa?	Objective 1: To gain a clear depiction of the current situation of pastoral care and counselling of families with deaf children in South Africa through empirical research.	Descriptive-empirical task The descriptive-empirical task involving a qualitative empirical study, grounded in a spirituality of presence and priestly listening, was embarked on in by means of data collection with interviews and analysis and being the methods of research.
Further question 2: What elucidation do other related sciences provide in the understanding and explanation of the current situation of families with deaf children in South Africa?	Objective 2: To conduct a literature study of various related sciences in order to provide understanding and explanation of the current situation of families with deaf children in South Africa.	Interpretative task A literature study of various related sciences was conducted in order to reach the second objective of this study, to provide understanding and explanation of the current situation of families with deaf children in South Africa, thereby setting the interpretative perspective. This literature from review drew on theories in psychology, sociology and philosophy in the search for insight and sagely wisdom into the current situation of families with deaf children.

Further question 3: What are the normative and ethical perspectives that Scripture provides for the pastoral care and counselling of families with deaf children?	Objective 3: To determine the normative and ethical perspectives Scripture provides for the pastoral care and counselling of families with deaf children.	Normative task The normative task focuses on determining the normative and ethical perspectives Scripture provides for the pastoral care and counselling of families with deaf children, will be reached by conducting exegetical studies of applicable passages in Scripture. These normative perspectives were then compared to the interpretative perspectives thereby determining how worldly wisdom appropriately relates to and interacts with the Wisdom of God.
Further question 4: What perspectives and guidelines can be given to pastoral practitioners regarding the pastoral care and counselling of families with deaf children?	Objective 4: To propose perspectives and guidelines for a model for pastoral practitioners in the pastoral care and counselling of families with deaf children.	Pragmatic task The pragmatic task involves the formulation of a model or strategy for solving the problem formulated in the descriptive-empirical task. Synthesis established by a hermeneutical interaction between the research results of the preceding three tasks was utilized in order to propose perspectives and guidelines for a model for pastoral practitioners in the pastoral care and counselling of families with deaf children.

CHAPTER 2

THE DESCRIPTIVE-EMPIRICAL TASK OF PRIESTLY LISTENING

2.1 Introduction

In the preceding chapter of this study a synopsis of the study to be undertaken was provided. Osmer's model of practical theological interpretation is used in the current chapter for the purpose of performing the first key task which examines the present situation. This descriptive-empirical task asks the question at the very heart of this task: "*What is going on?*"(Osmer, 2008:4). According to Osmer (2008:4), the descriptive and empirical research task encompasses: "Gathering information that helps us discern patterns and dynamics in particular episodes, situations, or contexts." The objective of this chapter is:

- To gain a clear depiction of the current situation of pastoral care and counselling of families with deaf children in South Africa through empirical research.

2.2 RESEARCH DESIGN OF THE DESCRIPTIVE-EMPIRICAL TASK

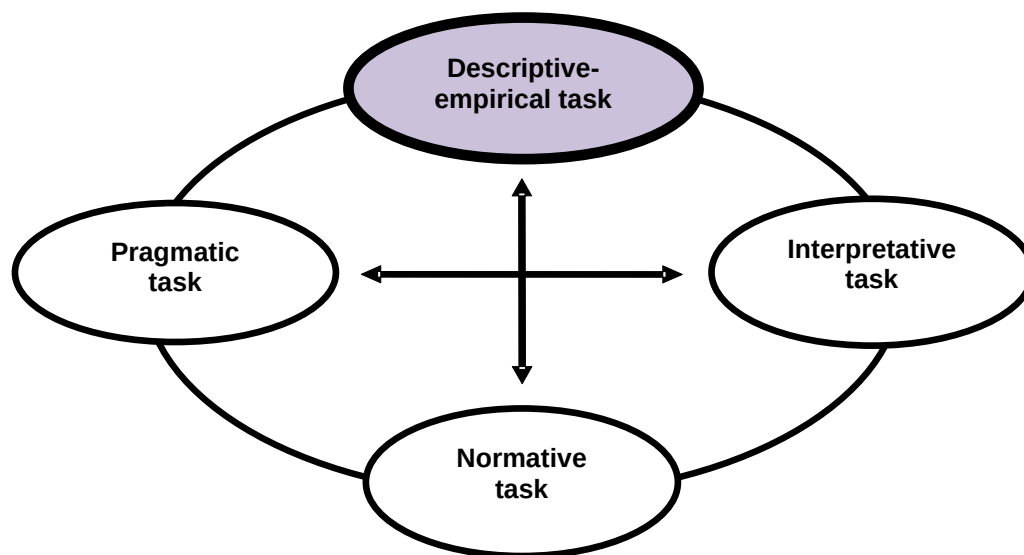


Figure 2-1: The descriptive-empirical task (Osmer, 2008:11)

Since the definitions of research design are quite ambiguous it is important to point out that research design is not associated with any specific type of data or method of data collection (Fouché & Delport, 2011:73). Durrheim (2006:35) describes research design as a strategic

framework or structure for action that serves as a bridge between the research questions and the execution or implementation of the research. The designed and planned nature of research is what distinguishes it from other forms of observation. Research design is about the logic rather than the logistics of the research. The main role of research design is to ensure that the type of data collected will answer the research question in a convincing way, thereby reducing ambiguous research evidence (De Vaus, 2004:16).

Combining the model of Osmer (2008:47) and the research process model proposed by Fouché and Delport (2011:70) research may be viewed as a process consisting of the following phases and steps:

Step 1: Defining and clarifying the purpose of the research

Step 2: Choosing a strategy of inquiry

Step 3: Forming and execution of a research plan

Step 4: Reflection on the assumptions informing the research.

Each step is to be incorporated subsequently in the rest of this chapter.

2.2.1 Purpose of the research

Cultivating a spirituality of presence really is a great challenge to pastoral practitioners, since they are often so busy and task-orientated that they do not necessarily truly listen with their whole mind. This often leads to pastoral practitioners making decisions too hastily without pausing to discover what is really going on or to make hurried value judgments about other people without taking time and making an effort to learn who they really are and what they are going through (Osmer, 2008:34). Osmer (2008:34) emphasises the danger of continuing in this way by stating that pastoral practitioners run the risk of failing to notice persons or groups who are suffering and in need. This task of priestly listening is therefore ultimately about attending to what is going on in the lives of everyone in the congregation and community. Attending is a prerequisite for leading since it is impossible to lead if one does not attend to other people in their otherness.

Herein lays the challenge to pastoral practitioners (Osmer, 2008:34):

What sort of influence do we have to offer if we have not struggled to overcome our own tendency to not listen, to rush to judgment, and to ignore suffering others in our midst? Struggling with these kinds of issues lies at the heart of a spirituality of presence. It is a matter of opening ourselves to the forming and transforming Spirit of God who remakes us in the image of Christ within his body. Unless we first learn to attend, we cannot really lead.

The purpose of this study is to attend to what is going on in the lives of families with deaf children in terms of the nature of support received, thereby attaining the first objective set out by this study, namely to gain a clear depiction of the current situation of pastoral care and counselling of families with deaf children in South Africa. Osmer (2008:48) views having clarity about the purpose and reason for the study being undertaken as an absolutely crucial first step in research design. The researcher seeks to develop a deeper understanding of the experiences and challenges of families with deaf children in order to draw reliable conclusions from the observations and interviews.

2.2.2 Research methodology

2.2.2.1 Selection of a research strategy

When deciding on the strategy of inquiry that will guide the research of this study, the two main categories of empirical research need to be considered. There is a clear distinction between the sampling techniques of data collection and the techniques of data analysis of quantitative and qualitative research, each with their own purposes, research methods, data collection and data analysis strategies as well as quality criteria (Fouché & Delport, 2011:63).

Quantitative research gathers data in the form of numbers, uses statistical types of data analysis and is particularly helpful in determining broad statistical patterns and relationships between variables in order to make broad and generalizable comparisons (Durrheim, 2006:47; Fouché & Delport, 2011:63; Osmer, 2008:50).

In contrast to quantitative research qualitative research collects data in the form of written or spoken language and seeks to understand the actions and practises in which individuals engage in everyday life and to determine what the meanings are that they ascribe to their individual experiences. One of the ways qualitative research attains the above aims by analysing data by identifying and categorising themes and is therefore better suited to studying small numbers of individuals, groups and communities in depth (Durrheim, 2006:47; Fouché & Delport, 2011:65; Osmer, 2008:50).

Following the description of what the abovementioned two principles entail, Osmer (2008:50) recommends the 'mixed method' of combining quantitative and qualitative research and viewing these two methods on a continuum.

2.2.2.2 Qualitative research

The selected method for this empirical study is qualitative research as attention is paid to naturalistic observation of and subjective exploration of social situations, trends, experiences and feelings and seeing as the collected data during this research is subjective in nature and as a result will be analysed by interpreting interviews thematically rather than analysing data statistically.

Janse van Rensburg (2007:7), Mohammed, (2009:28-29) and De Klerk and De Wet (2013:305) explain the characterising contrasts between quantitative and qualitative research by indicating the shift in research from:

- deductive reasoning to inductive reasoning;
- a context-less analysis to a contextual analysis;
- a focus on the “hard facts” in considering the context;
- statistical facts to an understanding of an individual’s deeper driving forces and emotions;
- reliability to authenticity;
- a rational approach to an experienced approach;
- the explanation of a phenomenon to the understanding of behaviour, events and emotions;
- an objective to a subjective and inter-subjective approach.

Specific characteristics of qualitative research that differentiates it even further from quantitative research (De Klerk & De Wet, 2013:305; Fouché & Delport, 2011:65; Janse van Rensburg, 2007:8) include that it is primarily based on a hermeneutical epistemology, deals with words rather than numbers, has a personal quality and is a client-centred approach.

From the discussion above it is clear that qualitative research is descriptive and exploratory and that it allows the researcher to study selected issues in depth, openness and detail as the researcher attempts to identify and understand the categories of information that emerge for the data (Hanson *et al.*, 2005:232). Since the researcher is concerned with describing and understanding phenomena and human experiences rather than explaining or predicting human behaviour (Fouché & Delport, 2011:65), the researcher embarked on a qualitative empirical study, grounded in a spirituality of presence and priestly listening as described by Osmer (2008:33).

2.2.3 Meta-theoretical assumptions

As a result of the vast diversity that exists in the different approaches to practical theological science as well as the tendency of researchers to not explicitly state their theological and other approaches, a lack of clarity pertaining to meta-theoretical assumptions has developed (De Wet & Pieterse, 2010:525). In the light of the previous statement the researcher considers it necessary to explain the meta-theoretical assumptions regarding reality, knowledge and science with which this study was approached.

Ontology specifies the assumptions of how the reality that is to be studied is viewed by asking “What is the nature of reality?” (De Wet & Pieterse, 2010:528; Fouché & Schurink, 2011:309; Mohammed, 2009:28; Terre Blanche Durrheim, 2006:6). When doing research the researcher’s view of God and view of man should be explained. The current study is observed and explained from the platform of the reformed meta-theoretical assumptions (Breed, 2013b:1–8) that include the view of man as a being in conversation with God; man as an imperfect being who can be renewed by God; change in man as closely related to man’s thoughts and convictions and the fact that change in terms of man’s thoughts and conduct results from knowledge of God.

Behind ontological beliefs lie various theories of epistemology, which specify the nature of the relationship between the researcher and the theories of knowledge and perception. The relevant question to be answered here is: “What are the principles by which the researcher believes reality can and should be known?” (De Wet & Pieterse, 2010:528; Fouché & Schurink, 2011:309; Terre Blanche & Durrheim, 2006:6).

De Wet (2006:66) mentions three main trends in the research methods of the social sciences to which Practical Theology can relate:

- The normative deductive trend, where the normative source of revelation of Scripture has the first and last say in the process of formation of theory, while results from the social sciences are noted as ‘auxiliary sciences’;
- The empirical-analytical trend which specifically relates to the empirical research methodology of the social sciences;
- The hermeneutically-mediated trend largely echoing the hermeneutic research methodology of the social sciences.

In the present study, a hermeneutical approach to Practical Theology was applied in order to come to a valid understanding of that which is observed. The researcher supports the design

of Osmer (2008:4) as a responsible meta-theoretical way in which to practise Practical Theology from a hermeneutical approach.

Breed (2013b:1–8) explains these epistemological assumptions as being that the purpose of the research is determined by the creational purpose of man and that a variety of realities play a role in the hermeneutical process, these being:

- The Word of God is the revelation of the truth for life;
- God is the revealed yet unfathomable God;
- The Holy Spirit alone can guide both the counsellor as the counselee to full truth;
- The integration of intellectual knowledge in order to gain a new perspective on reality can bring about peace and enable man to live regardless of unchanging painful circumstances and is a gift from God; and
- Hope plays a crucial role in any counselling situation.

Subsequent to ontological and epistemological assumptions, it is necessary to also indicate the nature and task of Practical Theological science. De Wet and Pieterse (2010:529) indicate the importance of answering the question: “How does Practical Theological science differ from other fields of Theology?” The definition provided by Breed (2013a:250) clearly differentiates pastoral science from other fields of study in Theology:

Pastorale wetenskap behels die wetenskaplike studie van die Woord van God, die mens, die werklikheid en ander toepaslike vakdissiplines, met die oog op die ontginning van die Bybelse beginsels, die ontwerp en toepassing van 'n pastorale model met die doel om gelowiges, deur die kragtige werk van die Heilige Gees, te begelei tot dieper kennis van God en hulleself, tot geloofsgroei wat hulle in staat kan stel om die krisis van die lewe met vrede te hanteer tot eer van God en tot verdere geloofsgroei, binne die gemeenskap van die heiliges.

[Pastoral science entails the scientific study of the Word of God, man, the reality and other disciplines, with a view to the formulation of Biblical principles, the design and application of a pastoral model with the aim of guiding believers, through the powerful work of the Holy Spirit, to a deeper knowledge of God and themselves, to spiritual growth which enables them to deal with the crises of life in peace, to the glory of God and to further spiritual growth, within the communion of the saints.]

The present study uses Richard Osmer's (2008:8) hermeneutical approach to Practical Theology as the foundational model of research. As mentioned in the previous chapter, Osmer's model for the application of Practical Theological interpretation revolves around the following four questions:

- What is going on / what happened?

- Why this going on / why is this happening?
- What ought to be going on / what should happen?
- How might we respond / how should we act?

The above-mentioned questions guide the researcher to concentrate on the four interrelated, intellectual tasks of practical theological research, viz. the *descriptive-empirical, interpretative, normative, and pragmatic* tasks.

2.3 RESEARCH PLAN

2.3.1 Sampling of participants

Sampling refers to using a portion of a specific population and considering it as representative of that specific population. When the results of a sample such as this are generalised, it means that it is assumed that the same results would be yielded by any other portion of the same population (Fouché & Delport, 2011:73; Strydom, 2011:234). However, sampling differs in terms of its application in quantitative and qualitative research. When utilised qualitatively, sampling is not as structured, as quantitative or as strictly applied as sampling in quantitative research (De Vaus, 2004:240). The sample of the population to be investigated is mostly determined by the purpose of the research as well as time and resources available.

Strydom and Delport (2011:391) conclude that in qualitative research investigations, non-probability sampling is practically used without exception.

Before participants were approached, attention was paid to the characteristics of the ideal participant for the purposes of the present study. As this is aimed at describing personal experiences, specific aspects were looked at in the search for ideal participants. Kelly (2006:293) describes the ideal participant as someone who has personal experience of what is being researched; has good communicative skills in order to describe his or her experiences in detail; is open and non-defensive; is interested in participating in the research; and has the perception that his or her participation might be of value.

Based on the above, a combination of purposive and sequential sampling was subsequently used in the selection of the participants for this study. Various authors (Babbie, 2013:557; Durrheim & Painter, 2006:191; Strydom & Delport, 2011:392) describe purposive (judgmental) sampling as a type of non-probability sampling that does not only depend on the availability and willingness of participants to participate in the research, but focuses on the special qualities, experiences and circumstances of participants and selects cases that are typical to the population to be investigated and is judged by the researcher to be most

useful or representative. Sequential sampling on the other hand refers to the process of gradually accumulating a rich and sufficiently sized sample for the research until saturation point is reached (Durrheim & Painter, 2006:139; Strydom & Delpont, 2011:393).

Due to the specific nature and purpose of this study a target population consisting only of hearing families with deaf children were involved in the research. Because of practical considerations families from Potchefstroom and surrounding areas of the North West Province were involved in the research. The size of the sample could not be predetermined, since the researcher is guided by continuous evaluation of the data, in determining when sufficient information has been collected and no new information is identified, thus when the point of saturation occurs (Greeff, 2011:350; Strydom & Delpont, 2011:392).

The participants consisted of Christian, Afrikaans, male and female parents of double parented families. The levels of deafness of the children varied from moderate to profoundly deaf. The mode of communication in the families varied from spoken language to limited sign language and the choices of education varied from mainstream to schools for the Deaf.

- Participants A and B are married and have three children. The eldest child is hearing; the second child is hearing for all practical purposes although the child does have unilateral hearing loss and the youngest child was born deaf.
- Participants C and D are married and have two children. The eldest child was born prematurely and diagnosed with deafness at the age of 22 months. The younger child is hearing.
- Participants E and F are married and have two children. The eldest child is hearing and the younger child was born deaf.
- Participants G and H are married and have two children. The eldest child is hearing and the younger child was born hearing but became post-lingually deaf as a result of progressive deafness.
- Participants I and J are married and have three children. The eldest two children are hearing. The youngest child became deaf at the age of three.

Due to sample size and community size as a whole, gender of both deaf children and their siblings are omitted in the above break-down of participating families.

The participants were expected to be an experienced and illustrative group who would be able to provide very valuable data and insight into the enquiry underlying this research.

2.4 RESEARCH METHODS

Osmer (2008:54) places emphasis on the essential abilities needed in order to execute qualitative research, i.e. that of description, observation and interviewing. In order to draw valid conclusions from the study, it is essential that the researcher has sound data to analyse and interpret. Research strategies or methods that are frequently used and dominate qualitative research include narrative research, case study research, ethnographic research, grounded theory research, phenomenological research and advocacy research (Fouché & Schurink, 2011:313; Lindegger, 2006:462; Osmer, 2008:51).

The qualitative approach of this research lends itself to the use of a combination of case study and narrative research strategy since the research is aimed at gathering information about the stories and experiences of individuals and exploring the events in their lives in depth.

2.4.1 Data collection

Data collection refers to the process of obtaining the necessary data for the research at hand and Poggenpoel (2003:146) views data collection as consisting of three stages: the preparation phase, the interview phase and the post-interview phase.

The method of collecting the data for research is partially determined by the research strategy, which in this case is qualitative research. Some of the most common methods for collecting qualitative data include interviewing, participant observation, artefact analysis, special analysis, focus groups, group interviewing and documentary sources (De Klerk & De Wet, 2013:306; Durrheim, 2006:51; Osmer, 2008:54).

2.4.1.1 The preparation phase

During the preparation phase of the information-gathering process the researcher is guided by the purpose of the research to decide upon the most effective method for data collection. In the case of the present study the researcher expected interviewing to be the most efficient method to gather the necessary information. More specifically the researcher opted for semi-structured interviewing in order to provide insight into and determine, explore and describe the meanings, experiences, challenges and perceptions of families with deaf children. Semi-structured interviewing is explained by De Klerk and De Wet (2013:306) and Osmer (2008:245) as a type of interviewing where both open and closed-ended questions are used in such a fashion that they could be adapted as the conversation continues and/or changes

direction. In conducting semi structured interviews the researcher hoped to have a deep conversation with each participant, rather than having a question and answer session. Semi-structured interviews were used because of their flexibility in scope and depth.

Audiologists in Potchefstroom were approached in order to establish contact with families with deaf children who could participate in the research process. The audiologists were informed that research regarding the pastoral counselling and guidance of families with deaf children was being conducted (see Appendix 1). The researcher mentioned that the research would be conducted under the supervision of two supervisors and that the research would be dealt with ethically and responsibly. This process yielded no participants. In the end, however, an independent search conducted by the researcher for suited families resulted in the identification of all the participants of the semi-structured interviews.

2.4.1.1.1 Voluntary participation and informed consent

The families were fully informed about the background of the research and why they had been approached to participate in this specific research. Before commencement of the interviews, all the participants of this study were provided with adequate information about the aims of the present research as well as the details of the research process (see Appendix 2).

After their willingness to participate in the research had been determined, the details of the research process were discussed with each participant. In terms of voluntary participation, participants were made aware of the fact that they were at total liberty to withdraw from the research process at any stage without providing reasons for doing so, since no individual should ever be forced to participate in any research (Hopf, 2004:335; Poggenpoel, 2003:147; Wassenaar, 2006:72).

In addition, participants were informed that the personal information they disclosed would be treated anonymously and confidentially, after which they were all asked to sign an informed consent form (see Appendix 2). Confidentiality was achieved by storing the audio-recordings in a safe place where no one but the researcher would have access to the recordings. Further, anonymity of the participants and their children was ensured by the use of pseudonyms. The data would be treated with respect and integrity.

Before the interview phase, each participant was provided with a brief questionnaire that they were asked to complete and return to the researcher before the inception of the interview phase (see Appendix 3 for the questionnaire to be completed by the families).

2.4.1.2 The interview phase

Soon after the questionnaires had been returned by the various participants, semi-structured interviews were conducted with the participants. Ten participants participated in the research.

The questions of the short questionnaire that the participants were asked to complete were used as stimulus questions during the interviews. The researcher made sure to take time during the interviews to make notes of important aspects that needed further investigation.

With the permission obtained from the participants, the interviews were audio-recorded with a digital recorder. As was explained to the participants, the recordings were necessary in order to ensure the accurate reproduction and processing of the data (Greeff, 2011:359; Poggenpoel, 2003:146). Before each interview, participants were again reassured of the anonymity and confidentiality of their conversations. The interviews varied in length, but lasted approximately 45 minutes to one hour.

The participants were all asked the same question, which corresponds with the questions in the short questionnaire (see Appendix 3): “What is your experience in being part of a family with a deaf child?” Further probing questions that flowed from the above question were directed to the participants:

- “How and when did you learn about your child’s deafness?”
- “What was, up to that point, your knowledge about and attitude toward deafness?”
- “What was your response and what emotions did you have to deal with?”
- “What was the response of your religious community?”
- “What were your family’s greatest challenges?”
- “Did learning about your child’s deafness have an impact on your spiritual life?”
- “Did you and if so to whom did you turn for guidance and advice in learning to live with deafness?”
- “What were your needs and expectations in terms of your religious community?”

The researcher was meticulous about avoiding common interview errors as far as possible. Typical errors for example would be interrupting the participants, asking too many, closed-ended, leading and ‘why’ questions (Greeff, 2011:346; Kelly, 2006:301). Careful planning was done in terms of ensuring effective interviews by applying good interviewing and communicational techniques.

2.4.1.3 The post-interview phase

During the post-interview phase, the researcher carefully made notes about her own thoughts, impressions and experiences of the interviews. In addition, the researcher tried to, as far as possible; attend to the words and actions of the participants without filtering them through interpretative and normative judgments in this descriptive-empirical task (Osmer, 2008:245). All the interviews were transcribed verbatim in sufficient detail as soon as possible after each interview. Data transcription refers to the activity of turning verbally collected raw data into a written text in order to have it permanently in written form for close analysis (Kelly, 2006:302; Osmer, 2008:56).

The researcher kept field notes about the observations made during the interviews. The non-verbal communication and specifically the emotions that surfaced during the interviews pertaining to parental experiences contain crucial meaning and would be very useful during the analysis and interpretation of the collected data.

2.4.2 Data analysis and interpretation

Data analysis is described by Patton (2002:432) and Schurink *et al.* (2011:399) as the process of inductive reasoning and theorising whereby the researcher turns vast amount of data into findings. The researcher followed the recommendations (Schmidt, 2004:254; Terre Blanche *et al.*, 2006:322) for the data analysis of qualitative data, by firstly immersing herself in and getting thoroughly acquainted with the mass of data collected as well as sifting the raw data for relevant data.

There has been an increased trend in qualitative data analysis to make use of CAQDAS (computer-assisted qualitative data analysis) in order to assist the researcher in the ordering and categorising the qualitative data collected (Schurink *et al.*, 2011:401). For assistance with the data analysis of the present study the researcher utilised the ATLAS.ti software programme.

Once the researcher was well acquainted with the collected data, coding followed as the next step toward an even more laborious data-analysis for interpretation. Coding entails a method that enables the researcher to break the collected data up in analytically relevant ways and to identify and label specific patterns, themes and categories (Schurink *et al.*, 2011:410). Richards and Morse (2013:154) explain: "It (coding) leads one from the data to the idea and from the idea to all the data pertaining to that idea". Subsequently, once the labelling and conceptualisation of the collected data had been completed concepts were

grouped by the process of grouping the various concepts together to determine applicable themes, sub-themes and categories. The researcher then read through all the collected data once more and selected the applicable sections to elucidate the various themes, sub-themes and categories.

Where the abovementioned process broke the data down, the subsequent process aimed to build the data back up again by means of interpreting the data and drawing conclusions from it (Terre Blanche *et al.*, 2006:326).

2.4.3 Reliability of data

As qualitative research is evaluated according to its credibility and dependability, it is of the utmost importance that every effort be made to ensure that the research conclusions are sound, reliable and accurate. Guba according to Shenton (2004:64), Schurink *et al.* (2011:419) and Van der Riet and Durrheim (2006:90) propose four general criteria that qualitative researchers should pay close attention to in their research, as they can in this way determine the trustworthiness of a research project:

2.4.3.1 Credibility (internal validity)

Here the goal is to indicate the extent to which the research results are congruent with reality (Schurink *et al.*, 2011:419). The researcher sought to establish the credibility of this research in various ways. Well-established research methods for identifying appropriate participants, collecting the data and analysing the data were used and appropriately described. In addition, producing a rich and credible account was attained by employing multiple methods of data collection, namely a brief questionnaire; semi structured interviews as well as the researcher's process notes. Each participant was given the opportunity to refuse participation in this research project as well as to withdraw at any stage during the research process, thereby ensuring that remaining participants were truly interested in the research and would tend to be more honest and open during interviewing.

By returning to matters participants raised earlier and repeating questions during the semi-structured interviews, the researcher attempted to promote clarity. During data analysis transcriptions were checked for errors by comparing them once again with the recorded audio interviews. Furthermore, opportunities for discussion and scrutiny of the coding of the collected data by the promoter of this study brought about new perspectives and assisted in the refining of the research results, thereby ensuring consistency.

The researcher has confidence in the credibility of the present research, as a detailed identification and description of the phenomenon under investigation were provided in the course of the research.

2.4.3.2 Transferability (external validity)

Transferability (also called external validity or generalisability) indicates the extent to which the results or findings of the study can be applied to broader populations and settings than the one being researched (Shenton, 2004:69; Van der Riet & Durrheim, 2006:90) and is achieved by producing rich and detailed descriptions of contexts.

Schurink *et al.* (2011:420) indicate that transferability may be problematic in qualitative research. Shenton (2004:71) concurs and questions whether aiming for transferability in qualitative research is a realistic aim, as context is such a key factor in qualitative research. Schurink *et al.* (2011:420) recommend that the researcher should state the theoretical parameters of the research by referring back to the original theoretical framework, thereby indicating how the collection of data as well as the analysis of data is guided by specific models. The researcher attempted to counter the challenges of transferability in qualitative research and made all possible efforts to ensure that sufficient contextual and descriptive information about the field was provided to address the problem of transferability.

2.4.3.3 Dependability (reliability)

The dependability (also called reliability) of the research refers to the degree to which the same results would be obtained if such study were to be repeated in the same context with the same methods and with the same participants (Shenton, 2004:71; Van der Riet & Durrheim, 2006:92). However, seeing that qualitative research is complicated by external variables, replication of qualitative research may be problematic. Dependability is an alternative to reliability and questions whether the process of inquiry is sound, logical and checked (Schurink *et al.*, 2011:420). In the light of the above the researcher attempted to address the issue and to increase the dependability of this study by including extensive detail about the research design, its implementation, the practical detail of the data collection as well as the data analysis, thereby ensuring a good understanding and comprehension of the methods used and to convince the reader that the findings indeed did emerge as the researcher reported they had done.

2.4.3.4 Conformability (objectivity)

Shenton (2004:72) defines the concept of conformability, or objectivity, as “the qualitative inquirer's comparable concerns to objectivity”. Deliberate steps were taken during this study to ensure that the data and the results that emerged from the data were truly those of the participants and not that of the researcher. The role of triangulation was once again kept in mind and the researcher discussed the findings of the research with the promoter of this study in order to reduce researcher bias. The researcher acknowledges her own beliefs; preconceptions and assumptions (see 2.2.3). During the semi-structured interviews, the researcher tried to limit subjectivity by allowing the participants the opportunity to express and elaborate on their own opinions. Subjectivity was further limited by not asking leading questions and by not steering the participants in a direction consistent with the researcher's presuppositions and beliefs.

Detailed methodological descriptions enable the reader to determine to what extent the data and results from it may be accepted.

2.4.4 Ethical aspects

Every effort was made in this research to adhere to prescribed ethical norms as stipulated by the guidelines and policy of the Research Ethics Committee of the North-West University (North-West University, 2013:26). Hopf (2004:335) and Wassenaar (2006:72) reiterate the importance of ethical research by ensuring voluntary participation, informed consent, confidentiality and trust that underpin ethical research. The researcher received the recommended ethical approval from the Research Ethics Committee of Theology, the NWU Institutional Research Ethics Regulatory Committee (NWU-IRERC) for this empirical research. The ethics number awarded to the present research is NWU-00122-15-A6.

2.5 RESEARCH FINDINGS

For the purposes of the present study, it was decided to present the emerged themes from the collected data in terms of the overarching questions directed to the participants in the questionnaire and during the interviews.

All the participants appeared relaxed and spontaneous during the interviews. The participants were eager to share their experiences and answered sincerely and expansively. A possible reason for this could be because of participants welcomed the opportunity to share their experiences.

Next, a discussion of the various themes that emerged from the data.

Theme 1: Diagnosis of and response to deafness

Theme 2: Adapting to deafness

Theme 3: Support received by family after diagnosis

Theme 4: Deafness and spirituality

2.5.1 Theme 1: Diagnosis of and response to deafness

From the findings that emerged from the questionnaires sent to and interviews with parents of deaf children, it is evident that the period of diagnosis is a period most parents recall with great detail. Since the journey in terms of adjusting to deafness officially starts with the diagnosis of deafness, the diagnosis of and response to deafness naturally came to the fore as the first main theme in the collected data.

Sub-themes to be discussed in the paragraphs below include the diagnosis of deafness, prior knowledge of deafness as well as the response to the diagnosis of deafness.

Table 2-1: The sub-themes and categories which resort under theme 1

Theme1	Sub-themes	Categories
Diagnosis of and response to deafness	Diagnosis of deafness	• Age of diagnosis
		• Cause of deafness
	Prior exposure to deafness	• Prior knowledge of deafness
		• Prior attitude toward deafness
	Response to diagnosis	• Shock, confusion and feeling overwhelmed
		• Difficulty in accepting diagnosis
		• Relief
		• Frustration
		• Guilt
		• Sadness
		• Fears in terms of the future
		• Acceptance

2.5.1.1 Sub-theme 1-1: Diagnosis of deafness

2.5.1.1.1 Age of diagnosis

Between a year and 24 months appears to be the average age the majority of the deaf children were when their parents started to notice their child's language development and social behaviour differed from what is usually expected from children at that age. Various participants described their initial suspicions as follows:

"When he was about two years old I had to shout at him when he was damaging a plant and he didn't react" (Participant A);

"I suspected that something was wrong at about 18 months...I would give him a task and he could not execute it" (Participant B);

"There were so many words that we have said to him that he did not repeat" (Participant C); and

"When I saw him crawling towards something dangerous, I had to tap him to get his attention and only then would he turn around...he also gave his first steps at...he was probably 18 months old" (Participant F).

For three participants the signs of deafness only became apparent later:

"It started with directions; the direction that sound was coming from. It made us realise that something is amiss...she also struggled with her balance, constantly falling over and walking into doorways. In addition her speech development was way behind that of her older sister" (Participant G);

"She was about three years old when we decided to do a hearing test, suspecting, but not knowing that something was wrong with her hearing" (Participant H); and "

He received cancer treatment and about after the third or fourth treatment we realised that he could not hear anymore" (Participant I).

The majority of the children were officially diagnosed around age two. One family recalled that the initial hearing tests done at age one indicated "no, everything is fine" (Participant D) while another family was initially informed that their child was autistic (Participant B). The children were predominantly diagnosed with profound bilateral deafness apart from the child of participant C and D who is profoundly deaf in one ear and mildly deaf in the other; and participant G and H's child who was initially diagnosed as profoundly deaf in one ear and became profoundly bilaterally deaf as a result of the progressive nature of the child's deafness.

2.5.1.1.2 Cause of deafness

The responses of the parents indicated that the cause of deafness could not always be determined as is reflected in responses such as:

"It's like searching for a needle in a haystack...we just couldn't...there was no reason (for deafness)...sometimes it can be as a result of neglected middle ear infection or...any viral infection in your first trimester...but how...sometimes you don't even realise that you have a viral infection" (Participant B);

"...her blood tests indicated that she was exposed to cytomegalovirus. But still, it is not to say that it was that (the cause of deafness). So all those thousands of tests and everything, and still we don't really know what it was" (Participant H); and

"No specialist could give us a diagnosis. And we were at biochemistry, they did all the tests under the sun, genetic tests, blood tests, you name it, just didn't find anything" (Participant G).

In some cases the deafness could possibly be related to complications before or at birth:

"...early on already he (the doctor) saw that something was wrong, I think I was 29 weeks along, he saw on my sonar, something doesn't look right, he is too small. He said, uhm, he is most probably going to take him out at 34 weeks...At 31 weeks I was admitted (to hospital)...my placenta was weakening and the amniotic fluid level was getting low" (Participant D); and

"He was in the neonatal ward for two weeks. He was born late, but too small, he didn't want to suckle and he didn't want to drink..." (Participant F).

In one family the child's deafness was caused by chemotherapy treatment for cancer:

"...he was diagnosed (with germ cell cancer) a day after his third birthday. We immediately started with treatment" (Participant I) and *"during his third chemo treatment I realised..."* (Participant J).

2.5.1.2 Sub-theme 1.2: Prior exposure to deafness

Here the intention was to determine the level of exposure participants had to deafness and also how much prior knowledge they had and what their attitude towards deafness was prior to their own child being diagnosed as deaf. Participants' reactions to the above questions can be categorized under the categories of prior knowledge of deafness and prior attitudes toward deafness.

2.5.1.2.1 Prior knowledge of deafness

In response to the question about what their knowledge of deafness entailed before their child's diagnosis, the majority of participants indicated that they basically had no prior knowledge about deafness and all the facets of deafness. Participants expressed their ignorance as follows:

"Not much. Basically zero. Our knowledge was really so limited before we approached specialists" (Participant A);

"My knowledge was an absolute nil. Thought you would give him a hearing aid and he would hear" (Participant E);

"Very basic. I thought when you're deaf you're deaf. Didn't know that there were degrees of deafness or hearing loss. You're not aware that there can be a legion of causes for it (deafness), from genetic to illness, viruses et cetera. We were very oblivious to these things... But we really didn't know anything" (Participant G); and

"Nothing, nothing, nothing. Totally nothing, because it does not affect you. No, so I knew very little, nothing. Not at all, it was a totally new world that we had to get to know" (Participant I).

Even the participants who did have some knowledge of deafness did so to a limited extent:

"Very little. A distantly related family member (niece of my father's), was deaf. I was very young, under ten years old, when I had contact with her... (and) close to us lived a lady who was deaf, uhm, that was about it. My parents communicated with her with limited sign language...So that was about what I knew (about deafness)" (Participant B);

"Only that it existed, that there was a school for the deaf in Worcester. Very basic knowledge about what causes it (deafness).Uhm, I mean, the first time that I heard about an audiologist...no, what does an audiologist do...didn't even know..." (Participant C);

"(I) only knew that compassionately join the parents in their wrestling with God and guide them to focus on things they as believers can understand and hang on to deaf people communicate with sign language. I respected deaf people as much as anyone else, but did not give it much thought otherwise. Yes, you know, it is one of those things that you know nothing about, because you don't have to know anything about it, because it doesn't apply to you, it is not applicable to your immediate situation. So yes, you know that it (deafness) exists, but that is basically all that you know" (Participant H); and

"I had general knowledge about deafness...that people can be born deaf, that there are various degrees of deafness, that some people can be helped with hearing aids...but yes, I think (I knew) pretty much what most people know about deafness. And sign language, that type of thing...but I didn't know anyone personally who was deaf" (Participant D).

The fact that deafness was not in her frame of reference, was expressed by one participant as follows:

“It (deafness) was a disability that was not in my frame of reference. Ugh, you know, it is so interesting how...removed from yourself one sees these things...You think that it (deafness) is not applicable to you...” (Participant B).

2.5.1.2.2 Prior attitudes toward deafness

From the answers provided by the participants a noteworthy phenomenon is the terminology used by the participants. **Words in line with the medical view** of deafness were used much more than words in line with the socio-cultural view of deafness, and some examples are:

“It was a disability that was not in my frame of reference” (Participant B); and

“One doesn’t look down on someone with a disability...” (Participant H).

Feelings of uneasiness were mentioned by two participants and they expressed it as follows:

“I am an accommodating person, but one does have uneasiness...but it is ignorance, inability...you want to help, but you don’t know how to handle it...” (Participant A); and

“Because one stands back, you are anxious; you don’t know if they are going to understand you or whatever...” (Participant B).

Attitude of sympathy/pity towards the deaf/deafness

Five participants indicated that, prior to their child’s diagnosis; they used to harbour feelings of sympathy, pity or compassion towards deaf people. Four explained it as follows:

“I guess I pitied deaf people on the few occasions that I encountered one...For me it is more, you feel sorry for them. Sorry as in pity. Not sorry as in you want to do something for them, just, you are glad that it is not you” (Participant G);

“I am a compassionate person and I had a lot of sympathy” (Participant A);

“In terms of deaf children – pity...I was sympathetic towards these people” (Participant D); and

“I felt empathy for deaf people same as for anyone with another disability...Sympathy rather than feeling sorry for them. You sort of think to yourself that it must be bad, you know...” (Participant H).

However, one participant specifically mentioned that he did not necessarily pity the deaf:

"I didn't have a specific feeling towards deafness. I didn't have negative feelings or pity towards the deaf. It is just another person with other types of challenges, you know. So you're totally...neutral" (Participant C).

The explanations participants gave about their feelings of sympathy, pity and compassion were diverse. Two participants alluded to seclusion and expressed it as follows:

"I guess I pitied deaf people since I always thought they formed a very secluded part of society that seldom engage or partake in the larger societal structures" (Participant G);

"It must be bad, you know, you can never hear what is going on around you, when somebody talks behind you, you don't even know it...that type of thing. But one wonders within oneself how they do it or how they cope with that" (Participant H).

Another two participants felt particularly sympathetic towards deaf people because of how deaf people sound:

"Ag, I...the times that I encountered deaf people, the few times, who were obviously probably born deaf, you know, they have a specific way of talking, that I think, can create the impression that they are stupid. Uhm, not that it was my way of thinking..." (Participant D);

"...when you hear deaf people talking...those monotonous, high-pitched sounds. That was very bad for me...like when the person would show emotion or whatever, then these sounds would come out. And it wasn't nice to hear...so you know, it makes you cringe and think that the person should rather not be making those sounds" (Participant B).

One participant mainly pitied deaf people because of the fact that they cannot hear music: *"I think my greatest thing about deafness was...they cannot hear music"* (Participant D) while another participant indicated: *"(I) didn't think that there was a normal future"* (Participant J). However, participant D added: *"In terms of deaf adults... I respected them if they could continue normally with their lives despite their disability."* This aspect of respect was echoed by Participant B who stated: *"I admire the people who overcome their disability...that this disability doesn't stand in their way."*

Although the above discussion indicated strong feelings of pity towards deaf people, quite a few of the participants indicated how their attitudes towards deafness and deaf people changed after being confronted with deafness in their own family:

“Afterwards (after own child was diagnosed as deaf), a lot of (deaf) people come to us and then [soft laughter] one has a different way of dealing with them...and at least you would say: ‘Listen, I understand you!’...hug...If you have something, then you give it to the person...” (Participant A);

“...ugh, now it (the way deaf people speak) would not bother me at all. Now I would think: ‘wow, this person is trying to say something’ and that is wonderful to me...” (Participant B); and

“...in other words, one is really ignorant, you are truly apathetic towards them...but I think...one is brought down to earth very quickly in terms of that...” (Participant G).

2.5.1.3 Sub-theme 1-3: Response to diagnosis

Participants answered the question about their response to the diagnosis of their children’s deafness elaborately. The categories gained from the data are discussed below in order of the initial responses to the later responses and emotions mentioned by participants.

2.5.1.3.1 Shock, confusion and feeling overwhelmed

Although many of the participants already suspected their child of having some degree of deafness, it is evident from the answers supplied that most parents still perceived the confirmation of their child’s deafness as sad and a shock. Some of them phrased it as follows:

“It was like, almost like news of someone’s death. It is like ‘what?!’ Yes it was astounding, I mean he was small, and I mean he was in hospital many times, and he...dear heaven, what else, poor child...” (Participant C);

“It was a huge shock. (Emotions of) anxiety, uncertainty and despair” (Participant J); and

“We were sad...we didn’t know that premature babies were at risk of having the condition that he has ...that there was a possibility...we never realised...” (Participant D).

Parents also reported this initial period to have been confusing and overwhelming:

“It was a rollercoaster experience. One is immediately on a roller coaster and yes, uhm, and you realise that something is happening now and it is running at an incredible speed. And you’re confused...” (Participant A);

“It couldn’t really get any more crazy and uhm, this whole struggle with the process, was a bit like a roller coaster action, where you just hang on to survive. But it felt like this whole thing pulled the carpet out from under me. You know...” (Participant B); and

"I have to tell you in all honesty, it was a chaotic time...very shocked..."
(Participant I).

For one parent the feelings of powerlessness and despondency characterised the initial period after diagnosis:

"Each place we took him to (to test his hearing), showed less and less hearing...and uhm, it just made me more and more despondent and more...I felt totally powerless. And everybody was very friendly and helpful, but nothing helped. It just made me feel more and more lonely and rejected..." (Participant F).

Not all parents, however, experienced the initial period after diagnosis in the above-mentioned way:

"I was positive and we decided to get her the help she needed to limit the effect of the unilateral hearing loss on her development. After the initial shock, which was not too bad initially, I did not ponder on it and approached it as practically and positively as possible. I think that the fact that she still had some hearing in her other ear, even without her hearing aid, made it less devastating for me" (Participant H);

"...but it wasn't really such a major shock when we found out, because it was still exactly the same child. I think, if the school phones you, for instance, your child was on a sport tour, there has been an accident and they say they had you amputate your child's leg, hypothetically speaking...that shock is massive, because there is a drastic change that occurred. But in terms of this (deafness), nothing changed, it is still the same child we have always known, we just found out that something invisible is going on..." (Participant G).

2.5.1.3.2 Difficulty in accepting diagnosis

It appeared as if the emotions of shock went hand in hand or were shortly followed by difficulty to accept the diagnosis for some parents:

"It must be something that can be fixed. And I asked the audiologist if there isn't any research done in terms of the nerve, to restore the nerve...I mean, surely there is research done on the topic...isn't anyone doing something like this? Or something in the line of a nerve transplant?" (Participant C);

"The whole time I kept thinking that nothing is really wrong, he just has glue ear of a blockage, maybe. It is kind of like, denial, I think. There is no way that something can be wrong. They are going to tell us that okay, they saw this and that but now we are going to do this and that and everything will be fine..." (Participant D).

2.5.1.3.3 Relief

On the other hand, a sense of relief was also experienced by some parents when their children were diagnosed as deaf:

“Because of a lot of wrong diagnoses, even autism, I was almost relieved when I heard that he is deaf. This is it and now we work with it (deafness). The autism was really bad for me, so anything other than autism was okay...”
(Participant B);

“For me it was more important that my child lives, so it is something that we will deal with. Yes, deafness, but I mean he has been through cancer! SO there wasn’t...yes, it is a setback, but he lives! You know, it is so minor...”
(Participant I);

“It was not that devastating, you know, all the audiologists say that they cannot believe how good this child speaks for someone with as little hearing as she has. So there must have been a time when she was able to hear well, when her language was formed and embedded. I think the realisation of how much we have to be grateful for, meant that it is isn’t as bad, because you realise how much worse it could have been...If you can’t communicate with your child, you know...at least there are ways...so you are grateful, that something can be done to help her...” (Participant H).

2.5.1.3.4 Frustration

From the gathered data, it is evident that a feeling of frustration was a commonality among various participants. The following remarks summarize this general feeling among participants:

“...uhm, yes, a bit frustrated with the inability of doctors to figure this out. We struggled to get the system to classify him as deaf. We wanted to do what we could for him. We felt a bit powerless because it seemed as if the knowledgeable people could not come to a simple deduction and finally classify our son as deaf...”; “Angry because the audiologists, who had tested him various times up to that stage, diagnosed him incorrectly each time and stole a year of his speech ability...” (Participant D).

“Your (level of) frustration is so high, your helplessness, your feelings of inadequacy...Here we are with something...Nothing that you do is right. I felt like something had to be done and I didn’t know what, uhm, it felt like I needed more help. There isn’t enough help, there isn’t enough knowledge...”
(Participant F);

“Frustration, because communication (with my child) was so difficult...”
(Participant I).

Therefore, the underlying root of frustration experienced by parents differed, ranging from frustration with the conflicting diagnosis and guidance received from professionals, frustration due to feelings of helplessness, as well as frustration in terms of communication with their child.

2.5.1.3.5 Guilt

Only one participant indicated feelings of guilt related to the cause of her child's deafness:

"...your feelings of guilt, that you have a child like this, because maybe you did something wrong...you probably committed sin...you ate something wrong when you were expecting him and all these things [emotional]...go through you each day..." (Participant F).

Feelings of guilt, although expressed by the participant above, was not a common feeling reported by participants in this particular study.

2.5.1.3.6 Sadness

As parents realised the impact deafness would have on the rest of their child's life, they were often filled with feelings of sadness:

"I felt intensely sorry for my child" (Participant I); "The reality hit me a few weeks after the diagnosis only, and I became very emotional" (Participant B);

"I was sad because my child was going to have even greater challenges in life than the challenges he already had" (Participant C);

"I was sad...I immediately wondered about his future and what his life is going to be like...He is just a normal little boy, and I want it to always be like that..." (Participant D);

"With a deaf child...it is an incredibly difficult uphill road full of rocks and rivers and I get so sad when I think of everything..." (Participant F).

2.5.1.3.7 Fears in terms of the future

When elaborating on the sadness they experienced, participants frequently referred to fears about the future as a contributing factor to their sadness:

"A million thoughts raced through my mind about her place in life in general and in all its infinite details...for example development in academics, sport, culture and personal relationships with her family members and others... I mostly felt

sad about the challenges that lay ahead, not for myself so much, but for her, her sister and her mother...” (Participant G);

“I don’t want him to be on the receiving end of bullying, he mustn’t get bullied” (Participant C);

“One of my initial fears, when we found out, was that he would be bullied...because children can...and even adults can be cruel...and I never want him to feel like he is inferior” (Participant D).

2.5.1.3.8 Acceptance

Participants reported the development of a sense of acceptance as time passed. However, it appeared that some came to accept the diagnosis much more quickly than others and that acceptance was an ongoing process since some events (like English in school for one parents) triggered previous emotions once again.

“I have to honestly tell you. We are Christians, we believe in the sovereignty of God, and we came to a point where we didn’t blame anybody. We realised that we couldn’t. And when you get to that point, then there is a sense of resignation that settles in your heart...It is a reality...we had to live with it and that is it...” (Participant A);

“Once we’ve worked through it, I viewed it positively and thought of ways to tackle it...as we gained more information about his condition we found peace...that everything will be okay...” (Participant C);

“Ag, but I think we accepted it quite quick. This is it, this is how it is now. And I think you cross the bridges as you get to them...” (Participant D);

“Because you are going through it, you don’t have time to sit and feel sorry for yourself. Uhm, as I’ve said, the deafness isn’t really an issue to me, literally, the Lord will provide, like He always provided in everything...” (Participant I).

2.5.2 Theme 2: Adapting to deafness

After learning about their child’s deafness and after the initial response to deafness subsided, it is evident from the collected data that parents and families faced numerous challenges in adapting to deafness and in learning to live with deafness.

Sub-themes to be discussed in the paragraphs below include general challenges faced by the families as well as the effect of deafness on other children in the family.

Table 2-2: The sub-themes and categories which resort under theme 2

Theme 2	Sub-themes	Categories
Adapting to deafness	General challenges	• Relocating
		• Dedication to programme/hearing technology
		• Communication
		• Finances
		• Responses from hearing people
		• Educational challenges
		• Spiritual challenges
		• Practical day-to-day challenges
	Effect of deafness on other siblings	• Challenges in terms of siblings
		• Adjustments made to accommodate siblings
		• Sibling relationships

2.5.2.1 Sub-theme 2-1 - Challenges

For the majority of participants the adjustment of learning to live with deafness posed challenges in many ways, possibly because deafness and all its implications are unfamiliar territory. The answers of participants with regard to the above six sub-themes were identified.

2.5.2.1.1 Relocating

Two families' educational choices for their children resulted in the families relocating to a different province:

"Moving to [city 1] and adapting to city life was challenging...And it was rough...We were away from our support structure, away from the congregation. Away from everything familiar...to the wet [city 1]. So yes, I think it (relocating) was the thing, more than the deafness itself, which was the burning issue..." (Participant A); and

"...we sold our house and our cars and everything and we headed for the [city 1]. There we sat in a rented house and arrived at Tygerberg..." (Participant F).

2.5.2.1.2 Dedication to programme/hearing technology

The challenges mentioned by the participants in terms of this sub-theme/category mainly centres around dedication related to verbal language development and hearing technology.

The parents of a child who went through a full-time habilitation programme reported the commitment to literally stick with the programme even though they experienced it as challenging them.

Another participant explained the challenge of working with an audiologist to enhance their child's verbal communication:

"...I would say that that is the most difficult thing that we have to do now...because you have to do extra things and homework. And practise things with him and...ag, it is something that you can work into normal conversation but then there are things where we have to go sit and say, okay, we are doing this now..." (Participant D).

Yet another participant confirmed the above and added the challenge of getting the deaf toddler to cooperate and focus for the required amount of time per day to be spent on therapy:

"I would sit him down and for at least an hour a day, which was not nearly enough, and help him to focus on my face, to focus on the fact that there is such a thing as speech...I had to get him to concentrate, to get him to sit...which is very hard for a toddler...difficult for mother and father..." (Participant F).

Children aren't necessarily always keen on wearing their hearing aids or cochlear implant processors and it required commitment of parents to get their children to do so:

"...it felt like I was being cruel, you know...a few times, when he didn't want to put on those aids, I had to pin him down, put it in his ears and say that I have made this decisions for you and that you cannot manipulate me...uhm, it was very bad. When the child wakes up, he must put his aids on...He may never ever switch it off if you were to speak or reprimand, uhm, it is an incredibly disciplined environment really..." (Participant B);

"There was a stage where he often rebelled against wearing his hearing aids and had to deal with that..." (Participant D); and

"Every now and then she refuses to put on the CI processor, which is incredibly frustrating, since she can be very stubborn...Not only at the beginning, it took us a good year, maybe even longer than a year, before she was really happy to put the thing on and to keep it on, without fighting and everything. So the fact that she is also positive about it and that it is not a big issue for her, makes it easier for us..." (Participant H).

2.5.2.1.3 Communication

Frustration and issues surrounding communication between hearing parents and their deaf children are definitely the challenge participants elaborated on the most. Participants recall these difficulties and a few expressed them as follows:

“Communication was a great challenge. Uhm, I recall one specific day when he tried to say something and we just couldn’t communicate, because remember this is after three month of treatment (chemotherapy), and now suddenly we are struggling to talk to each other. It is very frustrating. But one specific day he was so discouraged, he tried to explain something to us and we couldn’t figure out what he wanted, because we cannot communicate with each other, and my wife was impatient and I was impatient. That was in our room....and about four or five minutes later I walked out of our room and he was sitting on the steps, and when I saw that tiny body, I felt so sorry for him, you know, he is trying so hard, uhm...But he overcame it and I mean if you see him today, I mean, he plays good rugby, he does well in school, he doesn’t struggle in school...” (Participant I);

“To make sure he looks at you when you speak (was challenging)” (Participant J);

“...his father is an artisan and he can fix anything, but here is something he cannot fix. So it was a terrible thing for him as a father who cannot get through to his child...he didn’t have the tools; It is such a deep chasm that you fall into and you don’t get out of it until somebody shows you, (that) there is a way to talk to him...” (Participant F).

Other parents describe communicational issues relating to assisting their child with his language development:

“To help him with his speech and to help him to understand things; because concepts are more difficult for him to understand than for a hearing child. Ag, look, his problem at the moment is...his language (development) is behind...and that is what we must focus on this year, to elevate his language, because I mean, that frustration comes with him not knowing how to express himself” (Participant C);

“...the greatest challenge is really his speech, to help him to pronounce words correctly. He gets very upset when he says something wrong and we correct him and explain how he should say it. So the greatest challenge is to get him to catch up on his speech because he is still a bit behind. Another great challenge is his comprehension ability which in some areas is still like that of a three-year old instead of an almost six-year old. Sometimes he grasps something very quickly and other times it is as if it is difficult for him to comprehend...” (Participant D);

One parent of a child with a cochlear implant shared the communicational issues experienced in their home as follows:

“Sometimes having to repeat some sentences three or more times, accepting that she sometimes “tunes out” and does not try to follow the discussion at the table at mealtimes (is challenging). It is often very frustrating trying to communicate to our daughter when she does not have her hearing aid or cochlear processor on, like when she is having a bath or getting ready for bed. For some reason she doesn’t put on her device when she comes to eat in the morning. So she just sits there at the table and eats breakfast...” (Participant H).

2.5.2.1.4 Finances

Participants referred to the financial implications of hearing aids and especially cochlear implants. However, many also reported with sincere gratitude that they received assistance either financially or by means of donations to alleviate the strain:

“...It costs between R30 000 and R45 000 for a set of hearing aids...but it (a cochlear implant) is even more expensive...and medical aids don’t cover it...So you have to be either rich or you have to raise funds...and luckily people’s hearts were open...truly...people from all over the country opened their pockets and that really meant so much to us...” (Participant B);

“...the hearing institute assisted us a lot at that stage....these things (hearing aids) are R16 000 to R17 000 each, and we didn’t at that stage have....And then my grandfather said that he will pay for one and the hearing institute phoned and said they would lend us an extra one, a demo. So they basically gave us one...” (Participant C); and

“Those things cost R 20 000 a side. And we got top of the range hearing aids from a girl who got an (cochlear) implant....and the FM-system that the teacher wears around her neck, the church where we are now paid for the FM-system which was R 26 000” (Participant I).

2.5.2.1.5 Responses from hearing people

One participant explained in much detail the frustration experienced because of the ignorance as well as the attitude of the hearing community. He elaborated and mentioned several instances, specifically in the tertiary educational setting where he felt like his son was not accommodated enough during the examinations or even when special

arrangements were made for his son to write examinations in a separate venue there were still hiccups in terms of the administration that affected their son negatively:

“...then I will phone the exam department and they would say that the lecturer never came to collect the thing (answer sheet)...and then he feels singled out...it is a typical thing with the deaf” (Participant A).

Participant A also said that his son often gets stuck in specific situations (particularly help desks) and then contacts him to either accompany him or to come pick him up:

“...It is not because of inability from his side, but because people decide that...well they don't know how to handle it and then they just brush him off...” (Participant A).

Another participant mentioned the annoyance of their hearing friends with them as well as their annoyance with the hearing community's ignorance with regard to their child's deafness:

“We adjusted well, in the sense of (for instance) not talking to him when his back is turned to you...But we had had friends who, made me feel...you know, it doesn't help to yell at him, he is not going to hear you...[soft laughter] Ain't gonna help! You know, we were good friends with people, who later became irritated with us. You know, when somebody calls him, you remind them, 'he is not going to hear you.' And then they get irritated with us. They felt like we were favouring him...I don't know if it was indeed so, I doubt it ... (There were) many times that I punished him unnecessarily because he did not understand properly and then you get irritated” (Participant I).

One participant recalled a specific incident that still made her very emotional when telling of a barbecue they once attended where all the children ignored her child, just quickly walked past him and as a result he sat alone watching TV:

“I cried so much, I was so sad because my child was so lonely, that he is made to sit down, totally ignored, as if he is a statue sitting in that chair...and there were at least six cousins, nobody came to sit next to him or...made a gesture or touched his shoulder and asked him how it's going. No one!” (Participant F).

Although the above incident was very emotional for the mother, it ended on a beautiful note when this mother's deaf son came to her when he saw her crying and consoled her:

“...he said mommy don't worry... he says I'm deaf, they aren't, they hear, different. He understood more about what it is to be deaf and that he accepts it and that helped me with accepting how he felt. He was more mature in that moment than I've ever been” (Participant F).

2.5.2.1.6 Educational challenges

The four out of the five children were placed in mainstream schools or are destined for mainstream schools for various reasons. It appears that parents' decisions to place their children in mainstream schools are more often based on a sincere belief that it is in the best interests of their child:

"Because we want to mainstream school him, we want to place him in a normal school. And it is not that I can attest to...about the quality of those (schools for the Deaf) schools...But I would rather want my child to go to a normal school, because his career options are just so much better, for his future...I mean, if he doesn't...if we don't lay the foundation now, he will end up there; And I want him to go to university...even if he doesn't go...the option must be there; my dream for him is to raise a child who is entrepreneurial and can take care of himself and he shouldn't be dependent on somebody telling him 'take the spanner and do this'. ; I don't look down on manual (labour), and if he wants to do it, then so be it; But I do not want that to be his only option. When he is forty years old one day feel, but listen, life gave him a raw deal and that he didn't have opportunities..." (Participant C);

"I don't think he is a candidate for a special school" (Participant D); and

"So there are two approaches (to deaf education). We followed the other approach. We just we are a close-knit family; we just couldn't imagine dropping this child of at Worcester. We just couldn't do it...sorry, but to this day I don't regret it" (Participant A).

The decision to mainstream their children comes with unique challenges. The educational challenges that came forth from the interviews done with participants who decided on mainstream education for their children mainly centred around the additional dedication and hard work mainstreaming requires:

"We considered all the options and the principal of a school here said 'we will do everything from our side, bring that child' and we started with a programme where we...literally every year, the teachers who were working with him, we gave them guidance. So that he doesn't need anything additional, but that what he needed, was done for all the children... without him begin identified" (Participant A);

"Ag, the challenge is to get him ready for school. I think that is our greatest challenge" (Participant C); and

"So the greatest challenge was not for us to accept that he is half deaf, but to help him to catch up in terms of speech and to realise that although he can go to a normal school, his schooling will most probably always be an extra challenge for him and for us" (Participant D).

Participant H elaborated extensively on the challenges they experienced the first year of their child's schooling and explained these challenges as follows:

"This year, her first year in primary school, is so far the hardest for me. I always treat her like a normal child, but this year every possible difference between her and other children is highlighted, for example she does not have good balance, so running sports are a challenge; she struggles to keep up in class and so on. I'm concerned about her future schooling needs and whether she will be able to continue attending a normal public school.

...the teacher says when she sits on the carpet, she must tell her 'listen you've spoken enough, give the other children a chance now', whereas when she is sitting at her table, she struggles to get any reaction from her.

When the teacher told us 'listen, the English is a major problem. There is nothing. Doesn't matter which simple question she asks, she just looks at her with big eyes, she has got no idea what I'm saying'; and we were satisfied that she could hear and she can speak, and I didn't think that English was very important in first grade.

...And now we realise that we think that she never learned to concentrate continuously for long. The minute this isn't fun anymore, or if it becomes too much of an effort to me to concentrate on trying to hear, then I tune out and go into my own world...but now that we are in school, now it is becoming a problem. Because if you tune out when the teacher tells you what to do, and you don't do it, or do it wrong, then you're in trouble...so we are not sure what it is, did she not hear properly, wasn't she concentrating anymore, so...yes these are definitely some of the challenges..." (Participant H).

Parents spoke about the journey of their child's placement in a school where sign language was used, then moving him to an oral school for the deaf, only for their child to beg them to go back to the previous school:

"...but in the end we realised that you can't run after your child... that is out. He asked to go back and he went back to (name of school)... I believe it (name of school) simply is the best place..." (Participant E); and

"Because he constantly asked to go back, he said 'please mommy, blue school, because it's the blue shirt of (name of school). Because by then he had already made friends there, he already viewed himself as part of that school...and uhm...that is important for a Deaf person to feel. He didn't feel like that in (name of city of oral school)" (Participant F).

Although worried at first, one parent reported a good transition of their child into a mainstream school (3.6.1.3.3), which can maybe be attributed to the fact that their child only became deaf at the age of four and therefore was post-lingually deaf:

“Uncertainty about his school career; That was something that we were very worried about, how is he going to adjust to school, will he be able to?; but if you see him today...uhm he does well in school you know, he doesn’t get stuck. He integrated 100 per cent...” (Participant I).

2.5.2.1.7 Spiritual challenges

Participants also expressed challenges in terms of their spiritual lives. However, these challenges will be discussed under sub-theme 4.1 of this chapter where the effect that deafness has on participants spiritual lives will be discussed in full.

2.5.2.1.8 Practical day-to-day challenges

Apart from the major adjustments families had to make in learning to live with deafness, participants also reported the smaller, day-to-day things that have been quite challenging.

Two participants referred specifically to the challenge of keeping the household running:

“You know, I had to attend to parent guidance often, but you have a small baby that also needs your attention and everything...it was like I just didn’t have enough arms and legs...” (Participant B); and

“To balance everything with my work and household that had to go on...Apart from having to go to [institution 1] for specialist treatment, he had to go to Wynberg, which was on the other side. My daughter was in primary school...dropping (her) off...the routines around that. The practical things, to keep all the balls in the air, which was quite a story” (Participant A).

On a lighter note, two other participants referred to the challenge of getting their child to get up in the morning:

“..But from the time you wake her up in the morning...you have to touch her, obviously. And then I shake her in her bed, I rock her like this (participant mimics rocking-action) until she responds. You can’t...with an alarm, I mean (participant chuckles). So there are small adjustments, but, ag, it’s all right. These are small compensations; where we have to stand back and say, let it be. And those day-to-day things...it is every day...” (Participant G); and

“He enjoys his sleep, because he doesn’t hear anything. If you leave him he will sleep till ten o’clock (participant laughs softly). So I physically pick him up and make him stand next to his bed...It doesn’t help to shake him, because he will just turn around and sleep again...Yes, it is very funny...” (Participant I).

Participant H's remark concisely summarizes the nature of these in terms of the daily challenges:

"So yes, the small things, but they aren't things you see coming. You only become aware of them once they're suddenly there" (Participant H).

2.5.2.1.9 Positive effect of challenges

Surprisingly, a few participants made reference to the positive impact these challenges had on their lives and marriages:

"I have to say, in other cases we've heard about, we heard that it gave marriages quite a shake. In our case I think our marriage got an incredible boost. Uhm. We are a team and we are a really close-knit family; you think you've lost something, but you've gained much more in the process..." (Participant A);

"We went through it together, but we both felt, our child lives, you'll hear me say it a thousand more times. Yes, but the rest of the time, when I was down she was up and the other way around. So we could support each other the whole time...and it is a fight that you fight together..." (Participant I);

"...and, ag, we had a good time in [city 1], honestly, with the children and as a family, incredibly...as marital partners we really grew much closer to each other. So we had each other..." (Participant B).

2.5.2.2 Sub-theme 2-2: Effect of deafness on other siblings

When a child is diagnosed as deaf it affects the entire family. Participants indicated the importance of not overlooking the hearing sibling(s) of deaf children. The categories that were identified under this sub-theme include the challenges in terms of hearing siblings in families with deaf children as well as the adjustment/adaptations made to accommodate the hearing siblings and also the nature of the sibling relationships.

2.5.2.2.1 Challenges in terms of siblings

Some participants' shared their sentiments about the effect having a deaf sibling had on the other hearing children in the family:

"These compromises are much easier for parents to make than for other siblings, since they perceive it as the parents favouring the other child, and thus loving the other child more. So in a strange way one of the biggest

challenges was dealing with the elder sister's emotions surrounding the situation with her younger deaf sister. She doesn't always understand our decisions and we don't always feel like explaining everything" (Participant G);

"It was a huge challenge...and then also the whole thing of the family context...you know, you have two other children as well...it was tough" (Participant B); and

"Because that one child is always in the spotlight, because first it is 'poor you', then it is 'come we have to take you for your hearing aids' and then is 'poor you' and then it is 'you are going to have an operation now' and we buy soft toys and it is major whoo-ha....and the other child...I won't say is in the shadows, but they don't experience receiving the same attention as the other child. And I don't think a small child has the capacity to realise that it is not that my parents love the one more than the other, it is just that this child needs more attention that I do at the moment. I don't think they can do that. And another thing is that child can get away with murder, because it is 'ag shame, she probably didn't hear or whatever, while the other one, when you say 'jump' they have to jump otherwise they're in trouble..." (Participant H).

Communication among siblings suddenly became difficult in the family where one child suddenly lost his hearing after receiving chemotherapy:

"Because it was such a confusing time, I have to honestly tell you, we were all influenced by it...We all struggled to communicate" (Participant I); and

"... (his siblings) struggled to explain things to him" (Participant J);

"...however, things (in terms of communication) quickly got much easier. Children adapt much easier to situations" (Participant I).

The intense difficulty hearing siblings may experience is highlighted in the following expression by participant H:

"At a stage she (the hearing sibling) said that she wishes she was also deaf and I realised she doesn't mean that she wishes she was deaf, I think she meant...she wishes she could receive all the attention that the other child does for a change..." (Participant H).

2.5.2.2.2 Adjustments made to accommodate siblings

Being aware of the above-mentioned effects of deafness on the other hearing siblings in the family means that parents are in a position to make the necessary adjustments in an attempt to address the situation:

"...she (hearing sister) breezes through school, she is a real beamer...but despite having so many talents, she still has that need of...it still feels to her as if...she doesn't always have enough going for her in life; So we are sensitive to

that...Consequently we need to constantly work hard at reassuring our eldest daughter that we love her equally, but words just don't cut it with her. She needs to feel loved by us showing her that we care, for example, I sometimes take her for a milkshake when her sister is otherwise engaged with either sport or visiting a friend. If we do not constantly work at this, she becomes distant and sad" (Participant G);

"And we did make an effort with her, she is an absolutely culture and dance and drama queen. We have enrolled her for things like that, because for the first time she feels, but it is now her turn to, you know...we care enough for her to do what is necessary and important to her, just like we did with the other one when she needed something...Yes, I think that did make a difference..." (Participant H).

2.5.2.2.3 Sibling relationships

During the interviews a clear picture was created by many participants of beautiful sibling relationships and the following are illustrative of this:

"Yes, uhm, and also his older brother will quickly correct people, (and say) he doesn't hear you, you have to look at him" (Participant I);

"She compromises to a great extent, because if she knows she can't hear, she will kindly go to her and say 'we have to do this or that now'...but you know, she will try to clearly explain to her; or she would tap her and say "Mommy is talking to you', that kind of thing; but also in terms of play and everything. You know, there are obviously small things that she can't do. And she (hearing sister) accommodates her beautifully in that way, I think" (Participant H).

Participant G confirmed the previous statement and added:

"Yes, I think she (hearing sister) is really amazing with her. They fight a lot, obviously. But really, she is very good with her sister, and she makes an effort to accommodate her, because she had to compromise just as much as we had to with her (deaf sister)" (Participant G).

2.5.3 Theme 3: Support received by family after diagnosis

Participants were asked questions to determine who families with deaf children turn to for advice and guidance when their child's deafness is confirmed, and then more specifically what the nature of the advice is that they obtain. Additionally respondents were also probed about the support they received from their families, friends and religious communities.

Table 2-3: The sub-themes and categories which resort under theme 3

Theme 3	Sub-themes	Categories
Support	Advice and guidance in terms of deafness	• Professionals participants turned to for guidance and advice regarding deafness
		• Nature of advice received in terms of communication, amplification and education
		• Information received in terms of Deaf culture, sign language, Deaf culture and cochlear implant research
	Responses from hearing community (family and friends)	• Responses from family
		• Responses from friends
	Responses from religious community	• Supportive
		• Not truly involved
		• Experience of faith healing

2.5.3.1 Sub-theme 3-1 Advice and guidance in terms of deafness

2.5.3.1.1 Professionals participants turned to for guidance and advice regarding deafness

Almost without exception, participants' answers to the question of who they turned to for advice and guidance in terms of deafness revealed that apart from reading up on the subject they received most of their information from audiologists and speech therapists:

"We went to ENTs, a few here...Audiologists; we also started reading about the subject" (Participant A);

"We joined a programme at [academic organisation], parent guidance...and read books. We followed an intensive parent guidance program..." (Participant B); and

"We read up on the condition that he has, auditory neuropathy, and to what extent there is a chance of recovery...none.... and that it can worsen but will never get better. We received advice and guidance from his audiologists and speech therapist in terms of the road ahead..." (Participant D).

Participant F's experience of the medical professionals was less positive as she states:

"...we went to [participant lists four places they went to] all these places, but there is no one...in those institutions who gave us advice and guidance and who said 'I will accompany you on this journey, I think you have to you...contact me..." (Participant F).

Only one participant mentioned receiving information and advice from someone in the deaf community:

"Well, she (name of sign language interpreter) helped us a lot, gave advice and referred us to people" (Participant I).

2.5.3.1.2 Nature of advice received in terms of communication, amplification and education

The themes that emerge from the data in terms of the nature of the advice received from medical professionals clearly indicate a medical approach to deafness. This attitude towards deafness is displayed in the advice participants received in terms of mode of communication, hearing technology as well as the advice received in terms of educational options. It appears the intervention in most cases revolves around mitigating the child's deafness in order for the deaf child to function, as much as possible, like a hearing child.

All the medical professionals whom participants of this study referred to focused on the importance of hearing and therefore proposed spoken language as mode of communication:

"...he (the doctor) came to us and said 'I know you are as confused as a chameleon on a Smartie box at the moment, but this is the road that lies ahead for you. This is what is going to happen now and these are your options'; he (another doctor) said, similar to what Hellen Keller said, 'It is not what you have lost what counts, uhm, maar what is left'...and what you do with it... and you must start early. If you don't start with some habilitation programme before (the age of) seven, you will never address the intonation problems that the deaf sit with...so he said as early as possible, so fitted hearing aids..." (Participant A); and

"We received a book from them, but you read a lot of medical facts, okay, yes, okay...It's cold and clinical...; When we heard that there are these programs

that...that you can actually teach a deaf person to speak normally...we immediately fell for it..." (Participant B).

Apart from one participant, none mentioned being briefed about the advantages of schools for the Deaf as well as the possible disadvantages of mainstream education for a deaf child. Only participant I mentioned receiving advice by a member of the Deaf community to consider a school for the Deaf:

"...she (member of the Deaf community) gave advice and offered...and (told us to) maybe consider a school for the Deaf..." (Participant I).

2.5.3.1.3 Information received in terms of Deaf culture, sign language, Deaf culture and cochlear implant research

Since the focus of the medical professions was on oral communication and mainstreaming, it is not surprising that detailed information about sign language and Deaf culture was not evident in the collected data from the interviews of this study. The following statements by participants are examples of this omission:

"It was almost a matter of, uhm, yes, your child is deaf, we confirm that, and we are going to fix it now, I almost want to say in quotation marks, by giving her an implant. Nothing of uhm I would for instance tell someone that it would be good for all of you to learn sign language because when those batteries are flat or that thing is gone...or whatever, then you can't communicate with your child. Then she is deaf. Simple. I mean if we started with that when she was three, we would all have been fluent in sign language. But you don't think that it is necessary because this solution is here at hand. So no, not at all, they didn't talk about Deaf culture at all" (Participant H); and

"...but they didn't say 'here are all the options and sign language for communication and here are the options for schools and so on. It was more...this is the medical route and these are the options that we can offer you..." (Participant I).

Participants E and F are the exception in that they became aware of the advantages of sign language, opted to send their child to a school for the Deaf and have great appreciation for Deaf culture:

"...from a young age, language must be present...there must be a language for the deaf. It is absolutely necessary. You see the need...you see, when a deaf person doesn't have...as soon as he has language, he can go on...it is absolutely the right thing to do..." (Participant E);

"...it (sign language) is important to a Deaf person...they are like brothers and sisters...; Look, it is such a tight knit culture, even more so than the Afrikaner culture. Much more..." (Participant F).

Worth mentioning, however, is the fact that along the line somewhere, directly or indirectly, participants did learn about the existence of the cochlear implant controversy that causes tension between communities holding a medical and socio-linguistic view of deafness:

“...there is also the possibility of cochlear implants, uhm, where you hear electronically basically...and the deaf don’t want to hear about it. And that is the one thing I just want to warn you about. You can really run into something there. They, they, they despise us, because we forced our child into taking a specific direction and really against his nature...I mean he is Deaf like English or Afrikaans. It is a culture on its own. And we didn’t grant him that. I’ve been attacked a lot and am used to it...but it’s not a problem...” (Participant A);

“...the astounding thing is that there’s politics among the deaf, about what is the best. [Participant chuckles] Is it signing or is it cochlear implants or is it hearing aids or not hearing aids at all. I’ve spoken to people who had cochlear implants done as adults. Then it is just too much, and they’ve taken it out again. We had the option, and we got very close to doing it, but in the end we didn’t” (Participant I); and

“You know, there is a great debate going on with the Deaf community who...the people who have cochlear implants say they are treated so badly by other deaf people who decide to not, for whichever reason, get the implant. Because they say it is as if they are trying to fix themselves and there is nothing wrong with them, they don’t have to fix themselves. But I don’t see it is fixing, I see it as, you are trying to enable that person to continue as normal as possible. Nothing can fix that, if she is not wearing those things, or the batteries are flat, she cannot hear, there is nothing you can do about it. But at least people can help them to forfeit as little quality of life as possible and that kind of thing. So you are so grateful, you know, that there is something that can be done to help her...” (Participant H).

One mother shared her complex feelings about their decision to get their child fitted with a cochlear implant and mainstreaming him as follows:

“With mainstreaming, there is a lot of work that goes into the child. But...Ag...I don’t know, I sometimes wonder why you do it. Because, I sometimes feel, with our son...he is neither fish nor flesh...He doesn’t completely adjust to the hearing world, but he will be totally....I think there is a sign for someone with amplification, you know, ‘he is one of those guys, watch out for him!’...But our decision was...within six months you can acquire signing...” (Participant B).

2.5.3.2 Sub-theme 3-2: Response from hearing community (family and friends)

The sentiments participants shared about the responses of their families as friends were very similar in terms of their experience of support and compassion. However, here and there were a few exceptions worth mentioning.

2.5.3.2.1 Responses from family

Overall participants reported sincere support experienced from their families and described their experience with words like accommodating, understanding, pitying, holding our hands high, supportive, encouraging, praying and sympathetic:

“Our family was incredibly supportive...we experienced fantastic understanding” (Participant A);

“Our family were supportive and everyone listened to the story and asked questions” (Participant H); and

“Something that was amazing was...my sister-in-law started a campaign to raise money for the cochlear implant...she placed it on the internet and money came in, even from Canada...So that meant more to us than somebody saying that they’re praying for us, because he shows it ” (Participant G).

Yet, one husband and wife reported exactly the opposite to have been their experience:

“Family? I can immediately say zero. We used to get together a lot as a family. Then you can see, because he is deaf...how the other children would look at him...he is totally excluded from the conversation...(you hear) how the children talk among each other...What happens then... he is deaf, and he will stay there (with the children) for five minutes and then go out and sit somewhere else and do something else...so we saw that the other children didn’t want to have anything to do with him, so you start to stay away from your family...” (Participant E); and

“My mother and father were totally floored by the deafness, because they are singers, and they didn’t know what to do with this little boy. They’d pick him up and so on...but not as much as they would his sister...So I feel there is a great lack of help...that one can give the grandparents, to inform them and change their view and their sense of helplessness. We were estranged from our family because they can’t talk to him and that makes us unhappy...” (Participant F).

2.5.3.2.2 Responses from friends

It appears as if participants generally experienced the same level of support from their friends as they did their family:

“Very supportive and understanding...with great compassion...” (Participant A);

“... (They) pitied him, but (they were) quite supportive and encouraging. The support came from everywhere, even people we didn’t know...But, I mean, how can they respond? It’s sort of sympathy and ‘ag shame’ ...you know?” (Participant D); and

“Almost everyone sympathised. They often used to enquire about the development of the situation...the continuous hearing loss and

interventions...Some stepped up and supported us financially, while others supported us with a myriad of prayers” (Participant G).

Participant I experienced the majority of their friend’s response to have been supportive, but that not all friends are equally understanding at all times:

“Okay, deafness. Ag then we will deal with it. The biggest thing is already over (cancer). Yet some (of our friends) of their friends felt that we were favouring him because of his deafness...” (Participant I).

2.5.3.3 Sub-theme 3-3: Responses from the religious community

From the data collected during the interviews it appears as if participants had mixed feelings about the church or the religious community’s level of support during these challenging times of diagnosis of deafness and adjusting to this new reality.

2.5.3.3.1 Supportive

Some participants experience the religious community to have been quite supportive, as can be seen from the following statements:

“Very understanding...a lot of compassion. When we left here they were a little upset with us but they understood” (Participant A);

“Very supportive and prayed for us a lot. We had spiritual friends who made an incredible input in our lives. So that was valuable” (Participant B);

“Very very supportive; many phone calls and prayers. We were truly helped a lot, financially, spiritually and emotionally” (Participant I); and

“...similar type of response as close family and friends, except it was only upon first learning about her hearing loss and not long-term as with family support; We had a personal relationship with our minister, you know, (we) spoke about it (deafness) from time to time and at times prayed and so forth...” (Participant G).

2.5.3.3.2 Not truly involved

On the other hand other participants felt that the religious community cared, but didn’t really get involved:

“Support and pity; Ag, everybody just wanted to know, you know, look no one is going to do anything for you...It’s just...’How are his ears’ doing now?’...” (Participant C);

“The members of the congregation who saw him wearing hearing aids were supportive, but there wasn’t specific support of visitation... With his birth I had

an expectation and a need for support from the congregation we were in, but didn't receive it...We had more of a need for churchly support after his birth and it was incredibly difficult for us. The minister never once came to visit us; the elder didn't visit us once. People who didn't know me came to pray for me at work, not our church. And we are not there anymore, partly because of the absolute...lack of interest or support or whatever that we experienced" (Participant D); and

"Our own church, the minister never came close to us. So we didn't receive pastoral help, we didn't receive prayer help, we didn't;...people sit in church, they worship the Lord, but the minute somebody needs something, help, or needs pastoral help, then there is just no one" (Participant F).

2.5.3.3.3 Experience of faith healing

Because all participants are self-declared Christians, it wasn't surprising that participants mentioned encounters with faith healers or members of the religious community who encouraged them to go for faith healing:

"We accepted that this is how it is and this is what the Lord gave us, but there were individuals, friends and members of the congregation who suggested we go for prayer. Which is fine, in many cases we went, just out of mere decency, but in our hearts we knew...After the second time, I told my wife that the approach is going to change from now on...thank you very much but I am not going to expose my child again to...one time someone told us, at a typical Renewal setup,...you know, a faith healer...uh...someone could easily say that it is because you didn't believe...but we didn't expose him to that again. And uh, it is quite difficult in the congregation setup...you know?" (Participant A);

"...During Easter weekend. Our minister was on leave and then the general minister came...and he said 'if there is anybody in the congregation that feels that they want to...you know, come to the back and then we'll pray for you'. We went to the back and he asked us what is wrong and I said this he (son's name) is our deaf son. He (the minister) listened and then he did a prayer and then said 'maybe you are praying too much [soft laughter] that is why he is not healing'..." (Participant E) and

"We had a friend in [city 1]. He told us how he goes into the township and a deaf woman that he doesn't know at all, laid hands on her and prayed for her, and she can hear. More than one case like this, you know, so he's always had this gift of healing...and he prayed for her (participant's daughter) and nothing...she didn't hear" (Participant H).

2.5.4 Theme 4: Deafness and spirituality

Due to the highly personal nature of this theme, informed consent was verified with the participants a second time in order to ensure they were totally comfortable with publishing their most vulnerable experiences.

Participants were enquired about how, if at all, having a deaf child has affected their spiritual lives. Specific focus was placed on what participants viewed as the greatest needs and expectations they had from their religious communities. By posing the above questions, the researchers attempted to determine how participants view the role of the religious community to be when members of that religious community have a deaf child.

Table 2.4: The sub-themes and categories which resort under theme 4

Theme 4	Sub-themes	Categories
Deafness and spirituality	Effect deafness had on spiritual lives of participants	• Spiritual challenges
		• Effect on faith in God
	Needs, expectations and recommendations in terms of the religious community	• Guidance and counselling
		• Support by people who have been through similar situations
		• Support from the congregational community
		• Prayer
		• Practical accommodation
		• No specific expectations from religious community

2.5.4.1 Sub-theme 4-1: Effect on spiritual life

The qualitative data gathered on the question of whether deafness affected participant's spiritual lives, shows that participants generally have a spiritual perspective on deafness. It therefore follows that participants also had to work through adjusting to deafness on a spiritual level. Participants mentioned spiritual challenges experienced as well as the effect deafness had on their spiritual lives.

2.5.4.1.1 Spiritual challenges

The spiritual challenges participants referred to mainly centred on challenges in terms of their child's spirituality and the sovereignty of God. Participants shared their thoughts and worries about their children's spiritual lives as follows:

"We had family devotions every night and usually we asked questions and suddenly he could not answer questions anymore, because he could not take in anymore. And that, you know, with a great shock, it hit me...my child cannot hear the Word, it was terrible..." (Participant I); and

"She (deaf child) has a very strong spiritual approach to life. She wonders a lot about God and about things and it is as if she is really moving closer to Him and is close to Him, because she is always busy thinking about Him or wondering about Him or talking about Him; ...and she gets very excited when she hears that she will be able to hear in heaven. It is very exciting to her; she just can't wait to go. So it is difficult for me. She is still small, but when she is a teenager and in high school, and times come that are not so easy, you know, how do you maintain her faith, you know...and how, yes, I don't know...how do you support her if there are bullies who say ugly things to her?" (Participant H).

Further, participants also elaborated on making sense of deafness in the light of the sovereignty of God:

"I do sometimes wonder why her hearing was taken from her and try to hold on to the fact that God works out everything for the greater good. What breaks my heart is when she asks me why we cannot pray to Jesus and ask Him to heal her. How do you explain to a young child that God is Almighty, that He can heal her, but sort of chooses not to do so? You can ask anything from God, but that it does not mean that He will grant you your request, without harming her faith and making her feel like He does not love her?" (Participant H);

"My wife really suffered a lot in the sense of...how do you pray 'Thy will be done'? Understand? That is a very difficult thing..." (Participant I); and

"I struggled through a faith crisis with the Lord; you know...it was difficult for me... You pray for your child...for every function and tiny finger and toe and for every single thing to be normal. And it isn't. You know...what now? And you don't understand; and I cried and said 'Lord I can't, I can't believe in you anymore'. I struggled with the Lord in the process...You know, you feel guilty because you feel the way you do, and because I fought with the Lord so much. But yet, when the full...realisation of everything, in working through it...you know... the Lord was actually so good to me...Really...." (Participant B).

2.5.4.1.2 Effect on faith in God

Participants really elaborated on the positive effect having a deaf child has had on their spiritual lives and therefore more remarks are quoted in this category since the researcher viewed them all as important in the light of this study.

Two participants did not explicitly mention deafness to have had an effect on their spiritual lives. Participant E remarked: "Difficult question..." and participant C merely stated: "No".

For participant A the positive effect having a deaf child had on his spiritual life, stems mostly from the new perspectives gained through the process:

"Yes, to the better. It made our faith more real because it challenged us. Before this much of our spiritual life was inherited...But I am...I would have been a poorer person without this child of mine and his specific challenges. No, absolutely, when I see what he observes and what he picks up on, without hearing. Then I tell you, We cannot hear the voice of the Lord, in all this cacophony that obstructs our view, we cannot hear the voice of the Lord; ...And in terms of the other things that have sharpened, his vision, his fine motoric (skills)...So, I am under the impression that we should be able to hear Father's breathing. And we cannot, because we don't use it. So I have to tell you that this child has opened up certain perspectives for me which I wouldn't have had" (Participant A).

Participant B struggled a lot in terms of her spirituality, but in the end experienced spiritual growth:

"Because I have a relationship with God, I mainly shared my feelings directly with the Lord...I struggled with the Lord a lot, but grew spiritually. I had to totally cast myself down before the Lord. I often heard the voice of the Lord clearly; That poem of 'Forget-me-not', it is of a flower that comes to the Father and says but 'The name Thou gavest me, alas I have forgot' and then the Lord says, 'Don't worry, Forget-me-not'....And it was like that for me, it felt like I came to a point where I said that it is not worth it to serve the Lord...and the Lord bowed himself down to me and picked me up. So it was a crisis, but precious...and from then on, truly, you know, it is the small miracles in your life, in which the Lord affirms himself" (Participant B); and
"Truly, I always say that old Jacob struggled and lost his hip; I was 32 years old, and grey, and all these fingers' joints like this [participant indicates to hands] from rheumatism. So these are my signs, when I see them, I know the Lord provides...to realise the Lord is faithful even if you are unfaithful, He remains faithful..." (Participant B).

The fact that the Lord carried her and strengthened her was a motif/concept that stood out in participant D's answer:

“Yes, a positive impact. Since his birth we could feel and see how the Lord carries us and sends people to us to help and support and that deepened my faith. And when we learned about his disability and saw how he handled it, I felt even more grateful towards the Lord, it made me realise that the burden He gave our son, could have been so much worse because of his early birth and low birth weight. I intensely experienced the knowledge that the Lord carries you during difficult times” (Participant D); and

“When I look back, it happened to us so that we could deal with his disability. Because there I absolutely felt how the Lord carried me. Yes, It definitely had an impact, ag I think, not only in learning to deal with it, but you learn that you can’t out of own strength. I also believe that the Lord also strengthens him (our deaf son). Ag, just the fact that...of how easily he adjusted, it’s not by chance. Yes, I think for me, it was, yes initially it was a great shock. But when you really think about it you actually become grateful. What happened to him, from his birth until we found out...uhm...it taught me to be more grateful. Because you look at what happens to other people and you hear things and then you think you have, wow the Lord gave us so little, almost nothing to bear. And in the end you don’t actually carry it yourself, because He carries you; it is not because you are this fantastic superwoman or superman, it is because the Lord carries you and strengthens you. And then it is like ‘no, ag, it’s not that bad’. Truly, the Lord only gives you what He knows you can bear, and then He even helps you to carry it” (Participant D).

Participant G believes that it did not change his relationship with God, but strikingly describes his view of grace:

“So to us it feels like it (adapting to deafness) was a reasonably normal, smooth transition, but I actually think that that is what grace is. Grace is just, I have, we, grace isn’t tangible. So it happens in...It runs in the background and you don’t even realise that it is happening...” (Participant G).

The experience of having a deaf child caused participant H to grow closer to the Lord and seek Him more:

“Yes, I think definitely, it brought us closer to the Lord. Not learning about the deafness, but the journey so far has made me seek the Lord more for guidance and wisdom. Initially, obviously, there is a lot of fervent praying of, you know, ‘Lord, You can heal her and please just don’t let it deteriorate even further and whatever. And later you kind of find peace and you just realise...I believe the Lord has an incredible plan for her, you know, it wouldn’t have happened if there wasn’t a plan. So yes, we now have quite a few hurdles to overcome and everything, but one day we will look back and we will see...; and we also tell her that, we tell her ‘you must be very very special, for this to have happened to you’...because somewhere ahead there is a great plan and I truly believe that...; Here and now might not be all that enjoyable, but you know, we are not here for our own pleasure. You don’t know. But I don’t think, there wasn’t, for

me, a terrible 'why' or a 'Lord I can't believe that you did this to us' or that kind of thing..." (Participant H).

For participant G and H the providence of God also stood out as a factor which strengthened their faith:

"The Lord also amazingly opened doors for us. Because I absolutely believe that we were destined to not be happy in [city 2] and went to the [city 1], otherwise we never would have gone to the [city 1]; really an amazing team of people...He guided us step by step. And when she had to get the operation, a R300 000 exercise, and that does not even include the hospital, just the device..." (Participant H).

Participant H continues to explain how their medical aid plan changed two months before the planned operation to also pay for cochlear implantation. However, they struggled to get authorisation from their medical aid for the operation. Participant I continue to explain how it finally worked out:

"Literally the day, that struggle went on for almost six weeks, we were writing letters, the surgeon wrote, the audiologists wrote...and that, I remember it well, that weekend my wife drafted a letter to send to the medical ombudsman, that she was to email that Monday. That Monday morning before she could mail that thing, the authorization letter came from the medical aid saying that they'll pay for it. So it is really, everything fell into place right at the end, after we have exhausted all our resources; it just fell into place..." (Participant G); and

"I mean, if you don't see the providence in that, then you're blind. So then I feel you have to say that there is a higher hand in this thing and God is with us step by step. I think that gives you a lot of peace. You're not panicky about what is going to happen to my child. No, really, yes, it is not a walk in the park, but it is not unbearable either, not at all..." (Participant H).

Although not directly applicable to the diagnosis of deafness, the following experience of the initial illness that lead to the deafness shared by the father of the boy who became deaf after receiving chemotherapy is an example of how affliction brought spiritual growth in terms of trusting God and experiencing His peace. Participant I spoke of the time spent next to his son's bed in the paediatric ward of the hospital where his son received chemotherapy for his cancer:

"Six months...then I stopped counting...Uhm, you know, you have that devastation of, here is a mother and a father, just like me and you. And they also prayed, just like we pray...and (their child) was taken. You understand? Grace upon grace. So we truly realised..." (Participant I); and

"One night specifically, we were anxious...'how is our child doing?' She (the doctor) just said, 'he is sick, he might not make it through the night.' He was on oxygen and moved to the intensive care unit. And that night I prayed next to his

bed and at some stage I realised that I was praising the Lord. My heart was singing Psalm 10 ... And then I understood, for the first time, that beautiful passage from Philippians 4, which says 'Rejoice in the Lord always. The Lord is near. 6 Do not be anxious about anything, but in every situation, by prayer and petition, with thanksgiving, present your requests to God. 7 And the peace of God, which transcends all understanding, will guard your hearts and your minds in Christ Jesus. It is an incredible, probably one of the most wonderful experiences and you know, I use it so often...The peace, the peace of the Lord, what it brings you. Not matter where you are, No matter where our son goes tonight...whether he lives...uhm...you will have peace. If he dies, yes, obviously, you will be sad, but you will have peace from God, and that was an incredible breakthrough in my faith... Yes, we learned to pray more, trust more and it definitely strengthened our faith...' (Participant I).

2.5.4.2 Sub-theme 4-2: Needs, expectations and recommendations in terms of religious community

In response to the questions pertaining to what the needs and expectations of parents raising a deaf child were in terms of the religious community participants shared their own experiences in great detail. These participants show great similarities with the next question posed to participants pertaining to what the religious community can do supplementary to the status quo. These two questions' answers are therefore combined in the categories below to indicate the needs and also the recommendations derived from the responses.

2.5.4.2.1 Guidance and counselling

A space to explore feelings, ask difficult spiritual questions and assistance with processing the challenges posed by deafness is a need raised by half of the participants, and a few of them expressed this need as follows:

"For us as parents, it would have been great if we could have received some guidance on how to adjust to the circumstances, how to explain it to her, how to answer her questions, how to guide her sister in dealing with receiving less attention, and so forth. Also how do I bring together knowing that God firstly allowed my child to lose her hearing and also that He can heal her in an instant, and yet, despite so many people, even some with the gift of healing who have healed other deaf people, praying for her, He chooses not to heal her" (Participant H);

"So you have questions about, obviously not everyone being prayed for will be healed. But, uhm, you know, you have this...I wonder about it a lot, not about 'why us' and 'why it happened' as much...but you know, I would have liked for a minister to just come and sit with us and just work through these things a bit, like...I know God can heal her now, He could have healed her yesterday, He can heal her in a year's time. It, He just speaks and it happens. But it doesn't.

So, He chooses, or it isn't now, at this stage, His plan for it to be so" (Participant H);

"... if you are a Christian, the first thing you would expect is, where do you go to first? You go to your minister; that is the first thing that you do. And now the minister must at least see you...he must be able to give you guidance, and he must absolutely know...He must have information (in terms of deafness), and I believe yes, he must be able to give it..." (Participant E);

"But we did have a need to...uhm for that psychological approach... We want to know and want to be able to gauge the children on that psychological, spiritual place...and my minister won't be able to do that for me, but somebody with your [participant points to researcher] your kind of approach with psychology and who knows which questions to ask and how to get answers from the child and how to evaluate the child. That is important to us, just to know, if we are doing something wrong, how can we do it right, or what can we do to improve the situation. And we absolutely see it as what happens to the one (daughter) affects the other and vice versa" (Participant G);

"I think spiritual care is very important, nothing is impossible to overcome..." (Participant I); and

"But we will see in the future...maybe he will develop that need (for counselling). Yes, as his identity develops and as he starts to figure out this world for himself and where he fits into the world and ... yes ... starts to ask questions ... maybe start to feel angry about why..." (Participant D).

2.5.4.2.2 Support by people who have been through similar situations

The need to have a platform to share experiences and an opportunity to have someone listen and understand was mentioned by two participants in particular:

"But you know, I think together with the pastoral guys and the spiritual leaders and so, if you can maybe....with other people who are also in the same, same spiritual community of who share your faith or even people who don't share your faith, but who can learn something from it" (Participant H);

"You know what, even if it just shows her there are other people who can't hear either, and it is okay to them that they can't hear, and they find another way to communicate...and in a way I do think that will make her realise that she is lucky to have a means to hear when she wants to or chooses to" (Participant H) and

"But I realise, you actually need people with experience, just to hear 'hang in there'. You hear someone's 'hang in there' better if he has been through the same thing as you. And I think that that is why people go through things, you know, there are people who go through a divorce to say to you 'hang in there'. Because something that was incredibly supportive to me, were other mothers

who sat with the same thing. And when we watched our children, we would brag with our children and say 'my child learned a new word'..." (Participant B).

Participant B explained further that she feels in a position to again assist others who face the same challenges:

"You know...I've been through the process. I can assist that mother and help and do...you know I feel that people who have these talents or gifts or who have been through the experience or whatever. That you can play a role there" (Participant B).

2.5.4.2.3 Support from the congregational community

Participants indicated that understanding, acceptance, involvement and general support by their congregational community were key needs in the initial stages but also specifically on a more continuous basis. Participant J simply answered that any help was needed, without going into the detail. The following statements express the need for moral support expressed by some participants:

"Moral support and to be given the space to deal with the issue without putting the matter into a religious context or to open up the issue of healing and the question "why". Some people might want to ask this question, but we accepted the reality of the situation and the sovereignty of God and it was not an issue ...thank God!" (Participant A);

"We were in a small but close-knit congregation. I could complain and ask without feeling judged" (Participant B);

"We needed the community to be accepting of her condition and accommodating in making her feel welcome and loved..." (Participant G);

"I would like for him to...as he gets older...experience the support and even more, acceptance of the religious community in depth, seeing as he is the one living with his disability every moment of every day and specifically experience how people treat him. As he gets older his needs in terms of support will increase" (Participant D);

"So as a parent my expectation is that the religious community trust my judgement when I make a recommendation that will enable my child to have that equal opportunity" (Participant G);

"...it's more a case of identifying the right person who has the heart for it and then expose that person to it and let him come see you and your child. His gift can have an effect on that person, but not necessarily with knowledge about these things. But that is the ideal congregation. The ideal congregation is one where everyone is sensitive to each other's needs and to place the needs of others above their own" (Participant G);

“So there, we felt, that is a moment when you feel, now you need someone to come talk to you. Because why did it happen? And, just a phone call would have been fine... ‘Wow, how are you doing, are you okay’... You don’t know anymore.... So that was, THERE was a moment where we needed someone...” (Participant D);

“That is what a congregation is about. I mean its part of the Apostles’ Creed, the communion of saints. Where is the communion of saints?” (Participant C);

“And you know, it’s not as if you want to talk about it the whole day, each day, but there were days that were difficult when you just wanted to tell someone ‘I’m discouraged, she doesn’t want to know anything, you know... Every now and then you just need someone to listen for a while and say ‘ag you poor thing. Shame’ you know?” (Participant H); and

“Everyone is different. When something traumatic happens in my life, I don’t expect the minister to come to me, but I know how incredibly much I appreciated it when they drove (to come visit). I can’t tell you what they read (from the Bible), but they were there, understand? They struggled with us. And yes, I think that is the most important – be a faith community, that whole thing of each other. How many times don’t we find those words in the New Testament? I think it is a 100 times or something, if not more. Carry each other’s burdens; pray for each other, love each other... It is indeed what we must do. I don’t want to single out, they remain our children and they remain people you are supposed to care for...” (Participant I).

One participant particularly referred to the importance of house visitation:

“House visitation would have... like in the old days, when I was young, your minister would just show up and knock on your door... but today (however)” (Participant E).

The importance of continuous involvement is stressed by participant G:

“So I think there should be better dialogue between parents and the religious community on a continuous basis since many of the needs change as the child grows and develops” (Participant G).

2.5.4.2.4 Prayer

Participants emphasised praying for the family confronted with deafness as a vital need to be met by the religious community:

“So we were prayed for so much and you know (that people are praying for you), maybe that is something I should say, pray for those people... incessantly. Make it part of your prayer list. I tell you and my wife also confirms this often... you know it (that others are praying for you). You feel you have strength, I am not talking about physical strength, you have inner strength, and it doesn’t come from yourself” (Participant I);

“The role of prayer should never be underestimated. The congregation did that...I never felt that the congregation disappointed me” (Participant B); and

“Yes definitely. So yes, the first thing, prayer, I think compassion and visiting, house visitation, not too much, just visit” (Participant I).

2.5.4.2.5 Practical accommodation

Apart from the needs and expectations above, a few participants also identified more practical ways in which the religious community can show compassion for and accommodation towards deaf people, specifically during the worship service:

“That alternative demands a few commitments...He (the minister) would have to look at his use of language, is he willing to use aids, uhm, which are available to wear...and seating arrangements...and things that can help and make it easier. But the main thing is, if he is a typical minister...where teaching is important, a lot of time is spent on that. And it is usually very technical and (in) a lot of detail and very long. So where one would want to say ‘heading, the main points and the crux’. That someone can look at. And can pick up on it and add it to the skeleton...It is a simple thing but, ag and bad habits for instance...; So there’s a skill that needs to be learned in (terms of) how you deal with your audience. So that is the alternative” (Participant A); and

“At the end of the day a deaf child wants to be treated normally like any other child, but unfortunately some adjustments have to be made, for instance where a child sits in a classroom whether at school or Sunday school” (Participant G).

Apart from the abovementioned practical recommendations related to the person leading the worship service and other church activities, participants also mentioned sign language interpreting:

“And that (sign language interpretation) can demand even more from the faith community. Because...people who interpret committedly...their hearts must be in it. If their hearts are not in it and that focus is not on the person who needs it. If their hearts are not in it and they don’t receive the support that they need. It is charity. And whether a congregation will be willing to do that for an individual, or individuals....But often you sit with the aged who are starting to go deaf, and they can’t benefit from an interpreter, because they are set in their ways. They also don’t lip-read. To deal with them is again a totally different setup.” (Participant A); as well as: “...there must definitely be someone who produces total communication and such things are absolutely necessary. Otherwise the deaf person is totally excluded” (Participant E).

2.5.4.2.6 No specific expectations from the religious community

During the interviews with the various participants, it became clear that although many suggestions were made and needs expressed, many participants were unsure about whether anything in particular could really be expected from the religious community.

Some participants had little to no expectations from their religious community:

“What we received was good enough and I didn’t expect anything more. There is nothing that they could do. We had everything we needed. I don’t see that there is a need...” (Participant C);

“I didn’t really have any expectations. I never really felt that I needed counselling or something in terms of him. I never felt that a minister must come and talk to me about my child, because I’ve accepted it long ago. For me it was a rock rolled into our and more specifically our son’s road and it was something that we and he had to learn to handle” (Participant D); and

“I really had no expectation of them. You appreciate it that they are interested and pray and everything, it is not that I felt that they neglected their duty...It might sound terrible, but it is almost like, if they can’t pray her healthy, then there is nothing that they can do...I almost want to say this is like a minor situation in comparison with those who are in a crisis at that stage. I feel like you can’t burden with the church with this as well. The minister has enough to keep him busy with” (Participant H).

Other participants felt that even though there were needs and expectations, the religious community won’t necessarily make major adjustments for the sake of just one or a few deaf individuals:

“You see, we experienced the sharp side of the thing...That, the greater gross (number of people in the congregation) is normal...to the extent which that is normal [silent laughter] and some people feel that it is a luxury to now cater (for the deaf person). Because what are you to do now? That is why they said in the past, ‘no you have to go that side for training, go sign’. Now there is an alternative. That alternative demands a few commitments, but not everyone wants to buy into this alternative...” (Participant A); and

“Yes, because look, that s again a difficult question, because let’s say there is one deaf person in the congregation, you can’t expect the church to...to such an extent...; Look, the way ministers see it...there are institutions, there are places for them (the deaf). And I know this and you can’t blame him, it is very difficult” (Participant E).

One participant in particular cautions against having unreasonable expectations from the religious community:

“Each minister is not necessarily a shepherd or a pastor. So now you expect a guy who might be strongly missionary orientated or someone else who is exegetically very good...to provide pastoral care to his congregant and he isn’t necessarily going to be able to do it well. What do you really expect from a minister or a church, or the compassion group, or the prayer group? It is really very difficult. This is probably the most difficult question to answer. I think that people are so different in many ways depending on their personalities, talents and interests that it would not be fair to expect of a religious leader to step in and provide the necessary support needed at that point. In other words not any single person is competent to deal with every unique situation that arises from these circumstances” (Participant G).

While yet another participant echoed the above statement and added the importance of well thought-through advice:

“Very few people from the religious community have the experience or the know-how of dealing with such issues, even pastors. The wisdom, understanding and calmness of older people who have already walked the walk and who will not give cheap advice are of the greatest value in times like these” (Participant A).

2.5.5 Discussion of results

The task of priestly listening and of subsequently having a spirituality of presence is an important aspect in the role of the pastoral practitioner in the pastoral care and counselling of families with deaf children. Pastoral practitioners must increase their understanding of issues arising when working pastorally with families with deaf children in order to develop their ability to lead the family and also the community of believers more effectively.

Two quotes summarise the essence of the interviews, one illustrating the importance of the role a religious community has to play in the lives of families with deaf children:

“But it (the religious community) is a community that will have to get used to the reality of, this is what we have, and we have to deal with it. Otherwise we are typical...worse than Apartheid. And we chase them exclusively into a cage and we organise a separate venue or...There is a long way to go, (in) the practice of our faith and of our brotherhood” (Participant A).

The need for awareness, support and involvement of all significant people in the family is illustrated strikingly by Participant G:

“Rather, I think that everyone in a religious community with all its multiple facets, including family, friends, church, school, coaches et cetera...and people

who are directly in some way involved with the deaf child, have a definite role to play by using their own unique strengths and calling to facilitate the deaf person. And this will mean different things for the different people in the various sectors of society.”

2.6 A FEW PROMINENT FINDINGS TO CONCLUDE THE RESULTS OF THE EMPIRICAL RESEARCH

2.6.1 Diagnosis of and response to deafness

The participants indicated that they had little to no prior knowledge of and/or exposure to deafness prior to their child's diagnosis. Feelings of shock, being overwhelmed, frustration, relief and a difficulty in accepting the diagnosis were some of the emotions parents experienced after learning of their child's deafness. According to participants, these feelings were usually followed by feelings of sadness, fears of the future and finally acceptance.

2.6.2 Adapting to deafness

The majority of the participants listed relocation, dedication to programmes or hearing technology, communication, finances and encounters with the hearing community to have been challenging in adapting to deafness. Subsequent challenges mentioned also included educational challenges, spiritual challenges and practical day to day challenges.

According to participants the effect of having a deaf sibling on other hearing children in the family is generally that the hearing siblings show a great extent of compassion, tolerance and care towards their deaf sibling. Families make adjustments to accommodate siblings and to maintain healthy sibling relationships.

2.6.3 Support received by family after diagnosis

Although all the participants are Christians and are active members in their religious communities, it does not appear from the data collected as if pastoral practitioners were very involved, either formally or informally, in terms of guidance and advice in helping people learn to live with deafness.

The assistance families received from professionals was generally from the hearing related medical perspective and aimed at mitigating the child's deafness. The information families received in terms of hearing technology and educational, communicational and intervention

options focused also mainly on this pathological perspective of deafness with little to no information received in terms of Deaf culture and Sign language.

Generally participants were supported sincerely by both their families and friends and described the nature of the support as accommodating, understanding, pitying, holding our hands high, supportive, encouraging, praying and sympathetic.

There exists a great difference in the experiences of families relating to the support from their religious communities. Some felt well-supported, others experienced the religious community to not have been truly involved, while yet others associated the support by the religious community with the faith healing they had experienced.

2.6.4 Deafness and spirituality

Parents' spiritual lives were profoundly impacted by having a deaf child. In the majority of cases, participants indicated that their faith was strengthened and that their faith also made them stronger in dealing with deafness and they were convinced that their faith also brought them to acceptance of their child's deafness much more easily.

Participants shared the important needs and expectations families with a deaf child might have concerning the religious community. Their needs and expectations serve as recommendations to religious communities in this regard.

Participants indicate that families with deaf children might have a need for guidance and counselling, support by people who have been through similar situations, support from the congregational community, prayer and also practical language accommodation of the deaf child during the worship service.

CHAPTER 3

INTERPRETATIVE TASK OF SAGELY WISDOM

3.1 INTRODUCTION

In chapter 2 the focus of the empirical study was on the experiences of families with deaf children. Insights were gained in order to answer the question “*What is going on?*” (Osmer, 2008:4) in terms of the experiences, support, pastoral care and counselling of families with deaf children.

Subsequently, in this chapter, attention from a meta-theoretical angle is paid to the aspects as well as the impact of deafness as to respond to Osmer’s (2008:58) second, interpretative task that wants to understand “*Why is this going on?*”.

Osmer (2008:58) defines meta-theory as follows: “A metatheoretical perspective thus is composed of the assumptions about reality, knowledge and science that transcend particular research projects and theories.” The function of meta-theoretical perspectives in the science of practical theology is to investigate the universal points of contact between the phenomena in the research area of Practical Theology and other sciences to integrate the implications thereof into the person’s own approach. Because of the theological approach of a practical theological study, these phenomena (horizontal dimension) are always brought onto the intersecting line of the relationship of faith with God (vertical dimension) (De Wet & Breed, 2014a:57).

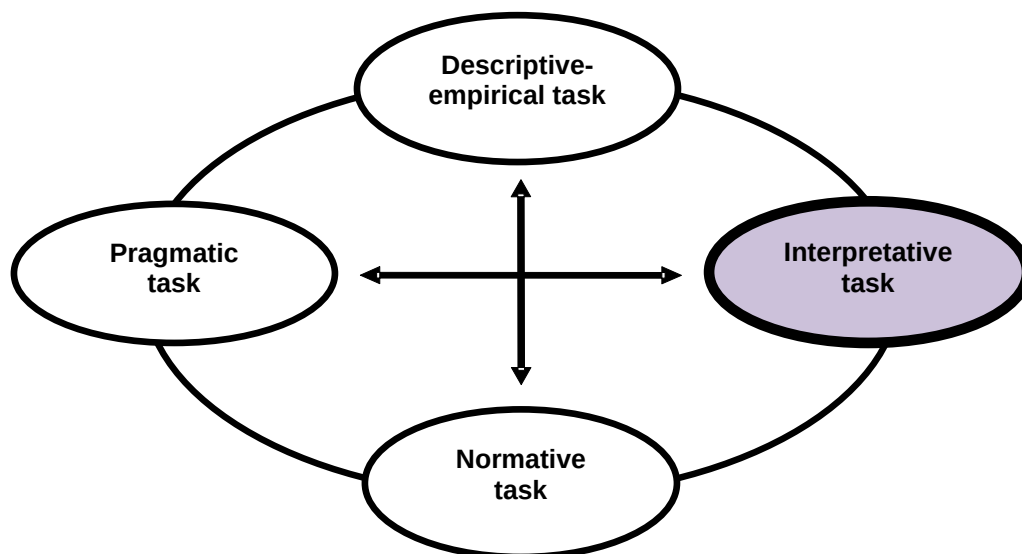


Figure 3-1: The interpretative task (Osmer, 2008:11)

Osmer (2008:100) suggests using a communicative model of rationality in order to facilitate cross-disciplinary dialogue. In this rational form of communication people provide reasons to others for their points of view. However, the pastoral practitioner must keep in mind that knowledge gained from the other auxiliary sciences is fallible and grounded in a specific perspective and as such does not provide the fullness of wise judgement.

3.2 DESIGN OF THE INTERPRETATIVE TASK

The primary aim of this chapter is to conduct a literature study of various interrelated sciences in order to provide a comprehensive explanation and consequently engender a clear understanding of the current situation of families with deaf children in South Africa, thereby setting up the interpretative perspective.

This literature study will draw on models and literature from the social sciences in the search for insight and sagely wisdom. Osmer (2008:4) describes the interpretative task as: "Drawing on theories of the arts and sciences to better understand and explain why these patterns and dynamics are occurring."

With the above-mentioned in mind, aspects to be addressed in this chapter include:

- understanding deafness;
- understanding society and Deaf culture;
- understanding biculturalism
- understanding hearing families with deaf children;
- importance of early identification and effective intervention;
- spirituality and deafness;
- pastoral care and counselling of families with deaf children;

3.3 UNDERSTANDING DEAFNESS

3.3.1 Definition and terminology surrounding deafness

Deafness can be described in various ways (medically, culturally, linguistically and educationally) but in general it can be defined as the sensory impairment of not being able to hear and is often viewed as synonymous with terms such as "deaf and dumb", "hearing impaired", "concrete bound", "having a hearing disorder", "handicapped" and "intellectually disabled" (Störbeck, 2011:383; Willcox, 2006:19).

The definition of deafness is further complicated by the fact that deafness can be understood medically, as described above; educationally, in terms of the individual's ability to acquire language through audition; and culturally, relating to a cultural-linguistic minority (Schirmer, 2001:4). The same measure of deafness can be experienced differently by different individuals. For this reason, as was indicated in chapter 1 (1.2.2), a clear distinction is made between deaf persons and Deaf persons. Generally, *deaf* spelled with a lower case “d” denotes the audiological aspect of deafness. “*Deaf*” spelled with a capital ‘D’ on the other hand describes deafness as a culture (Jones, 2002:52) and is used when referring to the linguistic and cultural minority group of people who share a common language, heritage and culture (NCTSN, 2006:13; Störbeck, 2011:383).

However, as is the trend internationally among researchers (Schirmer, 2001:5; Störbeck, 2011:383) this study attempts to move away from the above disability labelling by using non-discriminating terms. Therefore the terms “deaf” and “deafness” are rather used.

The above-mentioned definitions will be used accordingly in the remainder of this thesis.

3.3.2 Anatomy of the ear

A clear understanding of the anatomy of the human ear is necessary in order to understand the scientific terms used to classify and describe deafness in this chapter.

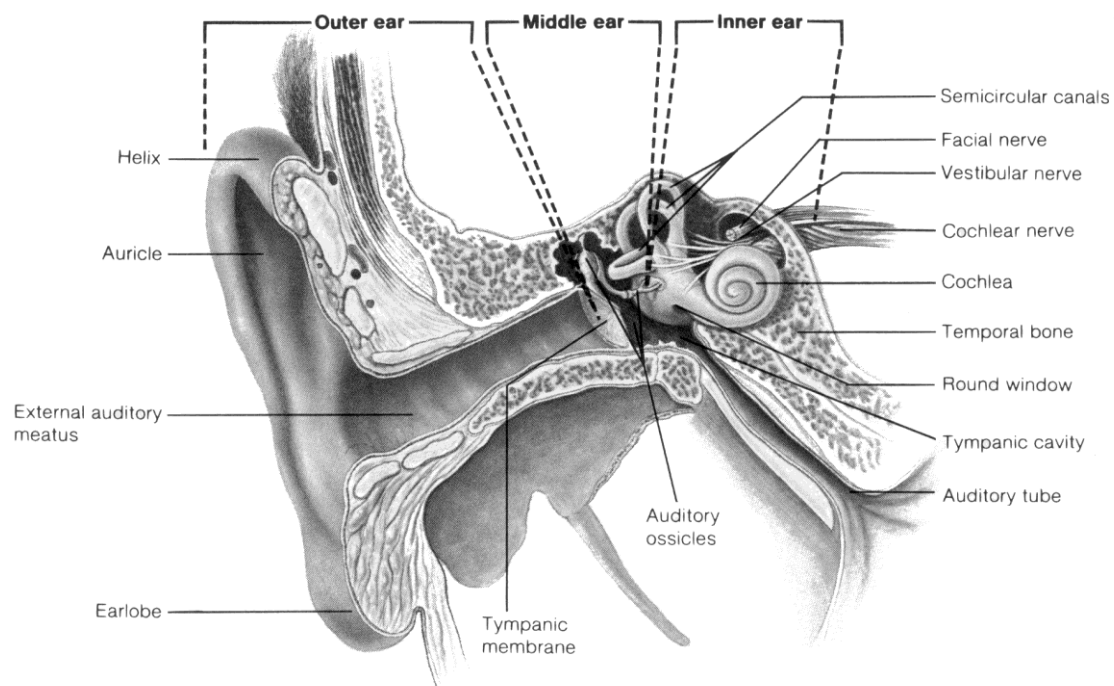


Figure 3-2: The anatomy of the ear (Diefenbaker, 2013:1)

Figure 3-2 is a depiction of the structure of the ear (the organ of hearing and balance) and shows the three sections in which the ear can be divided, namely the outer ear, the middle ear and the inner ear.

The external ear, consisting of the auricle (pinna) and the external auditory meatus (ear canal), collects the sound waves and directs them down the ear canal (which is approximately 30mm in length) where it enhances the speech frequencies at the tympanic membrane (eardrum) (which separates the outer ear and the middle ear) causing the eardrum to vibrate (Diefenbaker, 2013:1; Störbeck, 2011:384; Wright, 2003:4).

The middle ear (tympanum), begins at the eardrum and consists of a small air-filled area that holds three small movable bones (auditory ossicles), namely, the hammer (malleus), the anvil (incus) and the stirrup (stapes). The main function of the auditory ossicles is to strengthen the incoming sound energy and to conduct it from the eardrum across the middle ear cavity to the oval window (fenestra ovalis) and the fluid of the inner ear (John, 2009:41; Marschark *et al.*, 2002:47; Wright, 2003:8).

The inner ear (labyrinth) is situated in the temporal bone and consists of the cochlea, the vestibule and three semi-circular canals. The cochlea is a snail-shaped structure and the portion of the inner ear where actual hearing occurs. The cochlea looks like a snail's shell and is a hollow coiled tube filled with fluid called the perilymph. The cochlear duct inside the perilymph contains sensory hair cells that convert mechanical energy caused by the auditory ossicles in the middle ear into electrical messages that then travel along the hearing nerve (acoustic or auditory nerve), to the auditory centres of the brain, where it is interpreted and understood as sound.

The other part of the inner ear, the vestibule (for static equilibrium) and semi-circular canals (for dynamic equilibrium) are also fluid filled and can detect acceleration of the head in any direction. The signal caused by the movement in the fluid is then sent to the brain. These are therefore the parts of the inner ear that enable the individual to maintain balance but does not impact hearing at all (Clark, 2006:791; Diefenbaker, 2013:1; John, 2009:42; Störbeck, 2011:384).

Bearing the anatomy of the ear in mind, deafness will be described further by exploring the classification of deafness by the level of hearing loss, types of hearing loss, age of onset of hearing loss and causes of deafness.

3.3.3 Classification

3.3.3.1 Level of hearing loss

In order to better comprehend the nature of deafness, it is important to understand the extent of the impact of deafness greatly determined by the different levels or degrees of hearing loss. In order to have full access to sound, all the components of the ear must function effectively. If any of the elements do not function well, hearing loss (of varying degrees) occurs. The common unit of measurement of the loudness of sound is decibel (dB). The degree of hearing loss is measured in decibels or hearing levels (or dB HL) and this number represents the softest level an individual can hear (John, 2009; Lim & Simser, 2005:308).

Audiologists perform various diagnostic hearing tests to confirm the presence or absence of hearing loss (Murphy, 2009:15). A graph called an audiogram indicates the results of pure-tone hearing tests on a picture. The results of what the individual being tested can hear are matched to “normal hearing” in order to determine how it compares to or deviates from “normal hearing”. These results are indicated in terms of frequency, that is the high or low pitch of the sound (measured in Hertz) on the horizontal axis, and the intensity or loudness of common sounds (measured in decibels) on the vertical axis (ASLHA, 2015:1).

Figure 3-3 below illustrates the degree and pattern of hearing loss across frequencies:

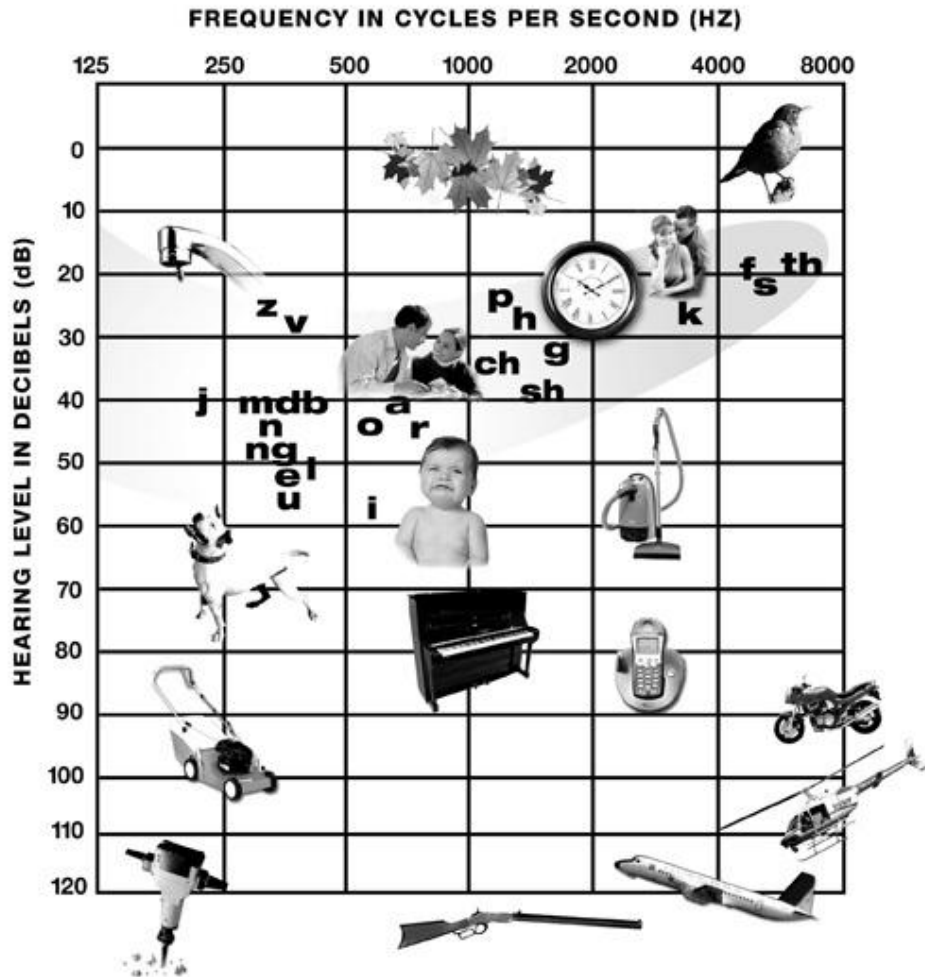


Figure 3-3: Audiogram of familiar sounds (Saunders, 2010:2)

The various levels of hearing loss indicated by the audiogram are summarized in table 3-1 below:

Table 3-1: Degrees or levels of hearing loss: Adapted from Hall and Mueller (in Lim & Simser, 2005:308), Marschark *et al.* (2002:44), Schirmer (2001:18) and Wright (2003:112).

Degrees or levels of hearing loss	
Type:	Extent of deafness (dB):
Normal hearing	0-15 dB HL
Slight hearing loss	16 - 25 dB HL
Mild hearing loss	26 – 40 dB HL
Moderate hearing loss	41 – 55 dB HL
Moderately severe hearing loss	56 – 70 dB HL
Severe deafness	71 – 90 dB HL
Profound deafness	91 dB HL and above

The degrees of hearing loss and its effects can be described as follows:

Normal hearing sensitivity and slight hearing loss

Individuals who are able to perceive sound intensities of 20 dB – 25 dB hearing levels, or softer, in a quiet environment, fall into the normal hearing sensitivity and slight hearing loss category (Lim & Simser, 2005:307; Marschark *et al.*, 2002:44; Schirmer, 2001:18).

Mild hearing loss

Individuals with hearing loss of between 26 – 40 dB hearing levels might find it difficult to hear faint or distant speech and therefore understanding speech in a noisy environment is challenging. For this reason, and without the use of audiological technology, a person with mild hearing loss might miss 25% to 40% of the speech signals. It follows that in a classroom situation, a child with mild hearing loss and without the use of assistive listening devices and hearing aids may miss up to 50% of discussions in class (Lim & Simser, 2005:308; Marschark *et al.*, 2007:34; Schirmer, 2001:18).

Moderate hearing loss

Hearing loss of 41 – 55 dB hearing levels, results in the individual missing 45% - 75% of regular conversational speech signals in a quiet environment. A limited vocabulary and affected speech production characterise moderate hearing loss, particularly without intervention and use of hearing aid technology (Lim & Simser, 2005:308).

Moderately severe hearing loss

According to Lim and Simser (2005:308) and Marschark *et al.* (2002:44) an individual with moderately severe hearing loss (56-70 dB HL) has trouble with everyday conversations that are not quite loud and clear. Hearing loss of this degree necessitates early and proper intervention as difficulties in school, speech impairment, delayed language development and sometimes even problems with social behaviours characterise moderately severe hearing loss.

Severe hearing loss

An individual with severe hearing loss (71 – 90 dB HL) finds conversational speech inaudible without an assistive hearing device unless it is loud and even then they may not recognise many of the words. In addition to that, the person might pick up sounds from the environment but will find it challenging to always identify them. The person's speech is therefore also not totally comprehensible (Lim & Simser, 2005:308; Schirmer, 2001:18).

Profound deafness

Individuals with hearing loss of 91 dB HL and above are considered to be profoundly deaf and cannot detect any sounds in the better ear without amplification and possibly even with amplification. The person might be able to hear some loud sounds but basically is unable to hear speech during conversations at all. Therefore the person's own speech, if developed at all, is difficult to comprehend (Lim & Simser, 2005:308; Schirmer, 2001:18).

3.3.3.2 Types of hearing loss

There are essentially three types of hearing loss, characterized according to the area of the ear in which the impairment occurs. The types of hearing loss are conductive hearing loss, sensorineural hearing loss and central hearing loss. Each of these types of hearing loss results in different kinds of hearing difficulties impacting on the individual's development and entire life (John, 2009:64; Störbeck, 2011:385).

- **Conductive hearing loss** refers to hearing loss as a result of a hindrance in the actual process of efficiently conducting the sound waves through the mechanisms of the outer and middle ear. This can be due to a blockage, problem or malfunction in either: the outer ear, the ear canal or the middle ear. Therefore even if the auditory nerves and their connection with the brain are normal, hearing loss can still occur (John, 2009:41; Marschark *et al.*, 2012:44; Störbeck, 2011:385; Wright, 2003:23).

Störbeck (2011:385) and Wright (2003:47-65) list obstruction in the ear canal by ear wax or foreign objects, perforated eardrums, glue ear (build-up of fluid in the middle ear) and ossicular problems as some of the probable causes of conductive hearing loss.

Although conductive hearing loss can result in quite a significant reduction in the volume of sounds heard, the degree of hearing loss usually only varies between 20 and 60 dB and can generally be corrected medically, surgically or with amplification. The effects of conductive hearing loss are therefore less severe than the effects of sensorineural hearing loss and many of the causes of conductive hearing loss are preventable (John, 2009:48; Marschark *et al.*, 2002:47; Störbeck, 2011:384).

- **Sensorineural or perceptive hearing loss** is usually a result of defects or damage to either the fine hair cells located within the cochlea or the auditory or acoustic route from the inner ear to the brain. Hence the term sensorineural is used to refer to the sensory (cochlea) and the neural (auditory nerve) part of the inner ear. The effect of

sensorineural hearing loss is a permanent reduction in loudness and clarity of sound together with some form of hearing distortion.

Halliday *et al.*, (2017:1551), Störbeck (2011:386), Schirmer (2001:5) and Wright (2003:24) view sensorineural hearing loss as permanent and mention that there is rarely any medical treatment for restoring hearing. In cases such as these, hearing devices are often recommended seeing that amplification might aid hearing in some cases.

It might also occur that an individual presents with a sensorineural hearing loss as well as conductive hearing loss, which is then termed a **mixed hearing loss** (Störbeck, 2011:386; Wright, 2003:23).

- A third type of hearing loss, called ***Central hearing loss also referred to as auditory neuropathy spectrum disorder (caused by Central Auditory Processing Disorder)***, does not cause deafness as such, but involves atypical processing of sound along the end of the auditory nerve and/or the auditory centres in the brain. In this case the conductive and sensorineural parts of the ear might function normally but the individual experiences difficulty in the reception, processing and effective interpretation of complex auditory information (Boudewyns *et al.*, 2016:993; Hall & Mueller, 1998:550; Schirmer, 2001:6; Störbeck, 2011:382–396; Wright, 2003:24). Hall and Mueller (1998:904) explain that although the individual with the auditory processing disorder may hear the sounds at a loud enough volume he or she does not understand the message, resulting in the individual acting like he or she cannot hear.

Types of hearing loss can be qualified even further as being unilateral, referring to one ear, or bilateral, where there is hearing loss in both ears (Hall & Mueller, 1998:460; Störbeck, 2011:385).

3.3.3.3 Age of onset of hearing loss

In addition to being classified by the degree and type, hearing loss can also be categorized by the age of onset of hearing loss. Determining the age of onset as well as the aetiology of hearing loss is imperative to understand, as the impact of the hearing loss on the individual greatly depends on the age of onset and aetiology.

Essentially, hearing loss is either present at birth, referred to as congenital hearing loss, or is acquired sometime after birth, called acquired hearing loss (Schirmer, 2001:6). These children might be born with complications with their eardrums or the ossicles or develop these problems later. If hearing loss occurs after birth it is significant in terms of language

development to also specify whether the hearing loss is prelingual or postlingual (Schirmer, 2001:6; Störbeck, 2011:387; Wright, 2003:42).

Prelingual hearing loss is considered to be hearing loss either present at birth, before the age of two, or before the onset of spoken language acquisition. Most children who present with hearing loss, as many as 95%, fall into this category. **Postlingual hearing loss** on the other hand occurs after spoken language acquisition, therefore after age two (Marschark *et al.*, 2002:44; NCTSN, 2006:107; Schirmer, 2001:6; Störbeck, 2011:387).

Marschark *et al.* (2002:46) view the onset of hearing loss as important for educational purposes seeing that children who have been exposed to language seem to be advantaged in linguistic domains. Children who experience postlingual hearing loss also benefit from the fact that they have comprehension of reference, learning tactics, and social experience. They therefore know what words and signs represent and have a spoken language base for communicating. It follows that the impact of prelingual and postlingual hearing loss on the child is very different and therefore requires different kinds of intervention (Schirmer, 2001:8; Störbeck, 2011:387).

3.3.3.4 Causes of deafness

The aetiologies of deafness vary widely. In terms of prelingual or early onset hearing loss, the most common factors being pregnancy and birth complications (prematurity and Rh-incompatibility), maternal rubella (German measles), maternal cytomegalovirus (CMV) infection, hereditary factors, meningitis and other infections including mumps and measles (Marschark *et al.*, 2002:45; NCTSN, 2006:17; Núñez-Batalla *et al.*, 2017:46; Schirmer, 2001:7; Wright, 2003:45). Maternal exposure to some medicines also causes damage to the auditory system, called ototoxic drugs, such as aminoglycoside antibiotics, loop diuretics, antimalarial drugs, salicylates and platinum-containing chemotherapy drugs (e.g., Cisplatin) (Butler, 2012:314; Hall & Mueller, 1998:436; Kral *et al.*, 2013:41; Núñez-Batalla *et al.*, 2017:46; Schirmer, 2001:9). Even though the above mentioned give insight into some of the more common factors, the aetiologies for approximately 33 per cent of prelingual hearing losses are still unknown (Schirmer, 2001:7).

The majority of postlingual hearing loss in children is associated with otitis media (inflammation of the middle ear) and meningitis but can also be attributed to accidents, high fever, mumps and side effects of certain medications (Hall & Mueller, 1998:436; NCTSN, 2006:17; Schirmer, 2001:8; Störbeck, 2011:388; Wright, 2003:48). While these factors

contribute to postlingual hearing loss in children, the aetiology of 60 per cent of postlingual hearing loss in children remains undetermined (Schirmer, 2001:8).

3.3.4 Models of deafness

Whenever reference is made to deafness, the content of the discussion as well as the choice of terminology quickly reveals a very clear picture of the attitude, view, model or perspective that the speaker or writer, knowingly or unknowingly, holds about deafness. Until very recently these perspectives mainly resorted under one of two schools of thought regarding deafness.

- The **medical (pathological) model** is the general view of the dominant hearing community as well as many speech and hearing therapists (Butler, 2012:317; Humphrey & Alcorn, 2007:111; Lim & Simser, 2005:311; Padden & Humphries, 2005:148). It is an exclusive model in which deafness is defined audilogically and regarded as a tragedy, a handicap, a physical disability or a defective or pathological condition that requires treatment, rehabilitation or compensation. Deaf people are therefore pitied (Morgan, 2008:6; NCTSN, 2006:69; Reagan *et al.*, 2006:188; Shakespeare & Watson, 2002:5). Deaf people who subscribe to the medical model often view themselves as disabled and different from hearing people and strive to blend into the hearing world (NCTSN, 2006:8).

Parents with children with deafness seek the help and support of medical professionals in their attempt to find solutions and ways of coping with the deafness. Professionals such as speech therapists, medical doctors etc. are seen as people who will “fix” the deficits of deaf people so they can be normalized (Humphrey & Alcorn, 2007:112). Seeing that the medical view assumes that time and money should be invested in search of a remedy, the focus is on rehabilitating deaf people through auditory enhancing devices such as hearing aids and cochlear implants so that they can fit into the dominant hearing society. These children undergo hours of speech therapy in order to develop speech and lip reading as this model views competency in oral language as the only means of cognitive development in the child. “Normal hearing people” are believed to be the ideal role models for deaf children and it follows that this model avoids the use of sign language since anything other than spoken language is viewed as inferior (Humphrey & Alcorn, 2007:111; Morgan, 2008:6; Munoz-Baell & Ruiz, 2000:40; NCTSN, 2006:8). In fact, Broesterhuizen (2005:311) notes that communication in sign language, according to the medical model, is seen as a failure of treatment.

- The **socio-cultural model** of deafness represents a more inclusive view of deafness (Humphrey & Alcorn, 2007:123; Morgan, 2008:6; NCTSN, 2006:10). Here, deafness is defined culturally as a unique characteristic which distinguishes normal deaf people from normal hearing people (Humphrey & Alcorn, 2007:123; Munoz-Baell & Ruiz, 2000:40). Deaf people who ascribe to this model of deafness do not regard themselves as disabled but primarily as members of a socio-linguistic minority group that share a common language, identity, norms, values, customs and common culture (Humphrey & Alcorn, 2007:123; NCTSN, 2006:10).

The socio-cultural model of deafness emphasises the use of visual, gestural communication as a positive alternative to the auditory channel of communication seeing as sign language is regarded to be the most natural way for deaf people to communicate and that sign language is a language in its own right and equal to other oral languages (Humphrey & Alcorn, 2007:123; Morgan, 2008:6; NCTSN, 2006:10).

The socio-cultural model supports the socialization of Deaf people within the Deaf community and within the larger hearing community and firmly believes that the best role models for deaf children are successful Deaf adults. They believe the role of professionals to be that of allies working together with Deaf people in the removal of barriers and their pursuit of equal access to the rights and opportunities hearing people enjoy (DeafSA, 2006:39:6; Humphrey & Alcorn, 2007:124; Shakespeare & Watson, 2002:6).

Gascon-Ramos (2008:68) and Munoz-Baell and Ruiz (2000:40) state, as emerges from the discussion above, that the model a hearing or deaf person subscribes to, will consequently determine the expectations, impact upon the home and decisions regarding educational placement and style of communication.

In a White Paper on an Integrated National Disability Strategy (Office of the Deputy-President, 1997:2) disabilities in South Africa in the general sense are approached more from the angle of the social model than from the earlier medical model. McIlroy and Störbeck (2011:497) on the other hand, indicate a paradigm shift away from these two seemingly opposing models of deafness as awareness and understanding increases about what it means to be deaf, towards a more multi-dimensional, bicultural dialogue approach which allows appreciation of the richness and intricacy of deaf ontology. Numerous authors (Chapel, 2005:24; Feher-Prout, 1996:159; Gascon-Ramos, 2008:59; John, 2009:21; McIlroy & Störbeck, 2011:510; Störbeck, 2011:383) also indicate this move away from the polarised medical and social models and incorporate Bronfenbrenner's (1979:4-12) bio-ecological model (developed from the ecological systems theory) of human development.

The above paradigm shift will be explained and become more evident in the remainder of this chapter, as it has implications for the understanding of Deaf culture, families with deaf children and the choices they are faced with in terms of communication and education and also for the intervention and pastoral care of families with deaf children.

3.4 UNDERSTANDING SOCIETY AND DEAF CULTURE

"Deaf people can do anything hearing people can, except hear" - Frederick Schreiber (as quoted by I. King Jordan in 1998 (Gallaudet University, 2014:2))

Traditionally, one is inclined to think of community and culture as concepts somehow associated with a group of people of a particular country, region or religion. Various authors define culture differently and therefore it is difficult to find a single definition of culture (Ladd, 2010:197). Most definitions, however, refer to a particular community's common traditions, customs, rituals, art, literature and language in their descriptions (Delich, 2014:319; Humphrey & Alcorn, 2007:52; Lane *et al.*, 1996:124; Sparrow, 2005a:139).

With the above explanation of culture as a point of departure, one might wonder how this definition can be translated to apply to the Deaf community. People who share a common characteristic such as being blonde or being wheelchair-bound generally don't form part of a community with their own culture. With the deaf, however, it is different. The Deaf community has a unique culture and does not view deafness as a disability but as something to be proud of and to celebrate (Lombaard & Naudé, 2007:145) and they would rather be defined by the positive aspects of their culture and language (Broesterhuizen, 2005:304, 2007:2; Sparrow, 2005:140). Additionally, culture "offers the possibility of making Deaf people whole" (Padden & Humphries, 2005:161).

3.4.1 Features of Deaf culture

Deaf people regard themselves as a linguistic minority and Deaf culture is the manifestation of this shared experience of life. This manifestation includes language, cultural values, beliefs and attitudes (Hamill & Stein, 2011:390; WFD, 2015:1:1).

3.4.1.1 Sign language

"Signs are to eyes what words are to ears" - Ken Glickman (quoted by Limlek (2012:1))

As is the case with the majority of cultures worldwide, members of Deaf cultures around the world have their own unique languages, each with a unique vocabulary and grammar (Deysel *et al.*, 2013:31; Gray & Hosie, 1996:221; Sparrow, 2005:141). Examples of these languages are ASL (American Sign Language), BSL (British Sign Language), Auslan (Australian Sign Language) and SASL (South African Sign Language) (Deysel *et al.*, 2013:31; Gray & Hosie, 1996:221).

Sign language is the natural language of the Deaf community and is at the very core of Deaf culture and is essentially what binds the members of Deaf communities together (DeafSA, 2006:6; Hamill & Stein, 2011:390; Lane *et al.*, 1996:42). Especially in the past, there was a lot of scepticism about the status of sign language and whether it really could be defined as a language. Sign language was believed to be merely a system, code, method or tool based upon a spoken language or a signed representation of a spoken language (DeafSA, 2006:6; Gravel & O’Gara, 2003:224). Even in South Africa, the Department of Education has based their arguments on this conviction that SASL is not a real language (Druchen, 2010:496).

A general misconception exists that sign language is universal and international. Although there are certain basic linguistic similarities, each country develops its own sign language and there are many differences among the various sign languages, mainly vocabulary, that make each one unique (Deysel *et al.*, 2013:31).

These misconceptions are gradually being dispelled as awareness increases and as research investigate sign languages further. Sign language is a visual-manual language with an entirely different modality than oral-auditory (spoken) languages. It develops naturally in a deaf community. Ample evidence for sign language as a complete and fully legitimate language in its own right exists (De Jong, 2010:2). Sign language grammar is not based upon the grammar of spoken languages but has its own lexicon, syntax and grammatical structure. In sign language placement, movement and expression of the hands (manual), face and body (non-manual) are part of the language and used to express information (De Jong, 2010:2; Gravel & O’Gara, 2003:244; NCTSN, 2006:18). William Stokoe’s (Armstrong & Karchmer, 2009:390) work is of paramount importance in this regard, since he found that sign language had all the main features common to spoken language and had the same potential for human communication. Stokoe additionally then devised a descriptive system that would convince language scholars of these facts and convinced a considerable part of the general public and educational establishment of the human and educational value of allowing deaf children to communicate in natural sign languages.

In the South African context, people tended to believe in the past that a separate sign language exists for each of the respective oral languages spoken in South Africa. This is in

line with the idea in many English-speaking countries that sign language is based upon English (or the language most commonly used in that specific country). What is true, is that there are various sign language dialects among deaf groups in South Africa (DeafSA, 2006:6; Reagan *et al.*, 2006:193). The existence of these different dialects can be attributed mainly to the fact that Deaf schools were divided according to race, language and ethnic factors during Apartheid (Deysel *et al.*, 2013:32; Ganiso, 2012:51; Magongwa, 2010:493). When Deaf people are exposed to different dialects of South African Sign Language, especially in urban areas, they adapt, understand each other and become multi-dialectal quickly by learning the variety in terms of the vocabulary used by other groups in South Africa (DeafSA, 2006:6; Ganiso, 2012:53).

3.4.1.2 Worldview

Members of the Deaf community maintain a collective worldview. In this view individuals define themselves in terms of their membership of this interconnected group and their shared common history and set of experiences in terms of the consequences of deafness in a hearing world are highly valued (Humphrey & Alcorn, 2007:42; McIlroy & Störbeck, 2011:508; Sparrow, 2005:141). These Deaf members find great enjoyment in spending time with other Deaf people and therefore actively search for ways to do so (Siple, 2004:2:1).

3.4.1.3 Norms, values and customs

The norms members of the Deaf community share determine what acceptable and unacceptable behaviour is. For instance, open and frank communication is of utmost importance and therefore withholding information or not sharing important knowledge will work against the above-mentioned interconnected collective (Lane, 2005:292; Siple, 2004:1).

Social norms and customs include the importance of taking turns in a conversation, of making and keeping eye contact during conversations and ways to get someone's attention by a light tap on the shoulder or asking someone else close to that person to tap them on the shoulder. Introductions of Deaf people to one another at social gatherings as well as the goodbyes at these events are usually lengthy processes and this is customary of Deaf culture (Humphrey & Alcorn, 2007:63; Lane, 2005:292; Siple, 2004:1; Smith, 2002:98).

Values shared by the Deaf community would first and foremost be their allegiance to Deaf culture and the fact that they regard deafness as a positive attribute, an identity to be embraced and celebrated and not as an abnormality that requires correction (Lane,

2005:292; NCTSN, 2006:49). Ciuba (2012:12) illustrates this view of deafness as an identity by quoting Hannah Lewis: *“Asking God to cure me of my deafness is comparable to asking God to make me a man.”*

Various authors (Ladd, 2010:46; Lane *et al.*, 1996:124; Morgan, 2008:219-212; Sparrow, 2005:140) mention that athletics, sports competitions and social organizations as well as expressive art forms are all important opportunities and sources of community pride and bonding forces of Deaf culture.

Each generation transmits the language, norms, values, practices and other aspects of Deaf culture to each successive generation through socialization and peer relationships (Theunissen, 2011:38). This passing down of some aspects of Deaf culture from generation to generation is similar to the oral tradition in hearing cultures, and referred to as a ‘face-to-face’ tradition (Bahan, 2006:22). Sparrow (2005:142) highlights the importance of the role of language once again by identifying language as the vehicle which transports the above aspects of a culture from one generation to the next.

3.4.1.4 Attitudes towards treatment of deafness

As mentioned earlier, people who identify with Deaf culture do not view themselves as impaired, disabled or challenged, but would rather be defined by the positive aspects of their language and culture.

In his illustration of what it means to be Deaf, Broesterhuizen (2005:305, 2007:2) mentions the Deaf community’s rejection of the medical (pathological) model of deafness and the importance of collectivism. Deysel *et al.* (2013:149:25) elaborate on the aspect of collectivism by explaining that Deaf people typically consider themselves as a close-knit group in contrast with individualism where independence and privacy are emphasized.

The different choices available in terms of the treatment of deafness as well as the controversy surrounding cochlear implants, will be discussed in greater detail in the paragraphs below, but it is important to take note here when discussing Deaf culture, that, despite change in attitudes over recent years, disagreement between Deaf and hearing cultures on the ethics of childhood cochlear implant surgery still exists (Lane *et al.*, 1996:407; Sparrow, 2010:455).

According to Padden and Humphries (2005:157) and Sparrow (2005:137) the majority of the hearing community might be shocked to learn that many Deaf people, because of their positive view of deafness, lead a happy and productive life without audition or a spoken

language and would not want to be granted hearing even if it were possible. They might insist “I don’t want to be hearing”.

As awareness is raised, more research is done and literature on the topic increases, the dominant hearing community around the world is given a new view on what it means to be Deaf. Corker (as quoted by Chapel 2005:8) explains that this awareness enables the hearing community to see that “the deaf world has a beauty, a richness and a vibrancy which is at least equal to that of the hearing world, and certainly complementary to it”.

3.4.1.5 Membership in Deaf culture

Deaf culture is unique in more than the ways already mentioned. Contrary to the way culture is usually transmitted from one generation to the next by parents to their children, Dolnick (as quoted by Jones, 2002:52) and Ladd (2010:42) explain that the majority of deaf children are not born into Deaf culture. This would mean that the hearing parents and the deaf child belong to different cultures and that this linguistic minority, in effect, is reborn with every generation (Singleton & Tittle, 2000:224).

Dolnick, as quoted by Jones (2002:52) and Lane (2005:302), demonstrates the above phenomenon strikingly by comparing the challenges hearing parents with deaf children are confronted with to that of parents adopting across racial lines. Therefore, in his opinion, bringing up a deaf child is similar to some degree to bringing up a foreign child. This is a crucial difference between Deaf communities and other minority linguistic groups. Only five to ten per cent of all deaf children are born to deaf parents and it follows that they acquire sign language as their mother tongue (Ganiso, 2012:51; Ladd, 2010:43). Ninety per cent of deaf children therefore are only exposed to and acquire sign language and Deaf culture when attending a Deaf school (Ganiso, 2012:51; Ladd, 2010:43; Lane *et al.*, 1996:125).

There is a great diversity when it comes to membership in Deaf communities. Deaf communities consist of people with deafness across the whole spectrum of the audiogram, but this is not the only criterion.

Various views Controversy exist about who really forms part of the Deaf community and what the criteria for membership in Deaf communities are (Ladd, 2010:32; Padden & Humphries, 2005:130). However, considerable research indicates identification with the Deaf community to be a personal choice (WFD, 2015:1:1). Some deaf and hard of hearing people, especially those who lost their hearing later in life, may identify more with their hearing culture of origin (Bat-Chava, 2000:426; Singleton & Tittle, 2000:222; WFD, 2015:1).

Membership in the Deaf community is more about an attitude toward deafness and the use of sign language than it is about one's hearing status. The Deaf community may also include, at least partially, sign language interpreters, sign language students, family members of Deaf people and other hearing individuals who work and/or socialize with Deaf people who identify with Deaf culture (Bat-Chava, 2000:426; Ladd, 2010:42; Munoz-Baell & Ruiz, 2000:41; Singleton & Tittle, 2000:222; WFD, 2015:1).

In summary, the above illustrates that the Deaf community does not automatically include all people with deafness, neither is it exclusive to people with deafness. One becomes part of the Deaf community by first self-identifying with the Deaf community and secondly whether other members of the Deaf community accept one as a member. This acceptance often goes hand in hand with competence in a signed language (WFD, 2015:1).

Burke *et al.* (2011:272) encapsulate the crux of the above discussion by stating:

The community needs to understand deafness as primarily a condition of gaining a culture and language rather than sensory loss, so that family and others evolve from grieving the loss of their expectations of what their child's life might be like to looking forward with hope to the unique contributions that child can bring to the world.

3.5 UNDERSTANDING BICULTURALISM

Individuals who are capable of functioning effectively in both the hearing world and the Deaf world are considered to be bicultural. These individuals feel comfortable in both worlds and can communicate well with both hearing and Deaf individuals (Bat-Chava, 2000:421; NCTSN, 2006:11; Theunissen, 2011:17). This is often the case with hearing children of Deaf adults, since they most potentially share their parents' culture and language (NCTSN, 2006:11; Singleton & Tittle, 2000:255). Where bicultural theories in general imply that children use one language (their mother tongue or first language) at home and another language (the dominant language as their second language) in the educational setting, it is exactly the other way around for Deaf children. Deaf children only learn their first language through exposure to and interaction with other deaf individuals either in the community or when they start to attend a school for the Deaf (Ladd, 2010:227).

3.5.1 Bicultural DeaF identity

Although identities of deaf individuals are generally categorized in Deaf studies as either deaf, Deaf or bicultural, McIlroy and Störbeck (2011:497) offer a new perspective to the

identity associated with bicultural Deaf individuals. Their research has indicated that many deaf individuals transition from one identity to another through their lives. These transitions suggest that for many deaf individuals, discovering their identity is not a static, once-off event, but rather a continuous self-reflective process (McIlroy & Störbeck, 2011:104).

This process of cross-cultural dialogue and the identity of bicultural DeaF individuals are located in the cultural space between both the Deaf and the hearing worlds. Here the term “DeaF” (with emphasis on the F) is used and functions as a linguistic indication of the fluid nature of the bicultural deaf person’s identity (McIlroy & Störbeck, 2011:510). One of the researchers, Guy McIlroy, was also a participant in the above-mentioned study and describes his own bicultural DeaF identity as follows (McIlroy & Störbeck, 2011:504):

Now I am much more comfortable with using the term “DeaF’.’ I have taken the D and F to explain that I belong in the Deaf community as an oral deaf person, who speaks well and signs, which I prefer with my Deaf friends, and I co-exist in a hearing world as an oral DeaF person who speaks, and is upfront about using an interpreter and hearing-aids. This is where I am right now.

3.6 UNDERSTANDING HEARING FAMILIES WITH DEAF CHILDREN

Becoming a parent is a joyous and momentous event in most parents’ lives. Each child brings a new dimension to the existing family life. The advent of a child might be accompanied by a mixture of feelings ranging from expectation, uncertainty, excitement and curiosity. Parents plan their children’s future with excitement and the continuation of the family culture and lineage are assumed to be a given (Lane *et al.*, 1996). When hearing parents realise that their child is deaf, however, these assumptions and expectations of the future do not hold anymore and parents are faced with challenging circumstances and decisions.

3.6.1 Hearing parents of deaf children

In the book *A journey into the Deaf-World*, Lane *et al.* (1996:24-40) describe the strikingly different reactions of hearing and Deaf parents upon learning that their child is deaf. Although reactions differ greatly, the reactions usually fall into two categories. Deaf parents in general celebrate the fact that their child is deaf as the deaf child is a reflection of themselves and because it signifies that the family’s Deaf heritage will be secure. They therefore do not view deafness as an attribute which will be harmful to their child (Lane *et al.*, 1996:28; Sparrow, 2005:137). From day one Deaf parents can communicate fully with their Deaf child and the Deaf child is surrounded from the very start by a world that is ideal for his

social, emotional and linguistic, cognitive and psychological development (Lane *et al.*, 1996:28).

As is also evident from the previous chapter 2.5.1 the response of hearing parents to the birth of a deaf child, is generally in great contrast to that of many Deaf parents. Hearing parents experience an array of emotions and feelings including feeling overwhelmed and inadequate to manage the very real challenges (e.g., communication, understanding and acceptance) of raising a deaf child successfully (Kurtzer-White & Luterman, 2003:232; Lane *et al.*, 1996:30), due to the fact they may have no prior experience with deafness.

3.6.1.1 Responses of hearing parents to the diagnosis of their child's deafness

Even if parents suspect their child to have some degree of deafness, having their suspicions confirmed can still come as quite a shock. If the child's hearing was not screened at birth, hearing parents might have many months of enjoying their "normal" baby and only start to suspect something to be amiss when their baby doesn't respond to sounds or is not showing signs of speech around the time when the baby is expected to say his or her first words (Lane *et al.*, 1996:32). As was evident from the empirical interviews in the previous chapter of this study parents might pick up on small cues that bother them, but may believe it to be only minor anomalies in their child's way of communicating. It often happens that parents would voice their concerns about their child's hearing quite early on to the paediatrician but that they might only be referred to an audiologist at a later stage upon a return visit to the paediatrician. After extensive audiological testing the news of the deafness is often communicated in a clinical or "medical" manner, similarly to a diagnosis of, for instance, diabetes (Butler, 2012:316; Lane *et al.*, 1996:33). Insufficient guidance is usually given to parents in terms of how to cope with this new reality or where to turn to for further information.

From the initial diagnosis it usually takes another few visits to the audiologists for further testing to determine the exact extent of the deafness (Lane *et al.*, 1996:33). A new journey then begins for the hearing parents, one that implies new terrains, new challenges and a world that they know very little about.

The new, unanticipated journey that hearing parents embark on with their child, is not an easy one. As was seen in the previous chapter of this thesis, parents' reactions to deafness vary greatly. Schirmer (2001:27) attributes these varying reactions to reasons including whether the road to diagnosis was lengthy or short and has or has not given the parents time

to consider the possibility of deafness; the degree of knowledge of deafness that the parents have at their disposal; parents perceptions and understanding of their child's deafness; and the resources parents have and the support they receive from professionals, family members and the community. Some experience it as traumatic and a journey that takes them through many of the stages of trauma and grief (Lane *et al.*, 1996:33).

3.6.1.2 Stages of grief

In response to the diagnosis of deafness hearing parents typically go through various emotional stages of mourning and grief (Feher-Prout, 1996:155; Houston, 2009:29; Lane *et al.*, 1996:33). Bosteels *et al.*, (2012:992) and Houston (2009:29) aptly describe the above as both an emotional and a physical rollercoaster parents find themselves on. This adjustment period can be compared to the stages of the grief cycle that Elizabeth Kübler-Ross first proposed in the 1960s to describe the grieving process terminally ill people typically go through as they approach death (McAlearney *et al.*, 2014:468; Penzo & Harvey, 2008:324; Schirmer, 2001:26; Worth, 2005:93).

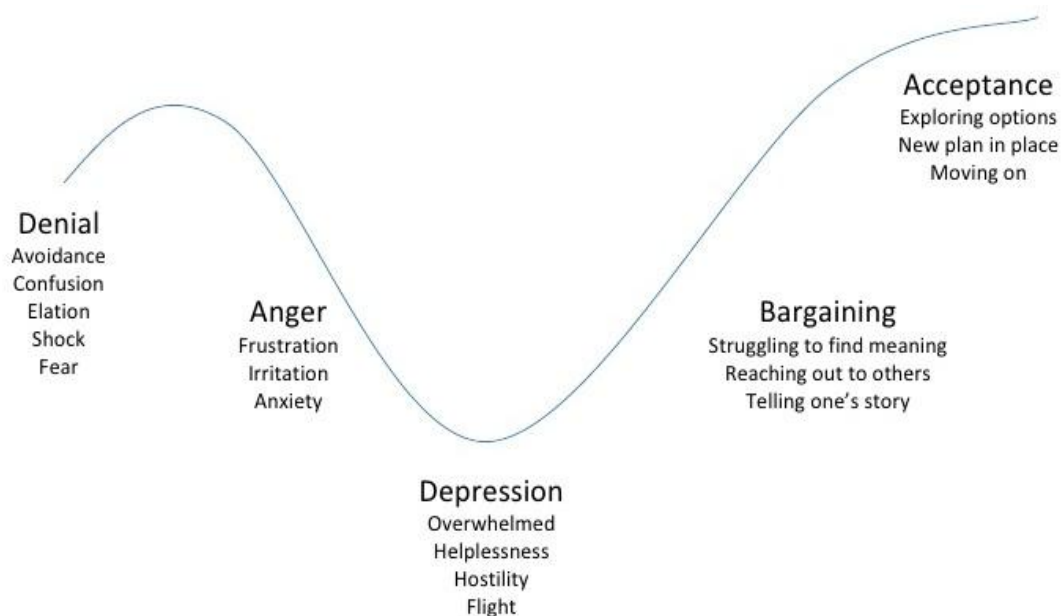


Figure 3-4: The Kübler-Ross stages of the grief cycle (Adapted from Anon, 2012:3; Kahn, 2015:2; Penzo & Harvey, 2008:326).

Although Kübler-Ross' model (see figure 3-4 above) has been challenged and criticized over the years (Hall, 2011:92; Worth, 2005:94) it has been applied to the bereavement process

and accepted as the framework for various forms of loss or change (Hall, 2011:9:2; Penzo & Harvey, 2008:326).

Kübler-Ross (Worth, 2005:93) did not believe that the stages always occurred in the same sequence or that the stages took equally long (Boushey, 2001:27; Worth, 2005:93). Though research on the terrain of families with deaf children shows similarities with the phases of Kübler-Ross, Kurtzer-White and Luterman (2003:234) as well as Penzo and Harvey (2008:326) caution that linear grief models might sometimes be inappropriate when applied to parents' reactions to diagnosis, seeing that death grief is terminable where parental grief is cyclically chronic. Although Penzo and Harvey (2008:338) refer to parental grief concerning the diagnosis of mental illness, the grieving process in terms of parental grief shows compelling similarities with that of parental grief about children diagnosed with deafness. With this in mind the adjustment period hearing parents go through can be described by employing the stages of grief of Kübler-Ross.

3.6.1.2.1 Shock and denial

In the initial stage of grieving parents might experience an array of emotions including shock, fear of the unknown, numbness, sadness, a reduced ability to concentrate and a general feeling of being overwhelmed and confused (Kurtzer-White & Luterman, 2003:234; Marschark, 2007:107; McAlearney *et al.*, 2014:468).

The initial shock is commonly followed by a period of denial which is a coping mechanism utilised by the body to cope with the unexpected news by regulating these intense emotions. Parents might try to deny that the deafness exists and avoidance and a sense of disbelief break through: "No, not me" (Kurtzer-White & Luterman, 2003:234; Worth, 2005:46). On the other hand, some parents might be relieved as they realise that it could have been something worse (John, 2009:74).

Facing the painful reality of the situation and acknowledging the loss are essential stages in the grieving process. Not postponing the pain, denying the loss or minimizing one's loss, means a person is integrating the loss into his life (Wright, 2000:43).

3.6.1.2.2 Anger

According to Kurtzer-White and Luterman (2003:234) the persistent feelings parents of newly-diagnosed deaf or hard of hearing children have is of being overwhelmed and inadequate to manage their child's deafness successfully. This fear of inadequacy and the feelings of helplessness and loss of control can often manifest as anger (John, 2009:76;

Kurtzer-White & Luterman, 2003:234). When the initial stage of shock and denial cannot be maintained, it is usually replaced by this second stage of grief, namely anger, as indicated by Kübler-Ross (Penzo & Harvey, 2008:329). It requires acknowledgement of the underlying pain and common feelings include frustration, irritation and anxiety expressed as: “*Why me?*” (McAlearney *et al.*, 2014:468; Penzo & Harvey, 2008:239; Worth, 2005:47).

Parents might start to feel angry because their child is different from other children; angry because they cannot control the situation and this anger can lead to conflict between the parents as well as conflict with other people the parents interact with. Parents have an expectation, like most other parents, that their child would be hearing and when this expectation is not met, they become angry and might feel that they have been dealt an injustice (John, 2009:76; Kurtzer-White & Luterman, 2003:234; Penzo & Harvey, 2008:329). Parental anger is also related to the frustration that frequent appointments with numerous professionals might cause. Parents have to answer endless questions, retell their child’s story to every professional they consult with and become angry when receiving confusing and often conflicting guidance (Feher-Prout, 1996:157; John, 2009:76; Kurtzer-White & Luterman, 2003:234; Penzo & Harvey, 2008:329).

The anger that builds up as a result of these intense, sometimes unacknowledged feelings of despair, helplessness, lack of control, frustration, fear and bitterness is sometimes transferred to the professionals working with the family (John, 2009:76; Kurtzer-White & Luterman, 2003:234; Penzo & Harvey, 2008:329). Various authors (John, 2009:76; Kurtzer-White & Luterman, 2003:234) warn that repressing this anger could lead to depression. According to Penzo and Harvey (2008:329), however, some parents are capable of using their anger as a point of departure for action and to advocate for their child thereby channelling their anger positively. If, however, this anger is repressed, it could lead to depression.

3.6.1.2.3 Guilt

Kurtzer-White and Luterman (2003:234) explain that parents might harbour feelings of guilt related to the cause of the deafness or because of feelings of not being able to protect the family from pain. As a result of not having had the opportunity to work through their feelings, parents tend to then either over-protect their child or to over-dedicate themselves to their child. Unfortunately, as much as the intentions are good, neither of the above behaviours is conducive to a good result for their child.

3.6.1.2.4 Depression

As parents come to realise that the change is permanent, and as the impact of the deafness hits them, their morale is commonly low. During this stage feelings might not be easy to express but are associated with sadness, sorrow, apathy, hopelessness, remoteness and feeling empty (McAlearney *et al.*, 2014:472; Penzo & Harvey, 2008:332). Not only are parents overcome with feelings of being disheartened and having little hope of the future, but they could also feel ineffective and might doubt their own skills and abilities. The sorrow and sadness experienced by parents are normal during this stage and a healthy part of grieving as it provides the opportunity for the parents to redefine competence in terms of having a child with deafness.

When, however, parents are rendered immobilized by the sorrow and grief, depression can set in (Kurtzer-White & Luterman, 2003:234; McAlearney *et al.*, 2014:472; Penzo & Harvey, 2008:332). Kurtzer-White and Luterman (2003:234) describe depression during this stage as anger turned inward. Parents often feel powerless to change the status quo and they might seem depressed but in fact what they are is angry, they simply do not have an outlet for expressing their anger and then despair may follow.

3.6.1.2.5 Bargaining

Although only for brief periods of time, parents may find themselves bargaining with God and the people around them, including each other and the health professionals in attempts to either avoid the change or to bargain in terms of contingency approaches (McAlearney *et al.*, 2014:471; Penzo & Harvey, 2008:330).

The benefits of the bargaining process for parents are threatened to be negated by the inconsistencies amongst the different health-care providers. Bargaining therefore is difficult for parents in these situations (Penzo & Harvey, 2008:331).

3.6.1.2.6 Acceptance, hope and integration

During this stage of the grieving process more optimistic moods start to emerge as feelings now include acceptance and hope. Acceptance does not imply a loss of hope, but rather an acceptance of this new reality, its implications and its permanency (McAlearney *et al.*, 2014:470; Penzo & Harvey, 2008:334). A level of acceptance by parents brings about feelings of hope for their child's future. Parents relinquish their expectations to 'cure' their child's deafness and understand that change is inevitable. Thus, instead of working against

the changes, parents now begin to work with the changes, by exploring the options available and getting new plans in place (McAlearney *et al.*, 2014:470; NCTSN, 2006:36; Penzo & Harvey, 2008:334).

Acceptance is an ongoing process of adaptation and adjustment and parents may find it hard to hold on to hope and acceptance during each new developmental transitional periods (e.g., entering school, adolescence) in the child's life, when the child has experienced a traumatic situation, or when the anticipated progress parents had hoped for does not materialise (Houston, 2009:29; NCTSN, 2006:35; Penzo & Harvey, 2008:326; Schirmer, 2001:27). This could once again trigger the grieving cycle and parents might well feel as if they have made little progress (NCTSN, 2006:35; Penzo & Harvey, 2008:334).

Kurtzer-White and Luterman (2003:235) caution that when hearing parents hang on to the hope offered by medical professionals for their child to be "normal" again, they suspend their grief, do not deal with their child's deafness and the accompanying emotions involved and subsequently cannot assimilate deafness into their lives. Therefore, various authors (Gascon-Ramos, 2008:65; Kurtzer-White & Luterman, 2003:235; Marschark, 2007:21; Murphy, 2009:14; Schirmer, 2001:35) place emphasis on the importance of the quality of the parent-child relationship, parental acceptance of their child as a deaf individual and adjustment to the needs of their child, as essential prerequisites of a normal childhood and subsequently, a successful deaf child.

3.6.1.3 Important decisions parents are faced with

To the majority of families deafness of a child is an unfamiliar experience. Most parents have no frame of reference and are therefore unprepared when having to deal with the consequences of the deafness and the adaptation and adjustments necessary to adapt to the unique needs of their deaf child (Feher-Prout, 1996:155; Houston, 2009:29; Kurtzer-White & Luterman, 2003:223). During this time, parents turn to professionals for guidance and assistance. Apart from being overwhelming, the information parents receive can also be extremely contradictory and unsatisfactory (Feher-Prout, 1996:157; John, 2009:76; Kurtzer-White & Luterman, 2003:324; Marschark, 2007:4;52; Penzo & Harvey, 2008:329).

Parents are faced with many questions and decisions in terms of the way forward. When parents knock on the door of professionals, parents are probably unacquainted with the debate relating to deafness as a cultural identity or a pathological condition (Schirmer, 2001:26).

Various factors contribute to the contradictory and frequently insufficient information parents receive. Professionals themselves are often also ignorant of the above-mentioned debate (Lane *et al.*, 1996:34; NCTSN, 2006:25) and in other cases personal beliefs, convictions and opinions interfere with the facts (Marschark, 2007:4). Parents hear about the “disability” of deafness and are influenced by hearing professional’s opinions and instructions. In this way, they are thus often “schooled” in the medical-pathological model which views the arrival of a deaf child as an unfortunate event that requires professional intervention (Lane *et al.*, 1996:28).

During this tumultuous period parents are often faced with an overload of novel information, which may make it difficult for parents to fully grasp and comprehend all that is communicated to them (King, 2017:38; Lane *et al.*, 1996:33). Since the medical profession’s premise is that deafness is a serious impairment, it follows that they may reinforce this idea in the minds of parents (Lane *et al.*, 1996:34). For the majority of the audiology profession early detection is prioritized in order to mitigate the child’s deafness with the view to intervene and do everything possible for the deaf child to function like a hearing child (Lane *et al.*, 1996:34).

It is therefore understandable that hearing parents would be recruited to this understanding of deafness and that the emphasis would be on the importance of hearing, since they can usually only think in terms of what is familiar to them – their hearing world (Lane *et al.*, 1996:34).

Parents are confronted with an array of decisions to be made relating to acceptance of the deafness, amplification, early intervention, language, communication, education and culture (Störbeck, 2011:388). When it comes to these complex decisions that parents are challenged with quite early on, the most prominent are arguably decisions relating to the options in terms of amplification (if any), language and communication and education as uninformed decisions could result in negative consequences for the deaf child’s development (John, 2009:292; Lane *et al.*, 1996:38; Sass-Lehrer, 2016:7).

At the outset it must be emphasised that it is important to remember that given the enormous variations, every child and family are different and therefore the approaches to communication they choose will also vary (Kral *et al.*, 2013:267; Marschark, 2007:5). The family’s selection of an approach in terms of communication and education will be impacted by multiple factors including the age of identification and intervention, degree of deafness, family involvement, use of amplification, speech intelligibility and the presence of additional disabilities (Gravel & O’Gara, 2003:250). Wyant (2009:4) stresses the fact that irrespective

of the particular choices families make in terms of communication, audition and language, each attempt to make choices that will be in the best interests of their particular family and therefore their choices ought to be respected by others.

3.6.1.3.1 Amplification and hearing technology options

Parents of deaf children are confronted with complex choices they need to make (Kurtzer-White & Luterman, 2003:235) and delaying these decisions may cause even further difficulties for both the parents and their child (Marschark, 2007:18).

The first decision to be made is whether or not hearing technology in the form of amplification will be utilized (Störbeck, 2011:388). Amplification involves the use of one of several choices available in terms of hearing technology, ranging from amplification devices like hearing aids, assistive listening devices such as FM systems and cochlear implantation (Gravel & O’Gara, 2003:245; Lim & Simser, 2005:309).

Supporters of the spoken approach to communication feel strongly that the technological advancements in terms of hearing technology truly provide deaf children with more opportunities than ever before. The President of the Alexander Graham Bell Association for the Deaf and Hard of Hearing (Wyant, 2009:4), expresses excitement over advancements in hearing technology as follows: “There is really no better time to celebrate spoken language for children with hearing loss.”

- **Hearing aids**

Hearing aids are the most common amplification devices. Hearing aids are electronic devices designed to optimize auditory output. Hearing aids therefore do not correct or “fix” deafness but aid residual hearing, thereby overcoming the limitation of the individual’s hearing ability. Hearing aids work by collecting sound from the environment, which it then amplifies and delivers into the individual’s ear (Kurtzer-White & Luterman, 2003:235; NCTSN, 2006:20; Padden & Humphries, 2005:166; Schirmer, 2001:20). Based upon the degree of deafness, the most suitable kind of hearing aid (behind the ear, in the ear, in the ear canal and implantable hearing aid) is selected (Felzien & Harrison, 2009:21). Individuals with a level of deafness less than 90 dB HL, thus hard of hearing, usually benefit from hearing aids and other amplification systems (Gravel & O’Gara, 2003:143).

- **Assistive listening devices such as FM systems**

Hearing aids work well in environments that are not very noisy and also where the individual wearing the hearing aid is in close proximity to the speaker. Yet in environments like classrooms and boardrooms, which tend to be very noisy, hearing aids might not be very effective. In situations like these, assistive devices are incorporated to overcome the problems of background noise and space. Assistive hearing devices work by collecting sound from the origin of the sound, making it louder and transmitting it to the receiver set to a certain frequency (usually the hearing aid) (Odelius & Johansson, 2010:508; Schirmer, 2001:23).

FM systems refer to assistive hearing devices in educational environments and group settings which utilize FM radio frequencies and work much like a personal radio. In the newest development in FM systems, the microphone on the hearing aid or cochlear implant is not required as they have direct input receivers. In this instance the individual will therefore only hear the sound collected by the teacher's wireless microphone (NCTSN, 2006:21; Schirmer, 2001:23; Stith & Drasgow, 2005:8). The individual is therefore brought in closer proximity to the teacher, technologically (Stith & Drasgow, 2005:8).

- **Cochlear implants**

Cochlear implants (CIs) in hospitals and clinics form part of intervention options for both adults who have lost their hearing later in life and for deaf children. These are individuals who are profoundly deaf (more than 90 dB HL) (Gravel & O'Gara, 2003:243; Kurtzer-White & Luterman, 2003:235; NCTSN, 2006:20; Schirmer, 2001:20; Sparrow, 2005:135).

A cochlear implant is a surgically implanted electronic device which does not amplify sound or make sound clearer in the way hearing aids do but rather it enables the individual to distinguish sounds by converting environmental sounds to electrical impulses which directly stimulate the auditory nerve cells in the inner ear (Kral *et al.*, 2013:3; Lane *et al.*, 1996:141; Padden & Humphries, 2005:166; Schirmer, 2001:21).

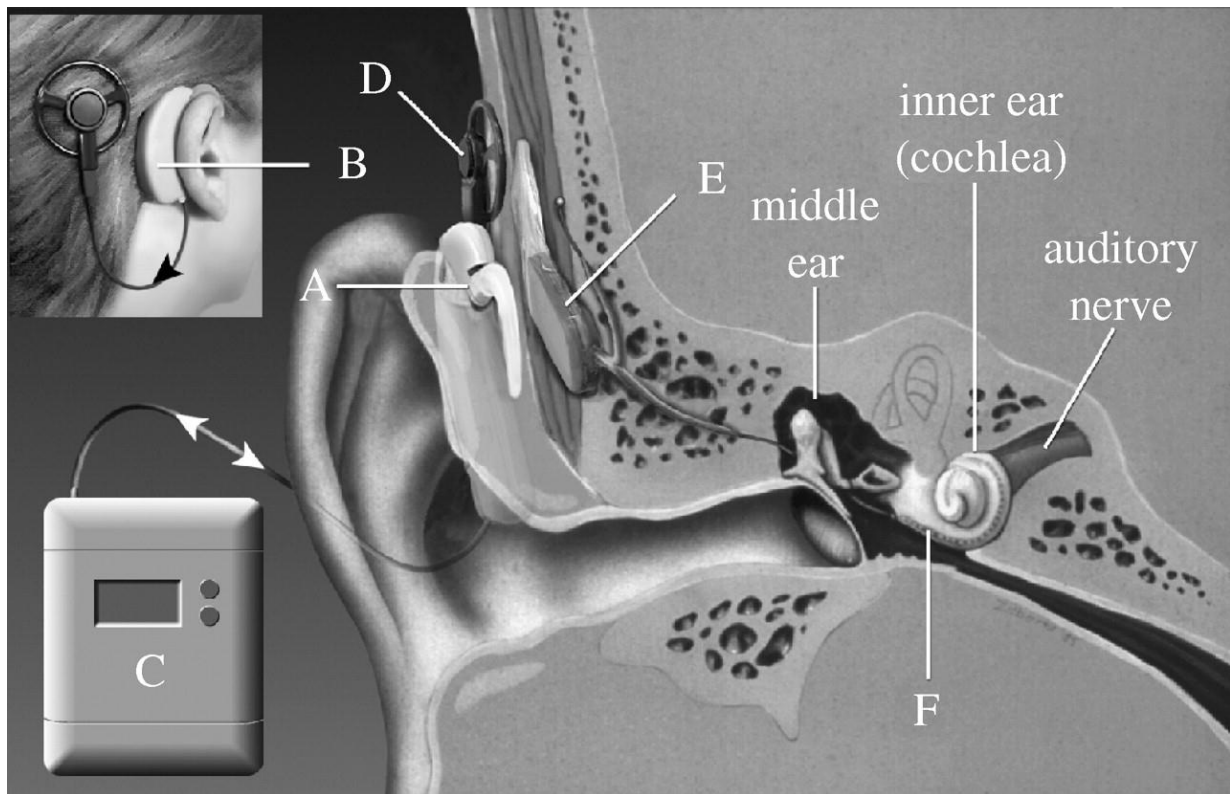


Figure 3-5: A diagram of a cochlear implant (Clark, 2006:792).

As can be seen in figure 3-5 above, a cochlear implant typically consists of internal and external components (Clark, 2006:792; Lane *et al.*, 1996:388; Schirmer, 2001:21; Stith & Drasgow, 2005:3):

- **External components**

- **A:** A small **microphone** on an earpiece is worn above the ear to capture incoming sound from the environment.
- **B & C:** An entirely **behind the ear speech processor or a body worn speech processor** (on a belt or in a pocket, pouch or harness) receives the sound/signals via a thin cable from the microphone. The speech processor selectively filters and analyses the sound to arrange audible speech and then translates the sound into a special pattern of distinctive electrical signals (pulses/currents/codes).
- **D:** The **transmitting aerial** is a small transmitting coil and antenna, mounted behind the outer ear, which is held in position by a magnet. The transmitter receives the electrical sound signals from the speech processor through a thin cord and then conducts power and the processed sound signals across the skin via radio waves to the implanted receiver device.

- **Internal components**

- **E:** The **receiver-stimulator** is a small electronic receiver coil behind the outer ear, surgically implanted on the skull beneath the skin. The receiver-stimulator receives the processed electrical sound signals from the external system and transmits them through a thin wire to the implanted electrodes implanted in the inner ear (cochlea).
- **F:** An **electrode array** is a wire of approximately 18mm long, carrying an array of electrodes which is wound through the spiralled cochlea. The process of inserting the electrodes in the cochlea destroys microstructure of the inner ear and most probably also destroys any residual hearing in the ear (Lane, 2005:299; Lane *et al.*, 1996:388). The sound signals from the receiver-stimulator are delivered to these electrodes. The electrical fields from the electrodes in turn stimulate the functional auditory nerve fibres to directly send sound information to the brain through the auditory nerve system, which the brain then recognizes as meaningful sound with varying pitches.

Cochlear implant controversy

The growing practice of the cochlear implantation of deaf children since the 1970s is a highly contested and emotionally charged subject with the ethical debate revolving around the view of deafness as an undesirable condition or a cultural difference. Although both have the welfare of the deaf child in mind, the medical community and the Deaf community often hold very strong and opposing views regarding cochlear implants in deaf children and this causes cochlear implantation to remain a sorely controversial issue (Gale, 2011:121; Kurtzer-White & Luterman, 2003:235; NCTSN, 2006:69:20; Padden & Humphries, 2005:166; Schirmer, 2001:22; Sparrow, 2005a:136, 2010:455).

On the one hand the medical community evaluates deafness pathologically and therefore assesses cochlear implantation positively as a treatment method which restores useful hearing (Clark, 2006:791; Gale, 2011:122). A “miracle” method which alleviates the condition of deaf children (Padden & Humphries, 2005:162) and enables them to acquire hearing and communicate orally in a hearing world and offers the best opportunity for education (Clark, 2006:791; Gale, 2011:122; Sparrow, 2005a:135). Their supportive research indicates that deaf children who are implanted before the age of 30 months are able to read age-appropriately after 5 to 7 years and results in these children moving more in the direction of spoken language for communication (Kral *et al.*, 2013:8). Sarant (2012:337) summarizes outcomes of various authors and recent studies undertaken in the field of cochlear implantation and concludes that the main benefits of cochlear implants are:

- Cochlear implants offer the deaf child an auditory awareness of what is going on in his environment seeing that the child would for instance be able to hear his name being called, birds singing and overall feel connected to the world;
- as cochlear implant technology advances the results of speech perception in implanted deaf children (spoken auditory information processing) also improve;
- more advanced hardware and speech processing strategies have resulted in improved speech production outcomes of implanted deaf children over the years;
- according to some authors, some recent studies indicate that children who are implanted at a very early age are capable of acquiring spoken language development at an equal rate to their hearing peers, given that they have had a few years of experience;
- although the results in terms of social development of implanted children vary greatly, some children do progress at the same rate as their hearing peers and some even progress faster;
- although current outcomes of implanted children vary widely, it is expected that prospective research will indicate a smaller margin of difference between implanted children and hearing children in terms of literacy and academic results.

Many parents of implanted children view opposition of the Deaf community against childhood cochlear implantation as “being romantic about deafness” (Padden & Humphries, 2005:167) and some in the medical field even argue that denying a deaf child a cochlear implant would be immoral since it would limit the child’s potential in life and therefore infringe the child’s right to an “open future” (Lane, 2005:304).

Most people from the hearing community would find it surprising that the cochlear implantation technology is not well received by a great part of the Deaf community and that members of the Deaf community do not view hearing and learning to speak as a priority (Sparrow, 2005:135).

Ethical issues related to cochlear implant surgery

The Deaf community, however, seeing that they regard their deafness as a cultural difference, feels very differently about cochlear implantation of prelingual deaf children. They have protested and continue to protest against childhood cochlear implants and base their objection on ethical issues with childhood cochlear implantation. They raise the following ethical issues:

- Firstly, persons who identify themselves as culturally Deaf are concerned that cochlear implantations are invasive and elective surgeries and entail medical and surgical risks. Lane (2005:299) and Sarant (2012:358) summarize the risks identified by various authors as including a 30 per cent higher incidence of bacterial meningitis due to cerebrospinal fluid leak, loss of vestibular function, permanent facial nerve damage, persistent tympanic membrane perforation and injury to the carotid artery. The surgery involved in combination with the oral rehabilitation after surgery might result in the child being without a real language for a substantial period of time. Additionally, the risks involved are still too significant in relation to the benefits to ethically justify cochlear implants of deaf children (Lane, 2005:299; Lane *et al.*, 1996:400; NCTSN, 2006:20). Cochlear implants will not be beneficial to all profoundly deaf individuals and they are not a permanent “cure” for deafness (Lane, 2005:300; Schirmer, 2001:22). It genuinely concerns the Deaf community that the medical community, however unintentionally, misleads hearing parents of deaf children into believing that cochlear implantation is a key for success in the hearing community as it will “fix” the deafness and thereby restore their child’s hearing (Kurtzer-White & Luterman, 2003:235; Lane, 2005:300; NCTSN, 2006:20).
- Secondly, the cultural values maintained by Deaf and hearing cultures often differ in significant ways. To not hear is a normal part of who Deaf people are and they view deafness as simply another form of human variation (Lane *et al.*, 1996:401) similar to the male and female variation recognized in humans (Sparrow, 2005:138). Therefore the Deaf community tend to view cochlear implant surgery on deaf children as unethical since it is unethical to perform optional operations on healthy children. They view cochlear implant technology as an attempt by the medical and hearing community to change a deaf person into a hearing person and to get rid of the Deaf community by “rectifying” audiological deafness (Lane, 2005:300; Lane *et al.*, 1996:400; NCTSN, 2006:20; Schirmer, 2001:20).

The Deaf community urges parents of deaf children to also seek counsel from members of the Deaf community when considering a cochlear implantation and to not only listen to advice from the medical community (NCTSN, 2006:20). Lane *et al.* (1996:401) emphasise the above and strongly suggest that parents of deaf children have an ethical responsibility to consider the values of Deaf culture, even if it contradicts their own hearing culture and values. In the end, the values of the Deaf community should be the determining factor when cochlear implantation is

contemplated, because the deaf child is already in principle, a member of the Deaf community at birth.

- Thirdly, the right of parents to decide upon a cultural identity on behalf of their child is questioned (Lane, 2005:300; Sparrow, 2005:140). For important decisions such as the decision about cochlear implantation, informed consent is required. Informed consent implies that the patient understands the risks and benefits of the procedure discussed. Seeing that scientific research is yet to assess the precise risks involved with the surgery and since the result of cochlear implants vary greatly, the medical team cannot predict the risks and benefits in detail, therefore the requirements of informed consent are not met (Lane, 2005:300). The parents make a decision on behalf of their deaf child seeing that the child is a minor and deemed temporarily incompetent to do so, without definite knowledge of what their child would have chosen if he/she could have. The general assumption is that parents know their children well and are therefore in a position to know what is best for their child. The reality, however, is that in the majority of cases hearing parents do not know their child very well since there is no common language between them and their deaf child (Lane, 2005:300). Lane *et al.* (1996:402) call this “surrogate decision-making” and state that if parents were entirely and accurately acquainted with the view of Deaf culture, they would know that many adult members of the Deaf community would not choose to be implanted and would definitely object to children being implanted (Lane, 2005:299).
- Fourthly, members of the Deaf community fear that the consequences of the increasing rate of cochlear implantation and the discouraging of the use of sign language in deaf children pose a threat to the existence and survival of Deaf culture. If the aim of the overall replacement of sign language (which the child would have acquired) with spoken language is attained, it could eventually lead to the systematic disappearance of Deaf culture (NCTSN, 2006:20; Padden & Humphries, 2005:7; Sparrow, 2005b:141, 2010:457). Sparrow (2010:455) and Lane (2005:302) evaluate the misunderstanding of the ethnic status of culturally Deaf people and refer to its consequences as ethnocide since a linguistic and ethnic minority is undermined and methodically obstructed from realizing.

Concluding remarks regarding childhood cochlear implants

Cochlear implant technology has progressed enormously over recent years, yet the controversy in terms of the ethicality of childhood implantation and a wide variation in terms of research results of the benefits of childhood cochlear implantation remain.

The decision to have their deaf child implanted is a very difficult decision for most parents, especially because it is elective surgery and because implantation surgeries these days take place around 12 months of age. It is understandable that the majority of hearing parents would want their offspring to be similar to other children, but the reality is that it is highly unlikely that a deaf child will ever sound exactly like his hearing peers and siblings, regardless of the intervention plan followed (Kurtzer-White & Luterman, 2003:235; Marschark, 2007:18).

The recent bilingual-bicultural paradigm shift (to be discussed in the following pages) as well as the fact that cochlear implant technology is here to stay and will only be advanced, brings a new dimension to the cochlear implant controversy. Although some believe that the Deaf community will never change their view of technology (Padden & Humphries, 2005:178) others expect that as more people are implanted and as the technology improves, members of the Deaf community will most probably change the view they maintain about technology. Sarant (2012:331) illustrates that these changes are already evident in the USA, by quoting the National Association of the Deaf stating in 2000 that “cochlear implantation is a technology that represents a tool to be used in some forms of communication, and not a cure for deafness”. Research done by Gale (2011:135) confirms this change in perception since her research indicated that despite the difficulties of choosing to use a cochlear implant, it was not rejected completely, possibly indicating that the Deaf community is not as resistant to the cochlear implant device when compared to the time the cochlear implant device was first approved for use in children.

3.6.1.3.2 Language and communication options

The amount of information concerning the options in terms of modality of communication and the related educational methods can be overwhelming to parents. Add to that the controversy surrounding these options and one can understand the immense stress it implies for parents feeling responsible for successful communication with their child (Kurtzer-White & Luterman, 2003:234; Sass-Lehrer, 2016:7; Störbeck, 2011: 389).

Parents of hearing children are able to instinctively communicate with their child. For parents of children with deafness, however, communication is not as easy. Lane *et al.* (1996:32)

explain that around the time children usually begin to speak, the deaf child would try to communicate, but in the absence of an accessible mode of communication, would resort to physical gestures, pulling on clothing, pointing to items and tantrums. Frustration can build up as it is difficult for hearing parents to understand and discipline their child. Gentzel (2007:18) states that an estimated 80 per cent of hearing parents struggle to communicate effectively with their deaf children and ineffective communication in the long run leads to internalized frustration and affects the deaf child's self-esteem.

As referenced earlier, there is a continued controversy over the various communicational options. Yet few professionals would disagree with the notion that every deaf child needs to develop language at an early stage in life and that it is crucial for the child to have a method of communication (Gravel & O'Gara, 2003:245; Lane, 2005:305; Marschark, 2007:16). Various authors (Marschark, 2007:16; Schirmer, 2001:30) indicate that the reason communication between parents and their deaf child is so crucial, is because communication is essential for the emotional connection between the parents and their child and since it is precisely through the conversations and discussions between children and their parents that children acquire language. Gravel and O'Gara (2003:244) therefore highlight the necessity of a method through which interchanges between the parents, the deaf child and the rest of the family can occur in a natural, fluent and meaningful way.

The languages deaf people use are categorized as either spoken or visual. The most common categories of the modalities of communication (that is the means by which the family members receive and express language) fall within a continuum with spoken language on the one end and visual language on the other (Gravel & O'Gara, 2003:245).

Though there are a lot of options available on the abovementioned continuum, and authors (Gravel & O'Gara, 2003:245; Lim & Simser, 2005:309; Störbeck, 2011:389) generally differentiate between the categories of communication methodology on the basis of the use or absence of amplification, and a spoken language (oral) approach or a visual (manual) approach. Approaches involving amplification fall under the spoken language (oral) approach and include auditory-verbal/aural as well as the auditory-oral communication (Gravel & O'Gara, 2003:245; Lim & Simser, 2005:309).

Gravel and O’Gara (2003:245) concisely summarize the various options of communication in the figure below:

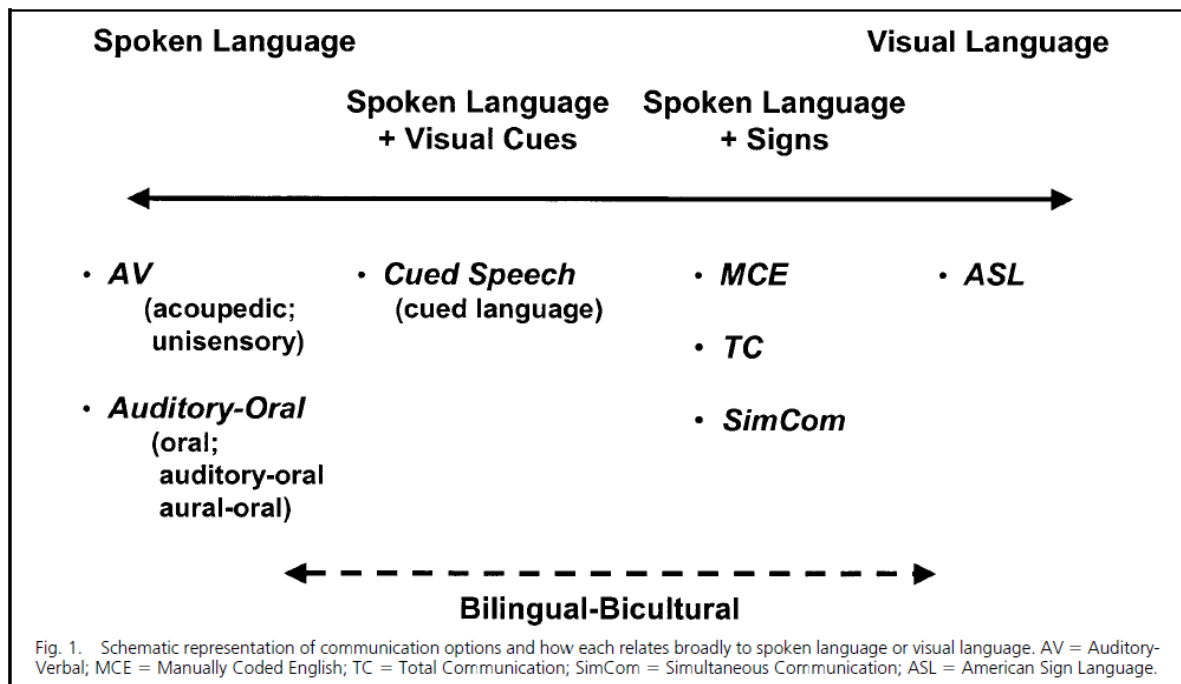


Figure 3-6: Communication options related to spoken language or visual language (Gravel & O’Gara, 2003:245).

a) Spoken language (oral) approach

The spoken language approach is in accordance with the pathological model and therefore the goal is to “normalize” the “different” deaf child by complete integration into the community of people who form the majority hearing culture (Butler *et al.*, 2001:44; Gravel & O’Gara, 2003:245; Störbeck, 2011:389). Deaf children are made oral in order for them to fit into the hearing world and therefore not encouraged to learn or use sign language to communicate (Ladd, 2010:7). Within the spoken modality there are a variety of different options:

- With **auditory-verbal communication** the emphasis is on developing spoken language by exclusively making use of amplification or cochlear implant technology. Seeing that listening is used as the primary modality in order to achieve the goals of this form of communication, aided residual hearing is utilized around the clock (apart from when sleeping) (Gravel & O’Gara, 2003:245; Kurtzer-White & Luterman, 2003:235; Lim & Simser, 2005:309).

Listening (audition) is emphasized to such a degree that not only is signing by the deaf child prohibited during language learning sessions, but looking at the lips and facial expressions of the person speaking is also not permitted (Gravel & O'Gara, 2003:245;

Lim & Simser, 2005:309; Störbeck, 2011:389). Teaching sessions consist of trained therapists who work directly with the families on an individualistic and diagnostic manner (Gravel & O’Gara, 2003:245; Lim & Simser, 2005:309). Furthermore, because the ultimate goal is total integration into the hearing world the family and the deaf child are not exposed to sign language or Deaf culture (Gravel & O’Gara, 2003:245).

Lim and Simser, (2005:309) state that by following the route of auditory-verbal communication, after the deaf child starts using a cochlear implant, the child’s hearing potential as well as spoken language development will be optimised. However, Störbeck (2011:389) adds that, although some deaf children with cochlear implants may develop comprehensible speech, it is found to be less fluent than the speech of their hearing peers.

- **Auditory-oral communication** differs from auditory-verbal communication in the sense that speech reading (lip reading), facial expression and natural gesturing is used in conjunction with aided residual hearing in order to develop spoken language (Gravel & O’Gara, 2003:245; King, 2017:38). This approach strongly supports cochlear implant technology. Education in a school with other deaf children, group sessions, speech therapy and speech reading practice are characteristic of this approach to communication (Gravel & O’Gara, 2003:245; Lim & Simser, 2005:309).

In terms of the oral approach in general the prominent features include the emphasis on early identification of deafness, early fitting of hearing aids or cochlear implants and early education (Gravel & O’Gara, 2003:245; Störbeck, 2011:389). Advocates for the auditory-aural approach to communication maintain the conviction that by assisting pupils to develop oral communication skills in order to communicate orally, they are helping them to participate and be fully included into the mainstream hearing world (Butler *et al.*, 2001:44; Kral *et al.*, 2013:267; Störbeck, 2011:389).

Seeing that most parents of deaf children are hearing, it is understandable that many parents still opt for an exclusively oral approach (Burke *et al.*, 2011:278). When following this approach to communication, an advantage is that the parents of the deaf child do not have to learn a new language in order to communicate with their child. Furthermore, when the deaf child grows up, he or she will be able to function in the hearing world seeing that he can use spoken language (Schirmer, 2001:67; Störbeck, 2011:389).

The disadvantages, however, include the fact that this approach only works with selected deaf children as it is impossible for a large number of deaf children to fully acquire spoken language skills via the spoken form of the language, even with amplification or a

cochlear implant (DeafSA, 2011:2; Schirmer, 2001:199). Marschark *et al.* (2007:14) emphasise this by referring to a study that indicated that, even in the most advanced programme where early identification was done at birth and early intervention started at the age of three, a mere 25 per cent of children with profound deafness developed intelligible speech by the time they reached their fifth or sixth birthdays. To add to the disadvantages of the oral method, the deaf child is not introduced to sign language and therefore does not participate in the Deaf community (Lane *et al.*, 1996:240; Schirmer, 2001:67).

The negative effect of trying to make deaf children communicate orally puts them in a more vulnerable position and could furthermore be detrimental to the deaf child's linguistic educational development and psychological wellbeing because of the conviction that who he or she is, is not sufficient or completely acceptable (Burke *et al.*, 2011:275; Gascon-Ramos, 2008:67; Ladd, 2010:7; Lane *et al.*, 1996:267; Störbeck, 2011:389). Furthermore, Burke *et al.* (2011:283) argue that additionally, deaf children are denied the use of a language in which to comfortably communicate in, falling in love in, build friendships in and joke in.

- **Spoken language with visual cues**

Spoken language with visual cues, called Cued Speech, is a phonetically-based language system (a visible representation of a spoken language) (Humphrey & Alcorn, 2007:106). The principle is to assist the deaf child to differentiate between mouth movements via the cueing system in conjunction with speech reading. No signs are used at all, but the speaker holds one hand raised to the face in one of four locations near his mouth while his hand forms one of eight hand shapes to provide information. In this way the capacity of a deaf child to learn spoken language is developed (Deyssel *et al.*, 2013:30; Gravel & O'Gara, 2003:245; Kral *et al.*, 2013:276; NCTSN, 2006:19; Schirmer, 2001:199). For this form of communication, hearing is not required. Gravel and O'Gara, (2003:245) mention that because hearing is not required, people who use sign language could utilise Cued Speech as a means to learn a spoken language.

- b) **Spoken language and signs (combination methods)**

- **Manually Coded English (MCE)**

In trying to represent the translation of English (or other spoken languages) visually with signs and fingerspelling manually coded English systems have seen the light (King, 2017:39). These, however, are systems based upon a spoken language lexicon and therefore not natural languages. The goal of these systems was to make up for so-called

deficiencies (by means of invented signs and suffixes) in sign language and to provide access to and teach deaf children English syntax and grammar by following the rules of the English language. (Gravel & O'Gara, 2003:247; Humphrey & Alcorn, 2007:104; Lim & Simser, 2005:309; NCTSN, 2006:18; Schirmer, 2001:67).

- **Total communication (TC)**

As the name might suggest, Total Communication refers to a philosophy of education which incorporates the benefits of both the spoken and the visual paradigms (Gravel & O'Gara, 2003:247; Schirmer, 2001:202; Störbeck, 2011:390). In the 1970s Total Communication replaced oralism as the main philosophy for educating deaf children in search of a middle ground between the visual language and spoken language approaches (Lane *et al.*, 1996:214; Schirmer, 2001:202). The philosophy behind Total Communication is that the method of teaching deaf children language should be tailored for the individual child (Chapel, 2005:38; Störbeck, 2011:390; Theunissen, 2011:15). This implies that language acquisition is promoted by utilizing any or all possible forms of communication at the disposal of the speaker, be it reading and writing, drawing, amplification, speech, listening, finger spelling, imagery (using pictures), speech reading, signs and natural gestures (pantomime) to promote language acquisition (Lane *et al.*, 1996:270; Lim & Simser, 2005:310; NCTSN, 2006:19; Schirmer, 2001:202; Störbeck, 2011:390).

Although Total Communication was initially an educational policy motivating all modes of communication, in reality Total Communication often merely implies accompanying speech (with spoken language structure) with signing. Thus, in short, Total Communication nowadays is reduced to simply mean that the speaker signs in the spoken language word order while speaking or with the spoken language on the mouth, which are the features of simultaneous communication (Deysel *et al.*, 2013:31; Ladd, 2010:184; Lane *et al.*, 1996:214; Lombaard & Naudé, 2007:142; Schirmer, 2001:202; Theunissen, 2011:15).

Although this approach to communication might improve general communication skills, neither sign language skills nor spoken language skills are fully developed by this approach. Yet this approach remains widely used in South Africa (DeafSA, 2011:3)

- **Simultaneous Communication**

Simultaneous Communication (SimCom) also referred to as Sign Supported English is often considered to be similar to Total Communication. Simultaneous Communication is a type of pidgin communication where a combination of signs and spoken language is

used. The structure of the communication reflects that of the spoken language (Chapel, 2005:66; Gravel & O'Gara, 2003:247; NCTSN, 2006:19; Singleton & Tittle, 2000:223; Störbeck, 2011:391). It was developed as a result of the conviction that sign language was not a true language and therefore could not be utilized as a means of educational instruction (Lombaard & Naudé, 2007:142).

Although Simultaneous Communication is similar to Total Communication in many ways, Gravel and O'Gara (2003:247) point out that it does differ in the sense that where amplification is an element of Total Communication, it is not regarded as indispensable in Simultaneous Communication.

The combinational methods described above are not languages but representations of spoken languages and, therefore, artificial. People who subscribe to Deaf culture deem these methods as a denial of their culture and the status of their language. These methods are not clear or efficient and essential non-manual information is lost. Furthermore, it causes confusion and frustration and therefore most Deaf people reject the use of the above methods (DeafSA, 2006:39:32; Deysel *et al.*, 2013:31).

c) Visual (manual) language approach

- **Sign language**

The visual (manual) approach to communication falls within the socio-cultural model of deafness and identifies sign language as the unique, native, natural language of the Deaf community. As explained in 3.4.2 of this chapter, sign language is distinctly different from spoken language. It is visual, gestural and spatial and the grammatical structure as well as the syntax is dissimilar to that of spoken language. Sign language incorporates placement, expressions of the hands (shape, location, orientation and movements), facial expression (including the intensity of emotions) and body movement to communicate meaning (Gravel & O'Gara, 2003:246; Humphrey & Alcorn, 2007:104; NCTSN, 2006:18; Schirmer, 2001:64; Singleton & Tittle, 2000:255).

Schirmer (2001:64) remarks that it is precisely because of the difference in the entirely different grammatical structures and syntax of each language, that it is not physically or cognitively possible to use sign language and speak simultaneously, in the same way that one cannot speak English and Chinese simultaneously. In fact, developing spoken language and therefore speech is not a component of a visual language at all (Gravel & O'Gara, 2003:244; Kral *et al.*, 2013:267; Kurtzer-White & Luterman, 2003:235; Marschark *et al.*, 2002:14).

Advocates of the sign language approach regard sign language as the first language of the Deaf (regardless of the first language of the rest of the family) and secondary to that only the predominant spoken language used by the hearing majority. Both Schirmer (2001:65) and Störbeck (2011:390) emphasise the importance of deaf children being exposed to sign language from as early an age as possible. It is important to understand that, in the same way that hearing children would not learn English or any other spoken language if it were not for their exposure to and interactions with native speakers of that language, deaf children are not cognitively programmed to learn sign language without exposure to and interactions with individuals using sign language (Schirmer, 2001:65). For this reason regular interaction with members of the Deaf community must enjoy priority.

If parents opt for the visual language approach, all communication among members of the family will be visually oriented and sign language as the primary communication mode will become a way of life. Because natural sign language development occurs in the same way as spoken language development, families of deaf children must learn and become fluent in sign language in order to become competent to sign to their deaf child from very early on (Gascon-Ramos, 2008:67; Gravel & O’Gara, 2003:246; Ladd, 2010:43; Lane *et al.*, 1996:125). Furthermore, opportunities for the child to interact with his or her peer group that uses sign language, as well as Deaf adult role models, are valuable and highly recommended (DeafSA, 2006:6; Gascon-Ramos, 2008:67; Gravel & O’Gara, 2003:246; Ladd, 2010:43; Lane *et al.*, 1996:125; Magongwa, 2010:493; Störbeck, 2011:390).

Although amplification is not used in this approach for the purpose of learning sign language, amplification or cochlear implants are sometimes used for an awareness of environmental sounds (Gravel & O’Gara, 2003:246).

- **Benefits of sign language**

The key objective of the visual (manual) approach is to provide to deaf children better opportunities to develop a firm cultural identity, exhibit typical language development, cognitive abilities and to be socially well adjusted and emotionally stable (Gascon-Ramos, 2008:68; Marschark, 2007:16; Störbeck, 2011:390). Written forms of sign languages are unheard of and although sign language cannot offer the connection or bridge from the inner language to written spoken language, it can offer the connection or bridge between the external (spoken) and the inner language. Furthermore sign language can develop mental power and therefore successful early sign language acquisition impacts the result of well-developed deaf children with real-world knowledge

(Schirmer, 2001:64). Relative to deaf children brought up in exclusively spoken environments, it has been shown that deaf children exposed to sign language from an early age perform better academically and also have better societal relationships with their families and fellow pupils (Marschark, 2007:16).

- **Mistaken assumptions about and criticism against the sign language approach**

Lamentably, mistaken assumptions are still maintained about the visual (manual) language approach to communication. This becomes evident in the kind of advice parents of newly-diagnosed deaf children receive when knocking on the doors of professionals (acting in accord with accepted practice and the recommendations of their textbooks) for guidance. Though the information medical professionals provide can assist in explaining deafness, their advice is often unsatisfactory and unsubstantiated. Unsubstantiated advice parents of deaf children still receive is that learning sign language interferes with the deaf child's learning to speak and therefore professionals discourage parents from using sign language with their child. On the contrary, where exclusive exposure to spoken language only results in substantial delays in language development, it has been shown convincingly that early sign language benefits the process of learning spoken language later on (Lane *et al.*, 1996:29; Marschark, 2007:4; Parkin, 2010:493; Singleton & Tittle, 2000:225).

Criticism often raised against the visual language approach is that it is likely to cut off deaf people from the mainstream hearing world in which they need to function. Advocates of the visual approach would differ from this view and argue that by not allowing a deaf child to use sign language, the deaf child is cut off from the Deaf community. Hence, a deaf person educated according to the spoken language approach might grow up not feeling completely comfortable or accepted in either the Deaf or the hearing communities and therefore experience social isolation (Störbeck, 2011:390).

When elaborating on the most common misconceptions in terms of deafness Marschark (2007:24) mentions that the notion that every deaf child can be taught to "lip-read" is not true. "Speech reading" is very difficult and not efficient. The average deaf adult will not be able to "lip-read" much better than the average hearing adult would (Marschark, 2007:15).

Advocates of the spoken approach to communication seldom acknowledge these well-established evidences (Marschark, 2007:4). Parents struggle to gain advice about the advantages and disadvantages of both the spoken and visual language approach. Rarely if ever are parents informed of sign language as an option for communication and

what the benefits are of acquiring sign language. They are not informed about how sign language, among other things, cultivates self-confidence. It follows therefore that information about the flourishing Deaf community and everything that Deaf culture entails, is omitted (Lane *et al.*, 1996:214; Marschark, 2007:17).

This was also the case with many of the parents interviewed for this study (2.5.1.2). Parents trust the advice they receive and therefore it is understandable that parents are often heard saying that they just did not know (Marschark, 2007:22).

- **Bilingual approach to communication**

As briefly mentioned earlier in this chapter (3.3.4) developments have shown a shift away from the two divergent models of deafness (medical and socio-cultural) as awareness and understanding increase about what it means to be deaf, towards a more multi-dimensional, bicultural dialogue approach which allows appreciation of the complexity of deaf ontology (McIlroy & Störbeck, 2011:497).

This gradual paradigm shift is also evident in the approaches to communication. The bilingual approach to communication combines the strengths and weaknesses of both the spoken language and the visual language approach with the goal of encouraging and developing a high degree of proficiency in both languages, with sign language as the deaf child's first language and a spoken/written language as the child's second language, or vice versa (DeafSA, 2011:3; King, 2017:39; Klein, 2008:24; Sass-Lehrer, 2016:6; Störbeck, 2011:391). Numerous members of the Deaf community consider themselves as bilingual and therefore use sign language for communication in the Deaf community and written or spoken language for communication in the hearing community (Gravel & O'Gara, 2003:244).

Since communication and education are so intertwined, this approach is explained in more detail when exploring the Bilingual-Bicultural approach to the education of deaf children.

3.6.1.3.3 Educational options for deaf children

Even though the immediate family forms the primary system in which deaf children grow up, the educational environment (school) is essential for both their social and emotional development. This significance of the educational environment will probably escalate dramatically if the deaf child is communication-deprived at home (Gascon-Ramos, 2008:66).

In terms of the educational environments for deaf children, parents are faced with other educational decisions. Störbeck (2011:392) states that parents need to consider either home

schooling or sending their child to school and additionally decide between private or public education. They then are faced with the number of different options available in terms of regular mainstreaming or residential school for the Deaf (specialised school settings) (Gascon-Ramos, 2008:66; Marschark, 2007:24; Störbeck, 2011:392).

Deaf children might attend more than one environment over the course of their education (NCTSN, 2006:23).

- **Mainstreaming educational option**

Mainstreaming refers to when deaf children attend regular mainstream public schools with their hearing peers, with the aim of including deaf children in all aspects of the public educational environment (Aarons & Akach, 2002:156; King, 2017:39; Miller, 2012:1).

The support services of the schools and the needs of the child will determine the experiences to a large extent (Miller, 2012:1), and especially when looking at the global trend, mainstreaming can vary greatly. Examples of mainstreaming around the world include:

- **Regular classroom.** The deaf child receives all educational instruction from the hearing classroom teacher and additional support services are not provided (Miller, 2012:1; Schirmer, 2001:185).
- **Regular classroom with supplementary support services.** The deaf child receives instruction in a regular classroom with hearing children, but the teacher is supplementary provided with supportive services. The support services usually involve itinerant consultants, like an additional teacher of the deaf or speech-and-hearing specialists (Lane *et al.*, 1996:248; Miller, 2012:1; NCTSN, 2006:14; Schirmer, 2001:185). This setting however, is mainly available in for instance the United States. The researcher could not find any material indicating the availability of this option in South Africa.
- **Resource room.** The deaf child receives the majority of his/her instruction from the classroom teacher but designated parts of each school day are set aside for the deaf child to receive special instruction in a resource room (Lane *et al.*, 1996:248; Miller, 2012:1; Schirmer, 2001:185).
- **Self-contained (separate) class.** In this instance the deaf child attends a regular hearing school but receives instruction from a teacher of the deaf, in a separate class (Lane *et al.*, 1996:246; Miller, 2012:1; Schirmer, 2001:186). In these classrooms, the method of communication varies from a spoken approach to a visual language approach (NCTSN, 2006:23).

Internationally, mainstream education of deaf children has been a controversial topic for many years (Miller, 2012:1) and Marschark (2007:24) warns against the mistaken assumption that the mainstream education option rather than a specialised setting is necessarily the best option for all deaf children. As is the case with all children, it is important to understand that although mainstream education might work for certain deaf children, it does not work for all deaf children.

One advantage of mainstreaming is that the deaf child can stay at home with his/her parents and family (Miller, 2012:1). However, this advantage needs to be weighed against the disadvantages of mainstreaming. In this educational setting, the deaf student does not have a lot of opportunities to interact with deaf peers and may also not have access to deaf role models (Bat-Chava, 2000:428; John, 2009:177; Lane *et al.*, 1996:253; Miller, 2012:1). Furthermore, a study done by McIlroy and Störbeck (2011:507) indicated that the experiences of deaf pupils in mainstream environments included that they thought that being deaf was unfortunate and that (incorrectly) there aren't many other deaf people around. Many authors (Burke *et al.*, 2011:284; Lane *et al.*, 1996:249; Miller, 2012:1) echo this theme of isolation experienced by deaf children in a mainstream educational setting and Lane *et al.* (1996:249) add that these children feel like outsiders in the hearing setting they are encased in 24 hours a day and to them, life is a continuous struggle.

One example of a personal experience of exclusion is illustrated concisely by T. Alan Hurwitz (tenth president of Gallaudet University)(Hurwitz, 2009:13:1):

Mainstreaming? Hardly, more like the "Dark Ages"...It is not a complaint, but rather a fact that I did not have many friends in school. Most relationships with my peers were superficial – like saying "Hi. How are you? It's nice outside, etc." There were no meaningful dialogues with my peers, all of whom were hearing.

Inclusion is viewed negatively by numerous Deaf people as they feel that being dispersed into mainstream schools is a threat to Deaf culture and sign language (DeafSA, 2006:14).

- **Special schools for the Deaf**

• **Residential schools for the deaf**

A residential school for the deaf is a separate school that provides education to deaf and hard-of-hearing children. The children live in hostels full-time during the school year and attend classes in daytime. Instruction in this setting is done by teachers of the deaf (King, 2017:39; Miller, 2012:1; Schirmer, 2001:186).

The most apparent disadvantage of residential schools would be that children are away from home and their families for the majority of the school year and as a result might feel somewhat isolated from their families (Miller, 2012:1). The advantages of residential school, on the other hand, include that the children will be around and interact with peers (maybe for the first time) and in this way develop communication and build relationships (DeafSA, 2006:14; Gascon-Ramos, 2008:66; Miller, 2012:1). It is mainly at these schools for the deaf that the student is exposed to and acquires sign language and Deaf culture (Ladd, 2010:43; Lane *et al.*, 1996; Miller, 2012:1; Theunissen, 2011:44). Furthermore, pupils can participate in extracurricular activities involving interaction with other residential schools for the deaf thereby creating a greater Deaf community for the child. It is also at residential schools that deaf children often gain access to strong deaf role models (Miller, 2012:1).

- **Day schools**

These schools symbolize finding a middle ground between mainstreaming and residential school. Day schools for the deaf differ from residential schools for the deaf in the sense that children live at home with their families and travel between home and school each day (King, 2017:39; Miller, 2012:1; NCTSN, 2006:69; Schirmer, 2001:186). In cases where the day schools are oral day schools, they mainly follow the spoken language approach to communication and therefore don't include sign language but would emphasise listening and speaking skills whereas sign day schools would incorporate sign language. Various day schools, however, might follow the total communication approach to communication (Miller, 2012; NCTSN, 2006:23).

The advantages of day schools for the deaf are similar to those of the residential schools with the added advantage that children can live at home (Miller, 2012:1).

In these special schools for the deaf the different communication systems and the educational approaches to be followed will be determined by the philosophy and policy of the particular school (NCTSN, 2006:23). Parkin (2010:492) explains the local situation in South Africa as that numerous schools have followed similar routes and trends seen internationally, being that the spoken approach was followed first, after that Signed English, thereafter Total Communication and most recently, the bilingual-bicultural approach. However, in South Africa deaf children still face significant obstacles in schools. It seems as if even in the light of evidence of recent research indicating successful ways in which to educate deaf children, many educators still maintain the same (oral) mind-set and even if sign language is used in these schools, it is not used as the most important method of communication and instruction (Parkin, 2010:492; Theunissen, 2011:44).

- **The Bilingual-Bicultural approach to education**

In the bilingual-bicultural (Bi-Bi) approach to education, sign language and the spoken or written language is respected and these are treated as two languages and their accompanying cultures as two cultures, and therefore kept separate in use as well as in the curriculum. Sign language is valued as the first language of Deaf pupils and the use of sign language is taught as the primary language of communication and classroom instruction (DeafSA, 2006:33; DeafSA, 2011:3; Lane *et al.*, 1996:293; Napier *et al.*, 2007:86; NCTSN, 2006:23; Schirmer, 2001:199; Störbeck, 2011:391).

As most deaf children are born to hearing parents, the majority of these children do not grow up with natural access to their first language and neither do they learn their second language in a natural way (Störbeck, 2011:391), depending on family choice.

The aim of bilingual-bicultural education is to utilize the assets of Deaf children (what they have and what they can do) in order for the Deaf child to develop proper linguistic skills in his first language in a natural way. Therefore this approach advocates early sign language acquisition. Part of the aim of the bilingual-bicultural approach is the belief that when children have a good command of sign language and have gained general knowledge through sign language it will serve as a point of reference in the acquisition of a written language. The written language (usually the language of the hearing parents) is then introduced later as the second or first additional language and acquired through the written form (by reading and writing) (Aarons & Akach, 2002:161; DeafSA, 2011:6:3; Gravel & O’Gara, 2003:248; NCTSN, 2006:69:23; Störbeck, 2011:390). However, various bilingual-bicultural options exist and some of these options would introduce both sign language and written language at the same time. Lane *et al.* (1996:297) elaborate on the implications of the bilingual-bicultural approach to education when stating that subject content is taught and understood better via sign language because it will impart skills and background knowledge which will facilitate learning written language. When children can communicate in both a written and a visual language, they are also able to experience both the hearing culture and Deaf culture (Gravel & O’Gara, 2003:248; Störbeck, 2011:392).

For schools in the South African context that have adopted this approach, this approach implies that SASL is recognized as the first language and written English, Afrikaans or any other of the official languages are introduced as second languages (DeafSA, 2006:33). For this approach to be seen as fully implemented the implication would be that all assessment, tests and exams (except assessment of written language) in all subjects could be done via SASL (DeafSA, 2006:33). According to those in support of the visual mode of communication and instruction, Deaf people themselves are the best teachers of deaf

children (Störbeck, 2011:390). The bilingual-bicultural approach is yet to be achieved practically in South Africa partially due to a lack of teachers of the deaf who are adequately fluent in sign language and who are equipped to teach via SASL (DeafSA, 2006:32; Störbeck, 2011:390).

- **Principles of Bilingual-Bicultural education of hearing children applicable to Bilingual-Bicultural education of deaf children**

The basic principles of bilingual-bicultural education of deaf children are similar in numerous ways to the bilingual-bicultural education of hearing children. The similar principles as concisely summarised by Lane *et al.* (1996:305) include that:

- The language of the deaf/hearing child is respected;
- cultural information is incorporated in instruction;
- the language of the hearing/deaf child is employed to increase comprehension of content material;
- the intricacy and metalinguistic understanding of the language of the deaf/hearing child are increased;
- ways of transference from one language to another are developed in order to gain information;
- a strong metalinguistic awareness of the second language as well as its application in various circumstances is developed.

Not all the principles of bilingual-bicultural education in general can be transferred to the education of Deaf children. For one, in bilingual-bicultural education of the Deaf, the two languages are separate and one language is visual and the other written (with a spoken optional, component) (Störbeck, 2011:391). there are many different models of how bilingual bicultural education could be implemented, exist, the goal of one of these models is for pupils to go from using their native language all the time to gradually transition to using English all the time. This is not the goal with bilingual-bicultural education of the Deaf; however, since the aim is to maintain sign language as the pupils' first language throughout their education (Lane *et al.*, 1996:306).

For hearing parents who desire to adopt this approach to communication and to facilitate the bilingual education of their child, making contact with the local Deaf community will provide opportunities to regularly interact with Deaf individuals and in this way the family can become familiar with Deaf culture and learn sign language. When following this approach,

the ideal is for parents to be fluent in sign language in order for sign language to be used consistently for all communication at home (DeafSA, 2011:6; Gravel & O'Gara, 2003:246; Lane *et al.*, 1996:306; Napier *et al.*, 2007:86). The reality, however, is that the full development of sign language as the first language of the deaf child (in most cases) is hindered by the fact that very few parents are totally fluent in sign language (Störbeck, 2011:390). Yet even if parents are not fluent in sign language it is important to still make use of sign language, since basic sign language is beneficial to both the parent-child relationship and the learning process (DeafSA, 2011:5; Lane *et al.*, 1996:310).

- **Benefits of the Bilingual-Bicultural approach**

According to Sass-Lehrer (2016:7) the bilingual approach has gained support since it has been shown that children who acquire language early acquire a second or third language more easily. Children following the bilingual-bicultural approach also reach a higher literacy level (reading and writing ability) to that of their deaf peers not exposed to this approach (DeafSA, 2011:5). Furthermore, self-expression among these children is more fluent and intelligible. A further implication is that this approach cultivates completely developed individuals with a greater self-esteem (DeafSA, 2011:6; Lane *et al.*, 1996:300). If children are brought up and educated bilingually and biculturally they are equipped from a young age to manage successfully in both the hearing and the Deaf world which would have a knock-on effect on the acquisition of a sense of self-sufficiency and independence (Lane *et al.*, 1996:312).

Thus, this approach provides both the hearing community and the Deaf community with the opportunity to contribute to the educational, social and emotional support of the deaf child.

Since making informed decisions are important. parents need to familiarize themselves with all information about deafness and have a deep understanding of the nature and the needs of their child and the available options in terms of communication, education and finally identity (Felzien & Harrison, 2009:21; Störbeck, 2011:392). It is crucial for parents (and teachers) to adequately comprehend that the deaf nature of the child is different from other hearing children although the deaf child is similar to other children in many ways. If they do not comprehend the nature of deafness their interactions with the deaf child are likely to be grounded in the knowledge and beliefs gained from their hearing experience of life. In effect, they will use this frame of reference to interpret the development of the deaf child and as a result fail in providing the most accessible and effective environment for the child (Gascon-Ramos, 2008:68). The ideal setting, or the least restrictive environment, is an educational environment which is the most suitable for the deaf child's communication and linguistic

needs - an environment therefore in which the development of the child's capacities can be advanced to the greatest extent (Lane *et al.*, 1996:249; NCTSN, 2006:22).

- **Contrasting worlds in conversation**

Broesterhuizen (2008:103) and Burke *et al.* (2011:284) indicate the significance and advantages of a bilingual-bicultural approach to deafness in all spheres where counselling, guidance, treatment and education are provided. The contrast between the medical and cultural approach to deafness is not in essence about which approach is wrong or right, but rather about differences between two totally different worlds (Broesterhuizen, 2008:122). These differences cannot be eliminated and therefore the solution would be to work through the differences in a genuine relationship. The supporters on the sides of both approaches will never truly comprehend the other view and this necessitates conversation in which hearing and deaf views are brought into negotiation. Conversation between the approaches would confirm the uniqueness of each other's otherness and thereby edify each other. Conversation also provides an opportunity to discover the value of the other party and in this way promote respect and acceptance of the other.

3.6.1.4 Impact of deafness on the immediate family

In the preceding pages of this study, much attention was paid to the overall adjustment of hearing parents to deafness in the family. Parents suddenly find themselves in a situation where they have to live up to an array of roles in which they are not only parents and spouses to each other but may also have to fulfil the roles of counsellors, teachers and advocates for their deaf child (Schirmer, 2001:40). Yet it is imperative to realise that it is not only the parents that are affected by deafness when they welcome a deaf child into this world. Family theorists view the immediate family as a system made up of various parts, but that the whole is greater than the sum of the different parts. Deafness has a profound impact on this whole system and families will utilise different coping strategies in their adjustment to the demands and complexities of deafness in an attempt to establish a state of equilibrium of the family system (Feher-Prout, 1996:157). All the members in the immediate family of the deaf child experience various emotions and feel the effects of having a deaf child in their midst (John, 2009:237; Marschark, 2007:19; Schirmer, 2001:41).

After the diagnosis of a deaf child in the family, it often happens that the mother of the deaf child automatically assumes the majority of responsibility of interactions with the deaf child and handles the additional needs of the child. Because her love for her child motivates her, the mother in particular is inclined to invest an enormous amount of her time in her child and

to the person who gathers information about deafness, to take the deaf child to the clinic or hospital and to handle the exchanges with the medical professionals (Lane *et al.*, 1996:39; Marschark, 2007:19). Consequently, it frequently happens that the other children in the family may feel shut out, angry or jealous as a result of receiving less attention than they were used to before this new and often taxing situation (Lane *et al.*, 1996:38; Marschark, 2007:19; Schirmer, 2001:40). The energy required to continue this balancing act among all the children can be a source of further stress for the parents. Schirmer (2001:41) and Raghuraman (2008:26) state that some siblings of children with deafness feel guilty about being hearing and are worried about the possibility of also going deaf, having deaf children of their own one day or having to care for their deaf sibling in the future. Additionally they might not be able to communicate effectively with their sibling, as hearing children can usually do with their siblings.

On the other hand, these hearing siblings of deaf children don't necessarily experience adaptation problems (Raghuraman, 2008:26; Verté *et al.*, 2006:103). Some studies have shown a tendency among hearing siblings of deaf children to be more tolerant of people who differ from them and develop more empathy and understanding for others. These studies also indicate that, compared to their peers, hearing siblings of deaf children exhibit more maturity and patience and are also more responsible, independent and adaptable (Raghuraman, 2008:13; Schirmer, 2001:40).

Each family is different and will opt for various ways of coping with the stress experienced because of deafness. If at all possible, siblings of deaf children should consider joining support groups as these groups can assist them in developing a deeper understanding of all the aspects of their sibling's deafness. The support group may also provide the hearing siblings the opportunity to really open up and share their own unique experiences and feelings (Schirmer, 2001:44; Verté *et al.*, 2006:106).

However, regardless of the coping method chosen by the family, an ultimate aim for both parents and children would be to create and maintain a comfortable and supportive atmosphere within the family home, a balanced atmosphere where every member of the family is involved and cooperates with tolerance and understanding (Marschark, 2007:19). All the members in the family should experience support and know that they have an important place and significant role in the family.

3.6.1.4.1 Parental needs

Deafness is long-term, changes the lives of all the members in the family and also has implications for the parents' careers, the family's finances as well as where the family will reside (Fitzpatrick *et al.*, 2008:41). An empirical study undertaken by Fitzpatrick *et al.* (2008:41) indicates the experience, decisions and specific needs identified by parents with deaf children in particular during the initial stages after learning about the deafness. The majority of the parental needs that emerged from the study are reiterated by a South African study undertaken by John (2009:184) and fall under the themes below.

- **Recommendations based on parental needs in terms of elements of formal support:**
 - More emphasis on access to and mandatory newborn hearing screening tests and services to identify deafness as early as possible;
 - Intervention in terms of timely access to early intervention services and intervention programmes, which will be facilitated by the increased focus on early identification (Fitzpatrick *et al.*, 2008:41; John, 2009:294).;
 - Strong social support in the form of psychological counselling of the parents of deaf children to address the emotional turmoil parents might face is highlighted. The importance of the emotional stability and well-being of parents is emphasised as it has an impact on the development of the deaf child (Jackson, 2011:348; John, 2009:294; Lane *et al.*, 1996:38);
 - Parents experience frustration as a result of perceived fragmented services in terms of the process from diagnosis to intervention. Parents indicated the need to have the different services coordinated and to have one central point of information on deafness. Thus, parents place emphasis on a collaborative team approach to services in guiding parents through the process (Fitzpatrick *et al.*, 2008:42; John, 2009:294);
 - Informational needs. Appropriate information on all the aspects of deafness (including the etiology, types, degrees and prognosis of deafness) is a strong need of parents, especially during the initial stages, but also on a continuous basis. Since parental ignorance related to these important decisions is often evident, parents ought to be properly advised about all the various options and resources specifically in terms of communication, hearing technology and school placement (education) available to their

deaf child (Fitzpatrick *et al.*, 2008:44; John, 2009:295). The probability of long-term adverse consequences that uninformed decisions could have for the development of the deaf child is once again stressed (John, 2009:292);

- Based on the importance of needs, exposure to Deaf Culture and learning sign language could form aspects to include in the informal and formal support of families with deaf children;
- Many parents experience financial strain as a result of the additional expenditure of medical bills, auditory devices and transport costs and the effect that it has on the family's budget. In some reported cases mothers opted to care for their deaf child full-time and therefore had to resign from permanent employment. Financial support in the form of funding is therefore an essential form of support (Fitzpatrick *et al.*, 2008:45; John, 2009:290).

- **Recommendations based on parental needs in terms of informal support**

- Parental support groups are identified by John (2009:293) as a form of informal support that should make up an integral part of support to parents with deaf children as it can be of great practical and psychological benefit. The establishment of a platform where parents can meet and connect with other parents of deaf children fulfils many needs, including an opportunity to share experiences, practical information and resource information. Hearing other parents with similar stories to their own may alleviate the sense of being alone and this support from other parents can become a source of encouragement and hope (Fitzpatrick *et al.*, 2008:44; Jackson, 2011:348; John, 2009:291);
- Support of the greater community. Parents of deaf children experience the majority of the hearing community to still be uninformed and apathetic to deafness. Deaf awareness and a more informed greater community could contribute towards a change in the community's attitudes toward deaf people and create a more supportive, accommodative and considerate community (Calderon & Greenberg, 2003:184; John, 2009:291);
- Establishing contact with the Deaf community could provide families with ample opportunities to widen their perspective and to gain exposure to a culture they were previously unaware of. This can open the door to training in sign language and could form part of the early intervention since the earlier the child and parents are exposed to sign language, the better for the deaf child and the entire family.

- Incorporating the above needs and recommendations in the planning and implementation of parental support will promote the emotional welfare of parents with deaf children as well as create an environment which facilitates the overall well-being of the whole family (John, 2009:293).

3.6.2 The deaf child in a hearing family

Since the majority of deaf children are born to hearing families (THRIVE, 2016:1) only a small percentage of deaf children usually acquire the language, cultural information and a sense of identity from culturally Deaf people. Most other children usually only acquire these aspects when they are exposed to other deaf people and peers either at school or in social settings (Chapel, 2005:23; Ladd, 2010:175; Lane, 2005:304; NCTSN, 2006:27).

3.6.2.1 Development of the deaf child

An abundance of research has shown that deaf children tend to be at a greater risk of social, intellectual, emotional and cognitive difficulties if no form of intervention is received. However, deafness per se is not the reason for this phenomenon (Chapel, 2005:34; John, 2009:50; Meijstad *et al.*, 2009:513; Smith, 2002:16). In a hearing environment, deafness implies that crucial information is hindered from reaching the child. This indirect impact of deafness means that un-accessed information (that hearing children acquire via passive exposure to incidental events and everyday discussions) has far-reaching consequences for all facets of childhood development (Calderon & Greenberg, 2003:178; John, 2009:50), if not identified early and if the necessary intervention does not take place (Störbeck, 2011:388). Additionally Marschark (2007:219) urges for caution to be exercised when considering older literature on deafness as much of this research reflects a long history of misdiagnosis, lack of knowledge as well as an array of skew assumptions about deaf people in general, though some authors (Van Eldik *et al.*, 2004:390) are of the opinion that the average percentage of deaf children who present emotional and behavioural problems, is at least the same average one would find among their hearing peers.

The higher incidences of the abovementioned difficulties can be ascribed to the following factors:

- **Communicational hindrances** in the family and educational setting as well as the absence of incidental learning, which may result in delayed language development as well as other social, emotional and behavioural difficulties (Berk, 2006:367; Chapel, 2005:40). Deaf children in Deaf families' use of language is equal to that of

their hearing peers and they tend to avoid the majority of the above-mentioned difficulties since the quality of the communication between the deaf parents and their child is comparable to the quality of communication between hearing children and their hearing parents (Berk, 2006:367). In order to stress the necessity of an accessible language in the first years of life (Burke *et al.* (2011:279) compare it to the importance of insulin for diabetic children, thus not at all optional.

Regardless of the communication option families opt for, the deaf child in a hearing family will most likely still feel “left out”, generally disconnected from the rest of the family and as if they are missing out on conversation (Gentzel, 2007:19). Gentzel (2007:19) elaborates on this isolation by referring to deaf children’s experiences of family mealtimes. When family members eat together at the dinner table, informal conversation will usually be going on around the deaf child and upon enquiring about the topic of discussion the deaf child will merely receive a brief summary by hearing family members and not be given much detail. Disconnection from the rest of the family is therefore most acutely experienced by some deaf children during mealtimes.

The isolation deaf children experience does not end here, however. Social isolation especially when entering mainstream school is a common theme for deaf children when they become painfully aware that they are “different” and attentive of the “glass wall” that exists between them and their hearing peers (Gentzel, 2007:34; Kurtzer-White & Luterman, 2003:234; McIlroy & Störbeck, 2011:507; NCTSN (2006:36).

Deaf children in hearing families cultivate strategies for coping by developing compensatory mechanisms to hide their deafness (Lane *et al.*, 1996:39; NCTSN, 2006:37). Especially when utilising residual hearing and speech to communicate, children will typically talk non-stop so as to avoid having to listen too much or they may pretend to understand when they really do not, particularly in social and family group settings (NCTSN, 2006:37).

Thus, language and communication hindrances are consistently labelled as the root cause of the higher incident of adversities experienced by deaf children since language is such a crucial component of development (Chapel, 2005:34; Gentzel, 2007:43). The risk factors below are subsequently also related to these higher incidences of adversities.

- **Multiple disabilities** which are more prevalent among deaf individuals than hearing individuals (Chapel, 2005:34);

- The deaf child's continuous exposure to **negative attitudes towards deafness and Deaf people** tend to result in a lower self-esteem which has the knock-on effect of other emotional and behavioural difficulties (Chapel, 2005:34; Gentzel, 2007:36);
- **Maltreatment and sexual abuse** appear to pose a greater risk to deaf and hard of hearing children (THRIVE, 2017:1) which would in turn increase the number of children who would experience these difficulties (Chapel, 2005:34). An investigation launched by Embry (as cited by (NCTSN, 2006:34) at the turn of the century, indicated a correlation between an increased risk of childhood maltreatment and lower quality family communication and attendance at a residential school.

As pointed out in the discussion above, it would not be correct to assert that all deaf children develop developmental difficulties. Resilience (the ability to successfully overcome difficulties or to rise above one's circumstances) can be fostered and promoted in deaf children and mitigate the effects of risk factors (NCTSN, 2006:35). The National Child Traumatic Stress Network (2006:35) claims that the following protective factors could mediate as well as moderate the effects of deafness and actually cultivate resilience in young children:

- early diagnosis of deafness and apt intervention;
- a supporting and caring environment in terms of family, peers and the community;
- social attachment with important others;
- the deaf child's parents' adjustment to deafness;
- the coping of the deaf child's family;
- the nature of the school and community resources; and
- the deaf child's personal characteristics (e.g. self-esteem, self-control and social competence).

3.6.2.2 Identity development of deaf individuals

The Deaf community, since it shares among others a collective name, language, history, feeling of community, norms, values, customs and knowledge, is an cultural and linguistic minority group (Theunissen, 2011:35). Therefore various authors (Glickman, 1993:62; NCTSN, 2006:27; Singleton & Tittle, 2000:224; Theunissen, 2011:35) compare the identity development of Deaf people to the identity development of members of other minority groups. However, Singleton and Tittle (2000:224) call for this characterisation of the Deaf community to be done with caution since the Deaf community differs from other ordinary

linguistic minority groups in the sense that the linguistic community is reborn with each generation as Deaf individuals are usually children and parents of hearing individuals. Additionally, other linguistic minority groups have boundless opportunities to learn the dominant oral language of the community whereas the deaf individual's access to the dominant oral language is limited.

In his dissertation Glickman (1993:62-100) defines the psychological processes underlying cultural identity development and presents a theory of Deaf identity development to indicate how deaf individuals develop culturally Deaf identities. Glickman's theory is still supported and maintained by many authors (Burke *et al.*, 2011:28; NCTSN, 2006:27; Theunissen, 2011:67) in recent and current research.

Based on his deaf identity development theory, Glickman (1993:117) additionally developed an instrument, the Deaf Identity Development Scale (DIDS), designed to measure and assess Deaf cultural identity. The DIDS has since been revised and results of this revised instrument affirm the existence of the following four relatively independent deaf identities or stages of identity development, as initially proposed by Glickman in 1993 (NCTSN, 2006:29; Theunissen, 2011:68).

Glickman (1993:62) describes the identity development of deaf individuals as consisting of four stages:

- **The culturally hearing stage** is specifically relevant to deafened individuals. This stage describes the stage where the deaf individual identifies with the majority hearing culture and also uses hearing norms as his or her reference point. The individual is in a state of isolation from the deaf minority community. During this stage, it is typical for the deaf individual to maintain a pathological attitude towards deafness and for his view of the Deaf community to be a stereotypical understanding due to being uninformed (Burke *et al.*, 2011:281; Glickman, 1993:68-74; NCTSN, 2006:27; Theunissen, 2011:69). Once again emphasis is therefore on the influence that parental acceptance has on the deaf child's self-esteem and self-concept;
- **The culturally marginal stage** is the second stage of identity development for deafened individuals, but forms the first stage of the majority of deaf children raised in hearing families. The deaf individual's isolation is interrupted as he discovers oppression and experiences marginalisation in both the dominant hearing culture and among deaf people. The culturally marginal identity is reinforced by oralism and mainstreaming programmes (Glickman, 1993:92). The deaf individual might still view deafness as pathological and therefore his view of the Deaf community might

alternate between positive and negative as he switches between the two cultures (NCTSN, 2006:27). In the absence of both a comfortable oral language and insufficient knowledge of a sign language communication is challenging. It follows then that the deaf individual would additionally find it difficult to establish and maintain intimate relationships and experience confusion regarding his or her identity (Glickman, 1993:92; Theunissen, 2011:70).

- The deaf individual then enters **a stage of immersion** where he immerses himself in the minority community (the Deaf world) and enthusiastically embraces all aspects thereof. In this stage the deaf individual has a cultural view of Deafness. Additionally, he maintains a positive, but non-reflective view of the Deaf community and feelings of generalised anger directed at hearing people is evident. Anything pertaining to the larger society (hearing culture) is eschewed (Burke *et al.*, 2011:281; Glickman, 1993:94, 2006:27). For deafened people who were previously culturally hearing, this stage is where they experience an “encounter” of realising what the social meaning of Deafness entails. However, for marginally deaf individuals who came from an almost language-less state, this stage is less about rejecting their previous identity and more about the establishment of an original identity (Glickman, 1993:94). Glickman (1993:94) characterises the emotional theme of the immersion stage as a “falling in love with Deafness”. In the final part of this the deaf individual is less concerned with criticising hearing people and more focused on supporting other Deaf individuals (Glickman, 1993:262:100).
- In the final, **bicultural stage** of Deaf identity development, the individual feels an intense connection with other Deaf people and expands his idea of what it truly means to belong to the minority (Deaf) community. Having the Deaf world as his point of reference, the individual affirms deafness as a cultural difference. In this stage he recognizes the strengths and weaknesses of both Deaf and hearing people and has a positive, integrated and very personal view of the Deaf community (Glickman, 1993:100; NCTSN, 2006:27). The individual enters the stage of biculturalism, where he appreciates and respects both sign language and the spoken language of the majority hearing community. He also attempts to find a viable way of interacting in both the Deaf and the hearing community and to feel, if not at home, at least comfortable in both worlds (Burke *et al.*, 2011:28; Glickman, 1993:104; NCTSN, 2006:27).

Earlier in this chapter (3.5.1) the concept of a bicultural DeaF identity as suggested by McIlroy and Störbeck (2011:494–511) was discussed. It would be relevant to once again refer to it at this point. The development of a bicultural DeaF identity ought to be considered in addition to Glickman's fourth bicultural stage. Bicultural DeaF identity differs from bicultural Deaf identity in the sense that it moves beyond concepts of deafness as either a disability or a cultural difference. DeaF individuals are continuously in dialogue with both themselves as well as their worlds. Identifying with a Bicultural DeaF identity also implies a shift away from the Deaf community's traditional rejection of dialogue with hearing or deaf persons, towards a preparedness to edify connections and build bridges and bonds with the hearing community (McIlroy & Störbeck, 2011:509).

3.6.2.3 Identity development of hard-of-hearing individuals

The process of identity development of hard-of-hearing children starts when their deafness is identified. Because these children are commended by their peers at school for appearing "hearing" they may view their own deafness as a negative part of who they are and a part that ought to be hidden (NCTSN, 2006:28). Hard-of-hearing children try to function between the two worlds of the deaf and the hearing. Although one on one interaction with hearing peers is possible for these children, interaction is hampered in group settings. Hard-of-hearing children also do not share a common language with deaf children and as adolescents would most probably not want to identify with a minority group that is viewed by the majority culture as 'disabled'. It follows then that hard-of-hearing children and adolescents may feel isolated from peer groups since they do not have a peer group to identify with. As adults they will most probably opt for career choices which will not demand a lot of spoken interaction and unlike deaf adults, they will most probably marry hearing spouses (NCTSN, 2006:28).

3.6.2.4 Factors influencing Deaf identity development

Throughout the current chapter of this study, various themes related to deafness have been described and discussed extensively. These themes (e.g., models of deafness, method of communication and education) surface again when considering the factors that contribute to and influence a deaf child's self-esteem and identity formation. The National Child Traumatic Stress Network (2006:30) confirms these important influences on Deaf Identity Development in the diagram below:

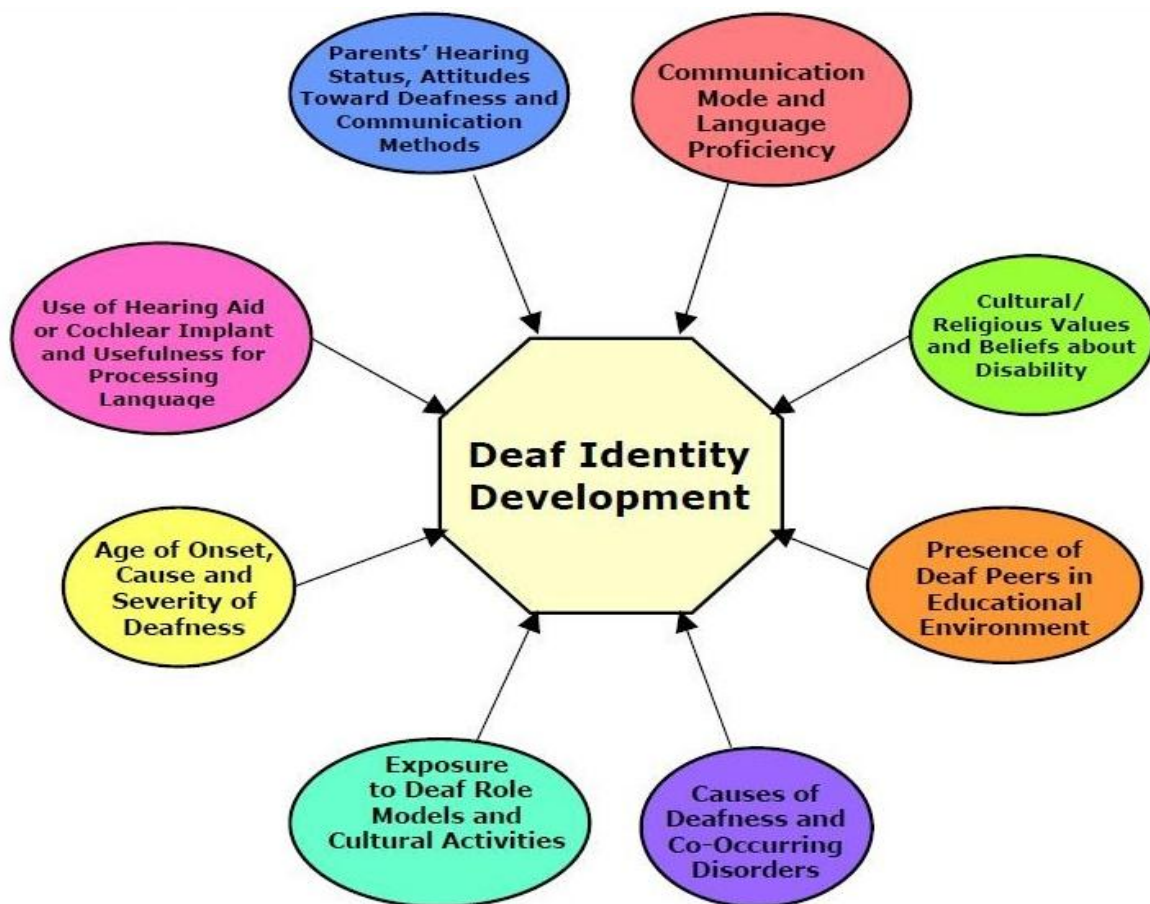


Figure 3-7: Factors influencing Deaf identity development (NCTSN, 2006:30)

3.7 IMPORTANCE OF EARLY IDENTIFICATION AND EFFECTIVE INTERVENTION

Around the world, universal newborn hearing screening (UNHS) by means of oto-acoustic emission (OAE) is the touchstone for hearing screening (Butler, 2012:316). If necessary, follow-up testing through brainstem audiometry is done to confirm deafness, the type of deafness and the level of deafness (Clum & Felzien, 2009:10; Murphy, 2009:15). In South Africa the majority of newborn babies are not tested (Swanepoel *et al.*, 2009:2). About one per cent of infants are tested in public hospitals and in private hospitals newborn screening is voluntary and only around 20%. This is in sharp contrast to for instance the USA where about 94 per cent of newborns are screened and as many as 64 per cent enter early intervention programmes (Butler, 2012:316).

The objective of the UNHS is for all children to be screened by three months and for timely implementation of communication strategies by six months of age (Butler, 2012:316; Hall & Mueller, 1998:439; Störbeck & Calvert-Evers, 2008:314). Early identification and intervention enable the deaf child to develop age-appropriate linguistic development (Störbeck & Calvert-

Evers, 2008:314), which in turn has a knock-on effect on all other facets of childhood development. It follows therefore that early identification of deafness alone, is not sufficient for newborn hearing screening to attain its goal. Subsequent early intervention is crucial in order to ensure optimal outcomes for children with deafness and their families (Störbeck & Calvert-Evers, 2008:315; Swanepoel *et al.*, 2009:1).

Ideal early intervention programmes are family-centred and consist of a detailed explanation and exploration of the various options and resources in terms of communication and also to then assist the whole family in the implementation of the selected option. Emphasis is placed on parental support and on the promotion of language development, parent-child communication and social skills (Felzien & Harrison, 2009:18; JCIH, 2007:900; Miller, 2012:1; Moeller *et al.*, 2013:430).

In South Africa, limited data is available on the status of early identification services for newborn deafness. Additionally, the focus used to be more on screening and diagnosis than on early intervention services (Swanepoel *et al.*, 2009:3). Early intervention programmes were not always accessible to the majority of families due to a lack awareness, services and also because transport to and from centre-based programmes is limited (Störbeck & Pittman, 2008:37). In 2006, however, the Wits Centre of Deaf Studies in Gauteng launched the HI-HOPES (home intervention – hearing and language opportunities parent education services) programme in the Gauteng Province (Störbeck & Pittman, 2008:37). The HI-HOPES programme encourages an unbiased, multi-disciplinary approach and strives toward serving and supporting every deaf or hard-of-hearing child and his or her family (Störbeck & Pittman, 2008:37). The HI-HOPES programme has since expanded its services to some of the other provinces (Western Cape, KwaZulu-Natal, Limpopo and Mpumalanga) in South Africa as well (Swanepoel *et al.*, 2009:3).

Intervention soon after deafness is diagnosed means that parents are assisted through the process of grief or adjustment and prepared for the journey ahead of them as parents of a child with deafness.

3.8 SPIRITUALITY AND DEAFNESS

Literature on the spirituality of deaf people in South Africa is scarce. A study done by Smith (2010:514) assumes that the religious demographic profile of deaf South Africans would differ from that of the hearing populations since communicational barriers complicate full participation in many denominations. Although some denominations and specific churches

do attempt to accommodate deaf people by utilizing sign language interpreters and various forms of visual communication, limitations to deaf people's full participation remain.

Where the doctrine of a denomination might be the determining factor in the choice of hearing individuals it tends to play a secondary role to Deaf people, whose choice would primarily be determined by the practising of Deaf culture and the use of sign language as the medium of communication and secondary to that only by the doctrine of the denomination (Smit, 2010:515).

Some of the features of Deaf culture that appear relevant to the spirituality of Deaf culture include collectivism (inclusion of all Deaf people, regardless of race, gender or nationality), the use of sign language as their first language and loyalty.

3.8.1 Challenges of Deaf pastoral ministry

Although many deaf people in South Africa have been involved in religion for decades, this has not always been the case. In the past, less deaf people were as involved in religion and communities attributed this lack of involvement to deaf people's problem with oral language acquisition. Broesterhuizen (2003:3) explains that it is precisely because of this lack of understanding of deafness that the spiritual challenges of deaf involvement were generally treated as a linguistic issue. Augustine's well-known quote reflects this hearing perspective of deafness (Broesterhuizen, 2003:3; Ciuba, 2012:12): "This defect (deafness) is a serious obstacle for reception of the truths of faith, since. As the Apostle (Paul) said, "Fides est ex auditu" (literally: faith comes from hearing)".

The following words of Jesus Christ in the gospel of Matthew aptly apply to the need in terms of Deaf ministry: "*The harvest is plentiful, but the labourers are few*" (Matthew 9:37).

The central issues in terms of the accessibility of the gospel to deaf people and the core challenges of Deaf pastoral ministry include (Broesterhuizen, 2003:3, 2005:307):

- a) The position of people with deafness as outsiders in the hearing church.** Deaf people run the risk of being marginalized in the hearing society and also the church specifically if they are very few in number and do not acquire spoken language. The lack of integration into the community of believers and their isolation from communication, results in the deaf remaining unreached by much of the information related to church. To many deaf people the liturgy in church is lifeless, static and distant and not a place where they enter into dialogue with God and fellow congregants (Broesterhuizen, 2005:308). Thus, the church ought to reach the deaf within their own life context.

b) Exposure to the Bible and religious material in their first language. The written Bible is not always as accessible to all the deaf as is often believed. The concepts and vocabulary in the Bible can be very abstract and difficult to comprehend, even for those in whose first language it is written. Add to that the fact that for the majority of Deaf individuals, any written language is their secondary language and the challenge it implies becomes more apparent (Lombaard & Naudé, 2007:143). Attempts to overcome this obstacle include improving language development and translating religious texts to simple written language (Broesterhuizen, 2003:3). In South Africa the *Afrikaanse Bybel vir Dowes* appeared as a written bible for the deaf. The aim of this project was to create an Afrikaans bible translation for culturally Deaf people who have acquired a limited degree of spoken language ability (Lombaard & Naudé, 2007:144). Although well-intended, the problem remains that the printed Bible translations will never be fully accessible to all deaf people since the majority of Deaf people use sign language as their first language and that sign language, as a visual language, has no written language equivalent (Lombaard & Naudé, 2007:145).

In terms of development on this front, a project called The South African Sign Language Bible Translation Project is in the process of translating the written Bible into visual South African Sign Language. The initial aim is to make 110 biblical narratives available in video format. The long-term aim is to have the whole Bible translated into SASL and thereby providing the South African Deaf community with full accessibility to the Bible in the language of their hearts (Hands With Words, 2013:2).

c) Differences in world-view. The tension between the pathological view of deafness as a disability and cultural view of deafness as a positive way of being different often causes a great challenge to deaf ministry. As discussed earlier in this chapter, many deaf people don't attribute the challenges of being deaf to deafness itself, but mainly to the oppressive way in which the hearing society treats deafness, being by the subtleties of marginalization (Broesterhuizen, 2003:5, 2005:312).

“This (deafness) is only an inconvenience insofar as it interferes with communication with some outsiders. Rather, deaf people celebrate what they have: their language, their eyes, their hands, their friends, their organizations, their art forms, their ideas and much more. They want understanding, not sympathy; they look for acceptance, not for repair.” (Broesterhuizen, 2007:2)

Deaf people often experience the Scriptural narratives in the Christian tradition to reflect many aspects of a hearing worldview. The remnants of a past in which “disability” and sickness as linked to original sin (the healing stories and deafness depicted as an

unwillingness to listen) or at least to being in need of salvation, makes the Christian faith inaccessible for Deaf people, specifically since Deaf culture provides a worldview, however secular, which does not feel the need of metaphysics and which conveys the message that it is okay to be deaf. For many Deaf people, this Deaf cultural worldview, has substituted religion (Broesterhuizen, 2005:308, 2007:5). The crucial conclusion that Broesterhuizen (2005:315) draws is that a church with a deep-rooted pathological view of deafness does not have a message for Deaf people.

- d) The role of Deaf people in the edification of the church community.** Because of the history of deafness as a disability, deaf lay people never really played a big role in the church, especially not in terms of leadership. Deaf congregants, however, in the Christian view, possess the same functions of priest, prophet and king and therefore Deaf ministry by deaf people themselves needs to be promoted by empowering deaf lay persons and establishing a religious Deaf community (Broesterhuizen, 2005:317; Smit, 2010:514). According to Broesterhuizen (2003:4) Deaf people are often heard to say the following in terms of not having the opportunity to give their own contribution: “So many things were done for us, but all things were done for us and nothing was done with us.”

In 2006, the National Institute for the Deaf created the first opportunity for Christian Deaf people in South Africa to undergo training in theology and become ministers and pastors of the Deaf by establishing the Deaf Christian Ministry Africa College. The idea is that Deaf students would return to Deaf communities after completing their training, for Deaf-to-Deaf ministry. This training is supported by various Christian denominations in South Africa (Smit, 2010:516).

- e) Sign language as a religious language.** The importance of a sign language lexicon for religious concepts and the translation of that message have already been discussed (see b) above). However, much more is needed to facilitate the comprehension of the gospel. The central point of the Word of God is not about the language (modality) in which it is conveyed, but the correct content (meaning) of the message. For example, even if signs are decided upon for religious concepts, like “grace”, the signs do not automatically acquire meaning. The true meaning of grace would be clear only if it expresses something that the receiver has existentially lived through and is part of his/her experiential knowledge. Religious concepts should not be abstract but be integrated into everyday life (Broesterhuizen, 2005:324). Many deaf people might go through the rituals and motions without truly experiencing the meaning and significance thereof (Smit, 2010:515).

A Christian community of Deaf people where emphasis is on a pastoral ministry of belonging, of working with a community where real dialogue, sharing and reciprocated respect transpires, would address the issue of the lack of a living Christian communion with deaf people as well as promote sign language as a religious language. Therefore the church can reach the Deaf community by accepting and appreciating the language of the Deaf as their choice in terms of proclamation of faith, religious communication and liturgy (Broesterhuizen, 2005:325). The picture below depicts George Veditz, lecturing in 1913 on the preservation and respect for sign language.



Figure 3-8: George Veditz lecturing on sign language (Padden, 2004:245)

In the video Veditz proclaims: “I hope that you all will love and guard our beautiful sign language as the noblest gift God has given deaf people” (Padden, 2004:245).

- f) Deafness as a context rather than an obstacle.** Deafness is neither a curse nor an obstacle for the development of faith but should rather be understood as a context in which faith development as well as theological reflection occurs (Broesterhuizen, 2005:325). This necessitates the gospel to be acculturated or indigenized into Deaf culture.

3.8.2 Spiritual development of the deaf child

Most children from a very young age, seem to have a natural spirituality, since they tend to express as sense of wonder and fascination and also since they tend to instinctively be aware of something greater than the mundane things (Zhang, 2012:43).

The choice of communication and education can influence the spiritual development of the deaf child. The deaf child who is expected to use exclusive oral communicational methods is

severely taxed. Both hearing and deaf children need friendship and a sense of belonging to a community in order to establish a strong identity and self-esteem. When a deaf child is not fully immersed in his/her hearing parents' culture the extent to which the deaf child will share his/her parents' religion is affected, probably contributing greatly to the reason an estimated less than two per cent of the world's deaf population have been reached by the Gospel (Anonymous, 2012; Newell, 2009).

The additional knock-on effect of not having a comfortable language to communicate in is detrimental in terms of the development of equanimity, internal harmony, love for both others and self, and the kind of honesty that allows for spiritual development (Burke *et al.*, 2011:286). God utilises the family as a central vehicle in the transference of the covenantal promises and demands (Larney, 2009:15) and consequently effective communication in the family is vitally important.

Weber (2010:4:46) warns that the consequence inaccessibility has on the spiritual lives of deaf children is that they might not attend church as adults since deaf children from an early age may experience church as being incomprehensible and as something that hearing people do. Characteristically, deaf children in hearing families are not always talked to about faith as much as hearing children in hearing families are because of the barrier in communication. Additionally, deaf children tend to think of God as hearing and since the adults in their lives are usually not fluent in sign language, this makes it incredibly difficult for deaf children to have a perspective of God as accessible to them (Weber, 2010:48).

It therefore seems clear that, as Newport and Meier (as quoted by Burke, Kushalnagar, Mathur, Napoli, Rathmann & Vangilder, 2011:275) state, when the language needs of deaf children are not met, it can profoundly harm their psychosocial health and spiritual development .

3.9 PASTORAL CARE AND COUNSELLING OF FAMILIES WITH DEAF CHILDREN

3.9.1 The void in pastoral care and counselling of families with deaf children

When parents learn about their child's deafness, the medical professionals are typically first at providing the family with advice, information and assistance, as discussed in 3.6.1 of this chapter. While the focus of the multi-disciplinary team of medical professionals is on explaining all facets of deafness, forms of communication and options in terms of education to parents and families, little attention is usually paid to the spiritual and emotional concerns of the parents and immediate family (Burke *et al.*, 2011:273). In the previous chapter it became clear that in families where religion and spirituality play a significant role, families

also turn to their religious community during this often challenging time on their life (Burke *et al.*, 2011:273). Interviews done in the second chapter confirmed the problem statement of this study (1.3.3) indicating a deficit of average, predominantly hearing, churches in South Africa which are equipped and focused on pastorally assisting families with deaf children, educating communities about the deaf, Deaf culture and South African Sign Language, bringing the Gospel to the deaf, accommodating deaf brothers and sisters, and pastorally caring for and guide the deaf children on their spiritual journey. Burke *et al.* (2011:273) attribute this to the fact that pastoral practitioners themselves are in need of such information.

Burke *et al.* (2011:274) elaborate on this deficit and further also focus attention on the fact that, as with the majority hearing culture, pastoral practitioners are often ignorant of the existence of Deaf culture. Turning to the internet for information on all aspects of deafness, will not be sufficient in equipping the pastoral practitioner with the necessary information in order to guide the family to understand and believe that their child can truly flourish in this world as a Deaf person (Burke *et al.*, 2011:275), since the internet contains an incredibly vast array of (not always accurate or relevant) information. If the pastoral practitioner is unfamiliar with deafness and unaware of the different views and attitudes toward deafness, hearing technology, Deaf culture, sign language, communicational options and educational options might be just as overwhelming to the pastoral practitioner as it is initially to parents of deaf children.

Since the majority of online resources are secular or not of a pastoral, spiritual or religious nature, pastoral practitioners often turn to books like *Christian Counseling* (Collins, 2007), *Competent Christian Counselling* (Clinton & Ohlschlager, 2013) and *Clinical Handbook of Pastoral Counseling* (Wicks *et al.*, 1993) in their search for apt advice and guidance in terms of specific counselling situations. When one looks up “deafness” in the above-mentioned books, there are no entries for “deafness”. Collins (2007:782) refers to deafness under “hearing impaired” in the discussion on “people with physical disabilities”, which contributes to the generalised view of deafness as a handicap or a disability from the medical perspective instead of understanding deafness as a culturally-linguistic difference. It follows then that deaf people in general have been and still continue to be treated as “objects of care” rather than “subjects of care” (Smit, 2010:514).

Pastoral practitioners generally do not receive training during their studies in dealing with families with deaf children (cf. Appendix 6). There also seems to be very little written in terms of the church’s responsibility towards families with deaf children and the Christian view of deafness.

The pastoral practitioner who is faced with the hearing family welcoming a deaf child into this world, will therefore most likely follow a similar approach to guidance and counselling that he would have followed in the case of a family with a physically or mentally disabled child or a child who differs from the norms of society. Or he might attempt to try to incorporate the information he has gathered about this unfamiliar topic of deafness into his pastoral approach.

3.9.2 Recommendations in terms of the role, competency and attitude of practitioners working with families with deaf children

The pastoral practitioner's role is not only to provide support but also to develop cultural competency in the guidance of families with deaf children, which implies (Burke *et al.*, 2011: 286; NCTSN, 2006:42; Theunissen, 2011:117):

- An awareness of his/her own assumptions about culturally different people and a sensitivity not to make premature conclusions about their status;
- An effort to understand the view of people who are culturally different and therefore gaining specific knowledge about the culture and understanding socio-political influences on that group;
- Intentionally developing and applying intervention strategies which are relevant and sensitive when working with culturally different people.

Although the above might seem only applicable to pastoral practitioners working with deaf counselees, it remains applicable in the pastoral care and guidance of families with deaf children since the pastoral practitioner plays a pivotal role in introducing the family to a culture they've probably only recently learned of, were they to choose to follow this route. Additionally, the spiritual needs of the deaf child (and other deaf people) in the congregation will necessitate the pastoral practitioner to not only be informed about sign language and Deaf culture, but to also become skilled in sign language in order to be competent to minister to Deaf people². If, however, families opt to follow the oral route, the pastoral practitioner will also have a large role to in the pastoral guidance of these families through their grief and challenges they might face.

² This study focuses mainly on families with newly-diagnosed deaf children who are probably not exposed to sign language yet. In the case of pastoral counselling and pastoral care involving deaf individuals who do use sign language, however, the pastoral practitioner would employ the assistance of a sign language interpreter. This also holds true for worship services and other forms of ministry to the deaf.

Hence, the pastoral practitioner himself must be well informed about all aspects of deafness and the models of deafness, as well as the diversity and complexities relating to deaf children and their families. Gaining knowledge of the Deaf community and Deaf Culture (3.4) is vital and provides an opportunity to gain insight into the intricacies thereof (Frankie, 2008:8; NCTSN, 2006:42).

Pastoral practitioners have a very specific role to play in terms of paying attention to the spiritual dimension of the family's life. They are to guide the parents through the process of adjusting to deafness, to provide perspectives relating to the complicated and important decisions families must make in order to ensure the optimal development of the deaf child and give the family hope for their child's potential-filled future.

In addition, some authors (Broesterhuizen, 2003:6; Weber, 2010:48) feel that the pastor should also be equipped and able to minister to the deaf child and other deaf congregants and be willing to bring the gospel to them in the format, language and way in which they understand and in which they can cultivate a relationship with God.

3.9.3 Important issues related to deafness to be addressed during guidance of families with deaf children

From the research many important issues are highlighted as important elements to be included in any programme aimed at providing helpful material to families with deaf children. Families should be well informed about:

- Deafness and the classification of deafness;
- The effect of deafness on children and their families;
- The importance of and development of early language acquisition;
- The different models of deafness;
- Deaf Culture and sign language;
- Language and educational options; and
- Amplification.

Subsequent to the above important information, the following are important aspects to focus on in providing guidance:

- Determining the level of hearing loss;

- emphasis on early identification and intervention;
- abandoning myths about deafness;
- stressing the importance of early access to an accessible language since it is essential to the deaf child's general well-being (including academic and personal matters);
- parental acceptance as indispensable to the welfare of the deaf child;
- the promotion of the far-reaching cognitive and social benefits of a bilingual-bicultural, or multilingual-multicultural approach.

3.10 SUMMARY AND CONCLUSION

In this chapter consideration was given to the interpretative task according to the practical theological model of Richard Osmer by conducting a literature study of various interrelated sciences in the search for insight and wisdom.

Deafness can be classified by the level of deafness, types of deafness, age of onset of deafness and the aetiology of deafness. Perspectives of deafness mainly resort under the medical (pathological) model of deafness as a disability and the socio-cultural model of deafness where deafness is understood as a cultural and linguistic difference. Sign language plays a very important role in Deaf culture and binds those Deaf communities which use sign language together.

Upon learning that their child is deaf, hearing parents typically go through emotional stages of grief and mourning and are also faced with very important decisions to be made in terms of hearing technology, communication and education among others. The assistance medical professionals provide to families faced with deafness, is highly determined by their personal view of and attitude towards deafness and must therefore be recognised. Parents and professionals can play a very significant role in the cultivation of the deaf child's social and emotional competency and should therefore always address the needs of the child directly and make decisions that are evaluated to be best for the deaf child.

Deafness as such does not affect emotional adjustment and social development, but the indirect impact of deafness does. The tremendous language barriers that could exist and subsequent lack of access to information cannot be overemphasised in terms of the hindrance it causes on all levels of development of the deaf child. Consequently, rather than a specific kind of intervention, early identification of deafness, followed by early intervention and full access to an accessible language determine the outcome of the communication

abilities and overall development of the deaf child. Parental acceptance and the quality of the parent-child relationship are crucial to the well-being of the deaf child. Thus, if parents and professionals were to make a paradigm shift from understanding deafness not as a sensory loss but as a condition of gaining a culture³ (keeping in mind that other choices also exist), the family would be empowered to progress from grieving for the loss of their envisioned future for their child to a hopeful future in which their child can flourish as a normal deaf individual and uniquely contribute to this world.

Deaf ministry in a hearing community of believers is scarce and even where it does exist, it remains challenging. Lack of awareness and understanding of the very different worlds from which hearing and deaf people experience and view their lives form part of the core of these challenges. In addition, there appears to be a deficit in terms of spiritual and religious resources on deafness readily available to pastoral practitioners in order to equip them to effectively and responsibly provide pastoral care and counselling to families with deaf children.

There is a need for the development of a practical theological model providing resources on the pastoral care and counselling of families with deaf children, to ensure optimal pastoral care and counselling of these families and optimal development of deaf children.

In order to act with sagely wisdom, the insights of this interpretive inquiry should be “priestly listened to” and assessed in combination with the insights of the empirical inquiry, keeping in mind that it does not yet provide complete wise judgment.

³ Although various approaches to deafness exist, the focus of this particular study doesn't allow for room to address all approaches elaborately.

CHAPTER 4

PASTORAL CARE AND COUNSELLING OF FAMILIES WITH DEAF CHILDREN: THE NORMATIVE TASK OF PROPHETIC DISCERNMENT

4.1 INTRODUCTION

In chapter 3 of this study, attention was paid to the aspects and impact of deafness in answering the question of *“Why is this going on?”* This chapter seeks answers to the question “what are the normative and ethical perspectives that Scripture provides for the pastoral care and counselling of families with deaf children?” thereby responding to Osmer’s (2008:245) normative task that asks *“What ought to be going on?”*.

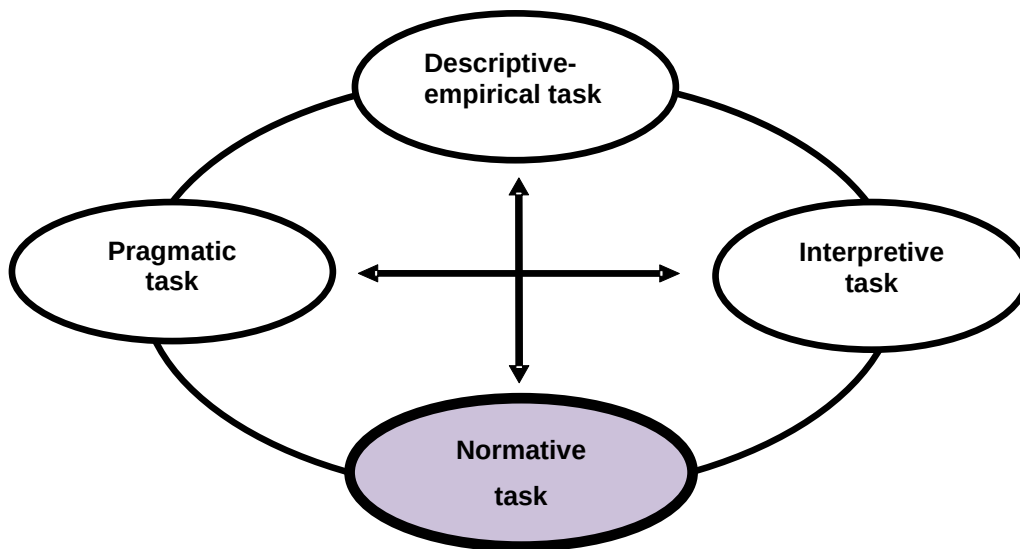


Figure 4-1: The normative task (Osmer, 2008:11)

4.2 SCRIPTURE AS REVELATION SOURCE

With a view to providing guidelines to pastoral practitioners from the Reformed tradition, this current study is done from a Reformed theological perspective which holds that Scripture is the authoritative revelation of God; that it is sufficient and clear and contains everything necessary for the understanding of the way to redemption and the renewal of the sinner (Vorster, 2014:60). The premise of this research is therefore that the Word of God bears overall authority and that it can provide the above-mentioned norms (4.1). The evidence for the authority can be categorised as both internal and external (Zukeran, 2003:2).

The internal evidence for the authority of Scripture as it can be found in the Bible itself includes:

- Self-proclamation as is clear in 2 Timothy 3:16-17: *“All Scripture is God-breathed and is useful for teaching, rebuking, correcting and training in righteousness, so that the servant of God may be thoroughly equipped for every good work.”*
- Confirmation by the Holy Spirit that Scripture is indeed the Word of God, can be found in John 16:13: *“But when he, the Spirit of truth, comes, he will guide you into all the truth. He will not speak on his own; he will speak only what he hears, and he will tell you what is yet to come.”*
- Its ability to bring about change, specifically to effect change in lives, as can be seen in Hebrews 4:12: *“For the word of God is alive and active. Sharper than any double-edged sword, it penetrates even to dividing soul and spirit, joints and marrow; it judges the thoughts and attitudes of the heart.”*
- The complete unity of the Bible. The Bible was written over a period of more than two thousand years by various authors, in different places, in different languages, for different reasons and covers many controversial topics (Chaffey, 2011:1; Zukeran, 2003:2). Remarkable, though, despite contrasting historical facts and all the factors mentioned above, the Bible displays internal consistency and one common theme runs through the whole Bible like a golden thread: God’s love for His creation and His salvation of mankind. The Bible therefore forms a theological unit containing the continuous unfolding of the revelation of God. This continuous revelation of God is independent of chronological history (Vorster, 2014:65).

The external evidence of the authority of Scripture according to Zukeran (2003:2) is the remarkable survival of the Bible, the confirmation of the Bible by archaeological findings and biblical prophecies that were fulfilled.

For the purposes of this study, therefore, the point of departure is that the Bible is a book of such precision and divine authority that a worldview can be built on it and pastoral guidelines can be developed from it. The researcher humbly seeks to understand God’s revelation and emphasizes that first and foremost it is about the honour and glory of God.

4.3 OBJECTIVE

The primary objective of this chapter is to determine the normative and ethical perspectives Scripture provides by actively seeking God's guidance regarding the desired situation of pastoral care and counselling of families with deaf children. Osmer (2008:4) explains this task as using theological concepts to interpret particular episodes, situations and contexts and creating ethical norms to guide our responses as well as to learn from "good practice". However, as (Smith, 2010:112) rightfully points out, Osmer's normative task focuses mainly on theological concepts and theories to direct practical theological interpretation and does not emphasise in-depth study (exegesis) of Scripture sufficiently. Consequently, this study delves much deeper in its investigation than Osmer's suggested use of theological concepts by means of exegetical studies of applicable passages in Scripture. The purpose of this task is therefore to anchor normative thinking in an appropriate reformed view of Scripture as well as use of Scripture.

4.4 METHODOLOGY OF THE NORMATIVE TASK

The task of reflection in order to determine theological norms can be approached from three angles (Osmer, 2008:160):

- a) Theological interpretation, which entails interpreting specific events, situations and contexts by using theological concepts informed by a theory of the divine and the human. Reflection on God's actions throughout the Bible and also throughout the believers' lives, allows believers to discern ways in which God may act in the present or the future and this recollection can guide the believer in times of change and crises.
- b) Ethical reflection refers to the use of ethical principles, rules and guidelines that are relevant to the current situation and can serve as a guide in the strategy or reaction. The role of ethical reflection is that it provides guidance in determining the goals to be pursued in specific circumstances.
- c) Good practice is an approach that derives norms from good practice by investigating past or existing pastoral models in order to identify and learn from the best model for the specific situation. These models are the generative source of new understandings of not only God, but also Christian life and social values.

This task of prophetic discernment involves conducting exegetical studies of applicable passages in Scripture. The method of exegesis to be followed for this study is the grammatical-historical approach recommended by De Klerk and Van Rensburg (2005). These normative perspectives gained from the exegesis will be compared to the interpretive perspectives thereby determining how worldly wisdom appropriately relates to and interacts with the Wisdom of God (Osmer, 2008:162).

Deafness, defined in terms of either a disability or a socio-linguistic minority issue as such, is not a Biblical term per se. Other related terms and concepts, as they are found in various places in the Bible (the Old and the New Testament) will be attended to. By investigating these text verses, possible guidelines and Scriptural perspectives concerning deafness and the pastoral guidance of families with deaf children might be derived.

Adapting to having a deaf child can imply various challenges for hearing parents and being deaf brings about challenges for the deaf child as well. In the preceding chapters of specifically the descriptive and interpretive investigation, themes were identified which ought to be addressed in this normative chapter. The current chapter will attempt to align the results from both the literature study and the empirical research with normative research. These themes ought to be addressed in the pastorate by asking what God's guidelines in His Word are for these themes.

The nature of this research makes it impractical to deeply delve into all the themes which came to the fore in the preceding chapters. Care is therefore taken in selecting core themes. thereby narrowing and focusing the research.

The core themes identified in the empirical and descriptive research as needs to be addressed in this normative chapter are:

- The grief process, by focusing on the book of Lamentations;
- Biblical perspectives pertaining to the attitude of hearing people towards deafness, by concentrating on the book of Lamentations, 1 Corinthians 12:1-31 and other relevant passages from Scripture;
- Ethical questions related to deafness, by engaging with pertinent passages from scripture.

Biblical perspectives on the role of the pastoral practitioner as well as the congregation in terms of ministry to families with deaf children will not be discussed as a separate theme, but rather be incorporated in the themes mentioned above.

The choices of Biblical texts revolve around the grieving process, ethical questions and matters pertaining to the matters of attitudes on the one hand and matters concerning the pastoral practitioner and the religious community on the other. The focus is specifically on the book of Lamentations in the Old Testament and on 1 Corinthians 12:1-31 in the New Testament.

In addressing the themes above, the researcher will employ various methods. The first two themes will be addressed by focusing on one Biblical pericope per theme and doing in-depth exegesis on passages from Scripture. However, space does not permit in-depth exegesis of passages in addressing the ethical questions related to deafness; therefore ethical issues will only be cursorily addressed by analysing passages so as to derive guidelines from Scripture.

Exegesis in the search for norms will utilise the guide of De Klerk and Van Rensburg (2005). The proposed grammatical-historical approach consists of exploration, intensive study and formulation of norms by a process of:

- The determination of the text and the textual context of the pericope, the place of the passage, the book and the genre of the pericope.
- The determination of the socio-historical context of the pericope and the choices of faith this pericope prompted from the first hearers/readers.
- Word study of key concepts in the key verse.
- The revelation of God and the facts of salvation in the pericope, and exhortations based on it.
- Consulting exegetical sources and Scripture with Scripture comparison.
- The current relevant socio-historical context and the choices of faith for this pericope's current readers.

4.5 NORMATIVE PERSPECTIVES FROM SCRIPTURE

4.5.1 Biblical perspectives regarding the grief process

4.5.1.1 Introduction to the process of grief and the book of Lamentations

Grieving is the process associated with various kinds of losses in life and varies from subtle grief to more intense grief, depending on the nature of the experienced loss. In the case of grieving about the deafness of a child, the loss most likely includes the loss of the anticipated future parents envisioned for their child (Kurtzer-White & Luterman, 2003:233;

2.5.1 & 3.6.1 of this study). This grieving process during which parents separate themselves from this imagined future is characterised by an array of emotions that include shock, denial, anger, anxiety, depression, bargaining and finally acceptance (2.5.1 & 3.6.1).

The evident need for normative guidelines from Scripture in addressing people's emotions and questions in the various phases of their grieving process emanated from the previous chapters of this study.

Considering that the book of Lamentations has one continuous theme centring on the articulation of grief, exegesis of the whole book of Lamentations will be done in this section.

4.5.1.2 Motivation of the book of Lamentations as focus

The purpose of Lamentations was to proclaim to the people of God that the cataclysmic fall of the Jerusalem and the exile of her people did not happen by chance or because God was unable to assist His people - it was because of God's judgment over their sin. The poems earnestly urge them to repent and encourage them to hope. They have to pray to their unchanging God in deep humility and hold on to His covenantal faithfulness (Helberg, 1984:9).

The suffering undergone by the first hearers of Lamentations was a consequence of their own sins. However, having a deaf child is not something that hearing parents bring unto themselves as punishment for their sin, yet intense sorrow and grief associated with the tragedy of destruction, suffering and loss can be seen in Lamentations. The content of the book of Lamentations expresses the loss that has befallen a community and further memorializes the disillusionment, sorrow and grief associated with this loss (Allen, 2011:4; Berlin, 2004:1; Helberg, 1984:1).

The motivation for the use of the book of Lamentations as a whole is that it echoes human emotions experienced during times of coming to terms with loss and validates the process of grief. Parry (2010:1) expresses the significance of the book of Lamentations to those who grieve quite well when he states:

Increasingly we lack the social practices, words, and concepts necessary to grasp our pain by the horns and stare it in the face. We have been robbed of a vocabulary of grief, and we suffer for it. The book of Lamentations accosts us by the wayside as a stranger who offers us an unasked-for, unwanted, and yet priceless gift – the poetry of pain.

The sequential stages as well as the applicability of Kübler-Ross's stage theory (3.6.1) on the grieving process are questioned by some critics. However, The criticism is not weighty

enough to justify total rejection of Kübler-Ross's theory yet care must be taken in the over simplified application thereof (Reimer, 2002:544). Grieving is different for everyone and therefore not everyone will go through all of the stages nor experience the stages in the same sequence. Reimer (2002:555) confirms this and explains that Kübler-Ross's stage theory not so much predicts or prescribes the course of the grieving process as much as it describes the various phases one might pass through in the process of coping with loss: denial, anger, bargaining, depression and acceptance.

Looking at Lamentations with the theory of Kübler Ross in mind, the book might be viewed as an ancient illustration of the various stages of the grieving process. It is clear that the author(s) of Lamentations is no stranger to grief and has intense experience of wrestling and struggling with God during these turbulent circumstances as a response to disillusionment. This disillusionment with the conduct of friends as well as God's actions is reflected in Lamentations. However, this disillusionment does not result in an inference that God is dead, quite the opposite - it leads to a turning point; a confession that God lives, creates life and that there is always hope in God (Helberg, 1984:1).

In the search for guidelines and norms from the Word of God in coping with loss during the stages of grief, it is clear that many people have wrestled intensively with God. Many examples of individuals wrestling with God during times of affliction can be found in Scripture. Old Testament examples include many Psalms of Lament (Pss. 13, 22, 74, 88), Job and the complaints of Habakkuk. In the New Testament Jesus's own wrestling with God in Gethsemane is described in Luke 22:39-45 and Matthew 26:36-46. This wrestling with God is evident in various other places in the Bible and therefore it can be concluded that it is not wrong to wrestle with God or to go through the grieving process. Believers also wrestle during the grieving process (2.5.1) and might have many questions about the significance of their faith, but the believer can talk and wrestle with God, reflect deeply on God and always turn to the Lord as the author(s) of Lamentations did.

4.5.1.3 Exegesis of Lamentations 1-5

a) The place of the book of Lamentations in the Bible

Lamentations is an Old Testament book, the 25th in the Bible, and forms part of the biblical poetic literature of the Old Testament.

b) The structure of the book of Lamentations

The book of Lamentations consists of five individual poems and so appears to have no pattern as a whole. Yet, a growing number of scholars argue that there is logic behind the overall arrangement of the book. Poems 1, 2 and 4 have 22 verses each with one to three lines each, whereas poem 3 has 66 verses with one line each. Each of the poems in chapter 1-4 is an alphabetical (acrostic) poem. The verses each begins with the consecutive letter of the Hebrew alphabet possibly to express the severity of the suffering and misery of the people (Helberg, 1984:4; Kent, 1983:12; Parry, 2010:13). Poem 3 intensifies the acrostic by starting each line with the designated letter of the alphabet. This, together with the unique number of verses that draws attention to poem 3, it can therefore be argued that poem 3 stands central in Lamentations (Parry, 2010:17). The 5th and last poem also consists of 22 verses, although it is not purely alphabetical, maybe because it is a prayer or maybe the poem is in its preliminary form and the author intended to rearrange it a later stage (Helberg, 1984:3).

- Poem 1: How lonely sits the city (1:1-22)
- Poem 2: The Lord has destroyed without pity (2:1-22)
- Poem 3: Great is Your faithfulness (3:1-66)
- Poem 4: The holy stones lie scattered (4:1-22)
- Poem 5: Restore us to Yourself, O Lord (5:1-22) (The Bible English Standard Version, 2001).

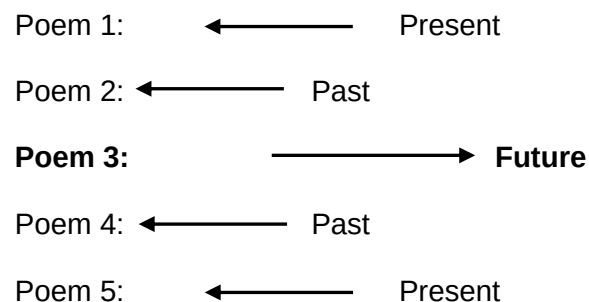
c) Analysis of the thought structure of the book of Lamentations

Reimer (2002:543) argues that each of these five poems exhibits a central perspective and brings them in close relation to the psychology and phases of grief. In each of the five poems, the first line indicates the trajectory of the rest of the poem. In the light of the above, the thought structure of the book of Lamentations is therefore analysed as follows:

- Poem 1 (1:1-22): “How lonely sits the city...” Standing deeply disillusioned before God. There is no comfort, no one who is assisting the sorrowing city Jerusalem.
- Poem 2 (2:1-22): “How the Lord in His anger...” Anger and the day of the Lord’s wrath.

- Poem 3 (3:1-66): “I am the man who has seen affliction...” Hope in God even in times of personal suffering and utter hopelessness.
- Poem 4 (4:1-22): “How the gold has grown dim...” What was precious and good once has now become worthless and lifeless.
- Poem 5 (5:1-22): “Remember, O Lord...” From misery to prayer. (Berlin, 2004; Bybel, 2007; Helberg, 1984; Kent, 1983; Parry, 2010; The Bible English Standard Version, 2001).

Parry (2010:17) sees a relationship between poems 1 and 5 and also between poems 2 and 4, where poems 1 and 5 focus on the present situation by describing the state of Judah, whereas poems 2 and 4 describe the past devastation of the siege and its destruction. Additionally, although poems 1 and 5 both describe the present situation of the city, there is progression since poem 5 contains the urge to submission to God.



The chiastic pattern again places poem three in a pivotal position since it contains a personal conversation with God and provides hope for the people of God. Poem 3 binds past, present and future together (Parry, 2010:17).

d) The genre of the book of Lamentations

Lamentations is a book consisting of a collection of five poetic laments. The content of the poems is about the destruction of Jerusalem and the temple. The genre of the poems respectively remains controversial, although it is widely agreed upon that poems 1, 2 and 4 reflect elements of both the dirge genre as well as the communal laments genre. Poem 3 contains elements of a number of genres and is quite unique in the Old Testament. Poem 5 is viewed as a variation on a communal lament (Parry & Thomas, 2011:43; Parry, 2010:11).

e) Revelation historical placing and significance of Lamentations

The book of Lamentations was written shortly after the fall of Jerusalem in 587 B.C. and illustrates the Hebrew people’s attempt to maintain their faith in the Lord during this time (Berlin, 2004:33; Helberg, 1984:16; Kent, 1983:17).

Traditionally, the authorship of Lamentations has been attributed to the prophet Jeremiah but is today attributed to an anonymous author (authors). There are valid arguments for and against the authorship of Jeremiah but regardless of who the poet was, it is evident that he was a man who lived in the period of the great prophets, a time of assailed faith, that he was deeply spiritual, a man of faith and that the book of Lamentations is a partial account of his personal struggle (Kent, 1983:16).

Continuous perspectives come to the fore in the poems in Lamentations and Reimer (2002:545) presents an alignment of these poems with Kübler-Ross's stages of grief:

- 1) Stage 1: Denial and isolation: "How lonely sits the city..."
- 2) Stage 2: Anger: "How the Lord in his anger..."
- 3) Stage 3: Bargaining: "I am the man who has seen affliction..."
- 4) Stage 4: Depression: "How the gold has grown dim..."
- 5) Stage 5: Acceptance: "Remember, O Lord..."

Next, a further investigation of the above themes will be done by adding the perspectives of various authors on the book of Lamentations.

- 1) Stage 1: Denial and isolation: "How lonely sits the city..."

Mourning emerges as the central theme specifically in chapters 1 and 2 of Lamentations. The city of Jerusalem is metaphorically described as a solitary widow, sitting empty and alone, seeking comfort after great loss (1:1-2); "*She weeps bitterly in the night, with tears on her cheeks; ...she has none to comfort her*" (1:2). Notes of isolation and desolation are deepened by the contrast of the once great Jerusalem's previous international status and friendships with neighbouring states (Allen, 2011:36; Berlin, 2004:47; Reimer, 2002:546). She has to endure suffering, misery and loneliness, the deepest of which the loneliness due to God not acting as comforter and helper. The comforter she is looking for is precisely the one who brought this misery upon her (Helberg, 1984:22). The lack of comfort and help is refrained three times (1:2,9,17) and emphasises her isolation and bereaved state (Parry & Thomas, 2011:45; Reimer, 2002:547).

The central perspective of Lamentations is that of isolation from the self (1:1, 8) without anyone to provide comfort, as well as of isolation from God (Reimer, 2002:547). This is in line with the isolation aspect of Kübler-Ross's first stage of denial and isolation. Yet there is no indication of the denial aspect Kübler-Ross

describes. In fact, the poet explicitly tells it as it is, for “...*she who was great among the nations! She who was a princess among the provinces has become a slave*” (1:1b-d) and “...*therefore her fall is terrible; she has no comforter*” (1:9b). In this regard he actually does exactly the opposite of denying their tragic reality. He describes the disaster, its aftermath and the present situation in great detail.

In this poem the city continues to raise its grieving voice to pray to God (1:9b, 11b) even in her deepest isolation. “O Lord, behold my affliction, for the enemy has triumphed!” (1:9b). Jerusalem continues to hope in God who is mighty to help, that He may hear her, see her, liberate her from her unbearable distress and comfort her once again (Helberg, 1984:23; Parry & Thomas, 2011:45; Parry, 2010:65; Reimer, 2002:546). This prayer to God indicates that regardless of this experience of isolation the poet remarkably does not feel totally isolated and forsaken by God since he still asks for help from God.

2) Stage 2: Anger: “How the Lord in his anger...”

Similar elements of suffering, onlookers’ contempt, tragedy as judgment on sin and prayer are found in the second chapter of Lamentations, with the description just much more passionate and concrete than the previous chapter (Kent, 1983:33). Where the tone of the first chapter was that of isolation and despair, the tone now changes in chapter two to a tone of anger. The emphasis is on the anger of God and although it is not explicitly described, one can sense that the poet is angry with God (Parry & Thomas, 2011:67; Reimer, 2002:547). There is no claim of innocence on the part of the poet, but he reiterates that the day of the anger of the Lord has come and that God is the one who brought this misery over his people. God has become like an enemy, showing no mercy but weakening Israel and destroying everything she cherished. “*He has bent his bow like an enemy, with his right hand set like a foe; and he has killed all who were delightful in our eyes*” (2:4). God even reduced his temple, the place where he met his people, to ruins (2:5) (Berlin, 2004:67; Helberg, 1984:28; Kent, 1983:34; Reimer, 2002:548).

The poet bewails Jerusalem’s destruction and helplessness. “*My eyes are spent with weeping; my stomach churns; my bile is poured out to the ground...*” (2:11a). It is as if words fail to express his emotions and utter grief as he concludes all of this misery to be the fulfilment of God’s previous warnings (2:17) and judgement (1:8;3:42) of disobedience (Helberg, 1984:32). The poet urges the walls of Jerusalem to fervently

cry out to God and seek refuge in him, the only one capable of healing the wound he inflicted on her (Helberg, 1984:32; Parry, 2010:83).

In 2:20 Jerusalem once again does not respond by claiming to be innocent but echoes elements of the prayer in chapter 1 (1:9;11;20) pleading with God to notice her. *“Look, O Lord, and see!”* (2:20a). the undertone of anger and accusation is evident in the outcries of chapter 2. However, the poet’s mind is focused on God alone, as the one who brought about this punishment for Jerusalem’s mistakes. This chapter ends with a prayer of supplication to God to bring an end to this ongoing suffering under his divine wrath (Helberg, 1984:32; Parry & Thomas, 2011:47).

The dominant theme of anger is very strong in this chapter. Although the anger referred to is mainly about God’s anger, there is also the implied anger of the poet towards God as the cause of the full scope of the misery. The poet experiences God as acting like an enemy and this can be brought in line with Kübler-Ross’s description of the anger phase of mourning, during which the persons grieving project their anger outwardly onto the environment (Reimer, 2002:549).

3) Stage 3: Bargaining: “I am the man who has seen affliction...”

Lamentations 3 is a very personal poem that urges the reader to self-abasement and prayer (Helberg, 1984:84; Kent, 1983:43). The poet opens this poem by joining the voices of chapters 1 and 2 in portraying an extended picture of a man who has personally experienced God’s wrath (3:1-18). Just as God has punished Jerusalem, he has also punished him (Kent, 1983:43; Parry & Thomas, 2011:46). In the Hebrew text, the poet uses only the personal pronoun ‘He’ to refer to God and omits the name of the Lord in verse 1-17, almost as if he cannot bring himself to even mention the Lord’s name (Helberg, 1984:37). He does not talk to God as in the rest of the poems, but only about what He has done. This shows that the feelings of anger have not completely subsided yet. He laments his unbearable pain, what God has done to him and how he has lost hope. *“My endurance has perished; so has my hope from the Lord”* (3:18).

Suddenly, an incredible transition then indicates a shift in the poet’s perspective from that of despair (3:20) to one of hope (3:21-23). Verse 20 phrases the focus on the misery and despair: *“My soul continually remembers it and is bowed down within me”* and then, the shift in focus in 3:21-23: *“But this I call to mind, and therefore I have hope: The steadfast love of the Lord never ceases; his mercies never come to an end; they are new every morning; great is your faithfulness.”* Although still in the

midst of affliction he recalls God's covenantal love and mercies (Helberg, 1984:39; Kent, 1983:44; Parry & Thomas, 2011:46; Parry, 2010:93). This remembrance that brought about the turning point is not unique to the poet of Lamentations but can also be seen in Psalm 73:16-17: "*But when I thought how to understand this, it seemed to me a wearisome task, until I went into the sanctuary of God; then I discerned their end*"; Habakkuk 3:18 after mentioning a list of troubles: "...yet I will rejoice in the Lord; I will take joy in the God of my salvation" and in the book of Job. In all these texts we see that they all come to a point of declaring that they do not understand their situations and then, suddenly, an inexplicable transition. This transition is the effect of changing the focus from pondering on the things one does not understand to focusing elsewhere and recalling the things one does know about God. Living one's entire life in the presence of and trust in the Lord (*Coram Deo*) brings hope where there is none and amidst anxiety and uncertainty (De Wet & De Klerk, 2014:39).

The poet of Lamentations focuses on what he does know about God and realises that being afflicted does not mean being forsaken. He reflects on God's characteristics - God is faithful (3:23); God is his life (3:24); God is good to those who wait on Him (see also Ps. 37:1-26). This provides hope and he silently submits himself to the Lord and waits eagerly for deliverance and justice to be restored (3:35-40) (Helberg, 1984:39; Kent, 1983:44; Parry & Thomas, 2011:44).

From here on the poet proceeds to urge his fellow sufferers to *Coram Deo*, to do thorough introspection of their ways and to return to the Lord; to raise their hands and their hearts to the Lord in prayer and to confess their sins (3:40-41). The poet laments to God, cries uncontrollably and states that he will continue to do so until God notices their situation and delivers his afflicted people (3:42-54) (Helberg, 1984:42; Kent, 1983:46; Parry & Thomas, 2011:46; Parry, 2010:94).

In an abrupt transition the poet once again describes the suffering of 3:1-18 at the hands of God, but this time, human enemies are the source of the affliction and God is described as being on the side of the sufferer, the sufferer's source of help (3:52-55) (Parry, 2010:94; Reimer, 2002:550). God greatly assures him in verse 57: "*Do not fear!*" The poet then cries for vengeance and asks God to uphold him and to punish his enemies for what they have done (3:59-66) (Kent, 1983:43; Parry, 2010:94).

Reimer (2002:550) discusses in great detail the importance of considering God's attributes in the interpretation of Lamentations 3, associating the recognition of God's merciful nature with the anticipation of forgiveness. Comparing Exodus 34:6 with

several passages from the Minor Prophets, he concludes from these passages that God's willingness to forgive implies that there must eventually be an end to his wrath. Yet this is no given, but the only hope. This hope entails an active "...*return(ing) to the Lord!*" (3:40b) (Reimer, 2002:551). In the light of Reimer's explanation above, the transitions in Lamentations would make sense. In verse 1-18 the poet is hopeless, but reflects on the attributes of God, is reconciled with God and finds hope in God. There is no certainty that the affliction will come to an end, but this hope is what brings God and people together (Parry & Thomas, 2011:46; Reimer, 2002:551).

If one reflects on the bargaining phase of Kübler-Ross, with the above in mind, certain parallels can be drawn. Bargaining for Kübler-Ross implied the endeavour of terminally ill patients to acquire a reward for good behaviour (maybe the postponement of death), yet in Lamentations the poet and Jerusalem fear that they are separated from God, their source of life (Reimer, 2002:552). Reimer (2002:552) therefore views this reflection of 3:22-39 on the characteristics of God as the element that facilitates the transition of a state of hopelessness to one of having hope. The poet of Lamentations' reflection on God can be interpreted as a way of bargaining with God. However, he bargains in a totally unconventional way. His clinical description of his situation indicates that he can face the reality and that he is acutely aware that his hands are totally empty. He has nothing to bring to the table in bargaining with God; nothing but the covenant. He wrestles with integrating that which he knows about God and how he would expect God to act based on the covenant with His people with what God is currently doing. In effect he is saying to God that he understand why they are in this situation, but that in the light of the covenant, God cannot reject his people indefinitely and surely will not let them go on like this forever.

The reflection on the covenant is thus used in this negotiating position in the hope that God will change his mind and provide relief (Helberg, 1984:44).

4) Stage 4: Depression: "How the gold has grown dim..."

In Lamentations 4:1-16 the poet once again reflects on the horrendous suffering of the people left behind in Jerusalem and vividly describes their physical changes as a consequence of the terrible famine brought about by the siege (Berlin, 2004:102; Helberg, 1984:47; Parry, 2010:132). Degradation is seen everywhere. Jerusalem is neglected and deserted. Her former state is sharply contrasted with her current degraded and wasted condition. Everything that used to be good, valuable, beautiful

and precious is no longer, but has now been reduced to worthlessness, ugliness and lifelessness (Parry, 2010:132; Reimer, 2002:552). The children beg their helpless mothers for food as they are starving (4:3-4) and the adults' health deteriorates (4:5-8). In verse 9 the poet states that those people killed quickly by the sword are better off than those who are still alive but are wasting away because of starvation, therefore dying a slow, agonising death. Verse 10 depicts the most horrid result of famine: cannibalism (Berlin, 2004:103; Helberg, 1984:48; Kent, 1983:53).

The cause of the Lord's anger is the overconfidence of the people and the religious leadership's failing to warn the people about their sin and participating in the oppression of the righteous poor (4:13-14) (Kent, 1983:53; Parry, 2010:138). As a result, Jerusalem's own God has brought about all the misery and the flame of His judgement has burned Jerusalem down to her foundations (4:11).

The discourse in verses 17-20 shifts from the afflicted community to the voice of an individual, representing the people left behind in the city. This voice speaks about waiting in vain and not holding out any hope for salvation (4:17) or even life itself (4:20) (Berlin, 2004:112; Parry, 2010:140; Reimer, 2002:552).

The conclusion of the poem offers a surprising change in tone when the poet suddenly addresses the personification of Judah's enemies, Edom (4:21-22). The poet tauntingly predicts that the most hated of enemies will be divinely judged and suffer for the way it treated Judah (Berlin, 2004:113; Kent, 1983:55; Parry & Thomas, 2011:47). The tone of hope in verse 22 is unexpected and resembles the hope underlying the middle part of Lamentations 3. The ending asserts the hope that Zion's punishment and suffering will come to an end and that her inhabitants will not have to endure captivity again (Berlin, 2004:114; Helberg, 1984:52; Kent, 1983:54; Parry & Thomas, 2011:47).

Lamentations indicate somewhat of a rollercoaster of emotions where the poet is found to turn to God in one place (1:9, 2:20) only to not even be able to mention God's name in another (3:1-17). Lamentations 4 echoes the first part of Lamentations 3 in the sense that God is only indirectly present in the poem as the one who is to judge the enemy and cause them to suffer for what they have done. This poem lacks any form of prayer to God; there is no direct communication with the Lord. This indicates that even though the poet feels unexpectedly confident, he does not address God directly in this poem at all (Reimer, 2002:553). Yet, there is some progression in the tone of Lamentations 4. Although the poet does not converse with God directly, he does involve Him. He does not necessarily feel close to God as he is

not yet in personal conversation with God, but he does experience God to be on his side and against the enemy.

Reimer (2002:554) draws a clear parallel between the features of depression in general as well as those described by Kübler-Ross during the depression stage of grieving, with Lamentations 4. Both are characterised by elements of great loss, hopelessness, meaninglessness, a negative view of the future and uncompleted mourning. Prayer is totally absent from Lamentations 4. At no point does the poet engage with God or wrestle with God. This, together with the fact that the only hope that the poet finds for the future is the hope that Edom will also suffer in the same way that Judah has done, correlates to a great extent with the features of depression.

5) Stage 5: Acceptance: "Remember, O Lord..."

This last poem is viewed as a communal lament, addressing God directly throughout. The voice of the community returns to God in prayer. It is a prayer to God to urgently remember them. *"Remember, O Lord, what has befallen us; look, and see our disgrace!"* (5:1). This *"Remember, O Lord... look, and see"* resonates with words found in other passages of the Old Testament (Ex. 32:13, Ps. 25:6 and Ps. 74:2) and signals an urgent invocation to God to pay attention, to intensely look at their dire state and see what is happening (Berlin, 2004:117; Parry, 2010:147). The complaints listed one after the other in 5:2-18 intend to draw God's attention to the sufferings and sorrows of the community and to act accordingly, not that God is truly unaware, but because they have experienced him as behaving as though He was unaware (Kent, 1983:59; Parry & Thomas, 2011:47; Parry, 2010:147).

Although this poem is depressing and bleak, it turns to confess God's everlasting sovereignty in verse 19. *"But you, O Lord, reign forever; your throne endures to all generations"* (4:19). This reference to generation after generation indirectly declares God's reign across the covenantal generations, His reign will endure forever and precisely that is the foundation for the community's hope and prayer (Helberg, 1984:58; Kent, 1983:59; Parry, 2010:153; Reimer, 2002:555). This is followed by the community's fundamental appeal to the Lord in their search for grace beyond their affliction. *"Why do you forget us forever, why do you forsake us for so many days?"* (4:20). This question does not imply doubt, but rather it expresses a sense of perplexity grounded in the poet's knowledge of the character of God and belief in the His covenantal relationship with his people: *"Is God's wrath and power then without his covenantal faithfulness and mercy? Surely that cannot be?"* (See also Lam. 3:31;

Ps. 102:13, 14; Jer. 3:5). The poet uses this question rhetorically as a plea to God to act in a way consistent with His character (Allen, 2011:160; Helberg, 1984:58; Kent, 1983:59; Parry & Thomas, 2011:42; Parry, 2010:154).

The prayer continues in verse 21 with the whole community pleading with the Lord, the only one who can turn His people back to him: *“Restore us to yourself, O Lord, that we may be restored! Renew our days as of old”* (4:21). Everything depends on God, on His mercy and His initiative. The suffering and pain have caused them to feel distanced from the Lord, but they long for intimacy with Him and to feel close to Him once again. For this reason, the poet cries out to the Lord. This action is indicative of the fact that the poet hasn’t given up on God but remains hopeful that God will bring restoration (Helberg, 1984:58; Parry, 2010:154) .

Kübler-Ross’s last phase of acceptance implies an acceptance of the loss and of coming to a point where one integrates the new reality and adjusts to its implications (McAlearney *et al.*, 2014:470; Penzo & Harvey, 2008:334). Reimer (2002:556) argues that Lamentations does not fit into this acceptance phase of Kübler-Ross. He feels that the whole poem (and specifically verse 20-22) is almost the exact opposite of acceptance and implies the longing for a future life. The poem ends with the statement: *“...unless you have utterly rejected us, and you remain exceedingly angry with us”* (4:22). There is hope of restoration, and that is what is prayed for - a favourable response from God.

The researcher agrees that Lamentations 5 does not reflect acceptance in the sense of positive resolution (Berlin, 2004:125; Reimer, 2002:556). However the researcher also understands the conclusion of the poem similar to Allen (2011:166) and Helberg (1984:60): The poet totally submits to God in a way indicative of a true covenantal relationship, thereby fully acknowledging God’s absolute sovereignty over everything. He does not conclude with doubt but rather with a question which presupposes a positive answer and a conviction that it cannot be that God’s anger and rejection will last forever (Helberg, 1984:59). The matter of permanent or temporary anger and/or rejection is often found in Psalms of complaint (Pss. 79:5; 74:1; 44:23; 89:38). Allen (2011:163) argues the function of this matter of anger and/or rejection to be an invitation to God to answer positively by denying the statement with the reassurance that it is not the case and that He will show favour.

To the researcher, therefore, there is a correlation to be drawn between the Kübler-Ross’s phase of acceptance and Lamentations 5, at least in the sense that acceptance also implies hope for life to continue (3.6.1.2.6). The Lord’s grace forms the grounds for the poet

(representative of the whole community) reaching out in prayer to God alone; he fully submits to God's sovereignty and his hope in God's covenantal faithfulness remains unwavering (Allen, 2011:166; Helberg, 1984:60; Parry & Thomas, 2011:42).

Yet, even though the poet's hope is unwavering, coming to this acceptance does not mean by any means that the previous phases have necessarily passed completely and are never to be revisited again. These phases are integrated phases and as mentioned earlier in this study, do not necessarily follow the same sequential pattern and often individuals may fall back to a previous phase. Elements of the various phases were seen throughout Lamentations and serve as a clear indication of the poet's continuous wrestling through this process of grief.

f) Sociohistorical context of the book of Lamentations

The Christian canonical order places Lamentations after Jeremiah, in line with the tradition of Jeremiahan authorship of Lamentations. The Jewish canon places Lamentations as an independent unit in a section of the Writings known as the Megilloth (five festival scrolls): Ruth, Song of Songs, Ecclesiastes, Lamentations and Esther, which were recited during Jewish festivals. After the destruction of Jerusalem by Titus (70 AD) Lamentations was read annually to commemorate the latest series of tragic times (Berlin, 2004:31; Helberg, 1984:7; Kent, 1983:16; Parry, 2010:19). Parry and Thomas (2011:90) note that the role of Lamentations in Jewish liturgy probably served the purpose that by reciting these poems, the worshippers are enabled to articulate feelings of despair, suffering and of separation from God, as it is expressed by the poems. It might additionally be interpreted that the recitation of these unmitigated poems imply that it is not wrong to wrestle with God and it also serves as a reminder that God remains faithful, despite the suffering He sometimes brings into our lives or allows in our lives.

g) Conclusion

At first glance, it might seem as if the book of Lamentations is mainly about describing and justifying Jerusalem's affliction, but it is rather primarily about the presentation of affliction and suffering (Parry, 2010:25). God created man perfect. Man was not initially created to endure suffering. But through the fall of man (Gen. 3) pain and despair entered this world. The pain of this world causes people to mourn because suffering is actually unnatural. However, the emotions associated with intense sorrow and grief, after experiencing profound loss are not unnatural but naturally part of the creation of God. There is neither shame nor sin in grieving about loss. The Word of God teaches about grieving and wrestling with God. People respond differently to loss and therefore also experience the process of grief in a

unique way, but the fact remains that God is the creator of man and also of all his emotions. The mere presence of Lamentations in the Bible validates and normalises the emotions and turmoil of the grieving process for believers as a natural psychological response to great loss and part and parcel of how God has created man. Consequently the believer can freely talk to God, boldly lament to Him and wrestle with Him through times of suffering.

From a psychological perspective Kübler-Ross's insights can be applied to Lamentations 1 to 5 as the contents of the various chapters describe stages of isolation and despair (poem 1), anger (poem 2), bargaining (poem 3), depression (poem 4) and finally acceptance (to a limited extent in poem 5). On the other hand, though, Lamentations shows that believers may pass through each of these phases in a unique way.

The author(s) of Lamentations had first-hand experience of intense misery and affliction. He is disillusioned by the circumstances and the emotions it stirs up. However, he does not avoid God or question His existence, but turns to God and wrestles with Him in prayer. This motif of wrestling with God is also found in many parts of Scripture (Pss. 13, 22, 74, 88, Job, Habakkuk, Luke 22:39-45 and Matt.26:36-46). The believer in the midst of grief can do the same. Lamentations offers believers the permission to bring all one's emotions, despair, anger, bargaining, depression and hope to God in honest prayer (Parry & Thomas, 2011:207). Be serious about sin, confession and repentance. Acknowledge God's absolute dominion over everything. God knows us, He understands us, and He acknowledges our pain and suffering. He reigns and only He determines what will happen and when it will happen. The believer can reflect on the meaning and duration of his suffering but should not dwell on it indefinitely. At some point he needs to make a conscious decision to look at it differently (Lamentations 3). He should voice his grief and complaint through honest prayer and in full realisation of his dependence on and hope in Him alone (Helberg, 1984:68; Parry & Thomas, 2011:208). This conscious decision the believer makes is by no means a once-off decision which guarantees a permanent immediate changed perspective. On the contrary, it is a process to struggle through. As emotions of pain and sadness flare up from time to time and threaten to cause him to lose focus, the believer is brought back to this point of once again being confronted with making this conscious decision to view his situation in another way. It is a struggle of focusing and refocusing on the known attributes of God time and again.

h) Normative principle

In an attempt to bridge the distance between a Biblical text written in a specific context and time and the situation in the 21st century processes of exegesis, hermeneutics and homiletics are utilised. Responsible hermeneutics requires an understanding of the

difference between elements of continuity (anchors of faith in the Triune God) and discontinuity (the gap between the first readers and readers today) (De Wet & De Klerk, 2014:11). In deducing normative principles from Lamentations it is therefore imperative to maintain a balance between matters with eternal truths which still apply today and matters that cannot be applied in the same way today as in the time of the Old Testament. It would be irresponsible to attempt to simply equate the context and circumstances of that time with circumstances and situations faced today.

The first and foremost line of discontinuity in Lamentations would be the matter of the punishment that the people brought upon themselves. The covenantal relationship between God and man on the other hand is an important line of continuity.

A deeper look into Lamentations revealed certain normative principles:

- The believer ought to be encouraged to converse with God continuously and to tell Him precisely what is going on in his heart. The poet(s) of Lamentations did not hold back in his accusations and complaints but was very honest and even quite harsh in the language used to verbalise his pain and sense of loss. Reflecting on Lamentations and other similar literature from Scripture can be valuable to the grieving believer. Feelings of isolation are alleviated by the realisation that others have also wrestled with God and felt cut off or distanced from Him. In working through grief it is important to, instead of being in denial, look reality in the eye and be willing to bring everything before the Lord. Believers don't necessarily experience isolation in the same way. Some might pass through it feeling completely isolated from other people and God, as Kübler-Ross's phases describe. Yet others may feel isolated, but not completely isolated from God since they can still turn to God. So, although it is not the same for all believers, faith can bring a believer to a point of not being in denial and of not feeling totally isolated from God.
- The believer ought to be encouraged to go through the grieving process, to earnestly pray to God with all his might, heart and mind, to wrestle with Him and to wait on Him in hope. *"And will not God give justice to his elect, who cry to him day and night? Will he delay long over them? ⁸I tell you, he will give justice to them speedily"* (Luke 18:7-8).
- When dealing with emotions of anger, the believer should refrain from projecting it onto his physical environment but can freely bring his anger to God in honest prayer. He is the only One who truly knows us and understands even our deepest thoughts and afflictions.

- When struggling to reconcile that which the believers knows about God and the pain he is enduring, remembrance can play a great role in working through grief. The believer should come to a point of understanding that we will never understand everything. Remembrance of and reflecting on the attributes of God as well as the believer's covenantal relationship with God brings about a crucial turning point as the focus shifts from the incomprehensible things of God to the things known about God (Lam. 3; Ps. 42;73 and Hab. 3). However, making this conscious decision once (to focus on God and His attributes) is not at all sufficient to permanently change one's view. It is a process of focusing and refocusing on God each time painful emotions arise and threaten to break this focus. In returning to the Lord in this manner the believer is continuously brought into the presence of the Lord (*coram Deo*) and hope and rest can then be found amidst hopelessness and despair.
- Although the enemy in Lamentations is not the cause of suffering today, the believer may still face different enemies in his misery. The poet experienced God as being 'on his side and against the enemy' and expects God to deal with the enemy. In the same way the believer can hang on to the knowledge that the Holy Spirit can help us in conquering these emotions of disheartenment, depression, anger etc., which may be experienced as enemies.
- Reaching a point of submitting to God's sovereignty and finding hope in His covenantal faithfulness can bring about a form of acceptance. This acceptance implies finding comfort in the knowledge that everything that happens to God's children flows forth from His love and covenantal faithfulness. Acceptance is often accompanied by a longing for an intimate relationship with God.
- Believers must be guided to understand that working through grief does not necessarily mean that each day will feel better than the one before, but that each person grieves in a unique way. There will probably be periods of unexpectedly returning to previous phases in the mourning process, but this is not necessarily a sign of weak faith. Different emotions and their varying intensities may come like waves which ebb and flow. This should by no means discourage the believer(s) or make them feel guilty for not 'feeling better by now'. Believers need to be encouraged to express their emotions and wrestling with their grief in their own distinctive way and in their own time.

i) Significance of the normative principles from the book of Lamentations for a model of pastoral care of families with deaf children

Parents who mourn the deafness of their child characteristically go through a process of grief as they grieve, among other things, for the loss of the anticipated future they had envisioned for their child. Lamentations can be very valuable to the grieving parents and serve as an aid in working through the various phases of grief with these families.

Lamentations validates the grief of families with deaf children. In working through the poems of Lamentations, parents may find their own feelings articulated by the poems and be assisted to work through them. Parents are to be encouraged to go through the grieving process, to seek God continuously and to voice to him precisely what is going on in their hearts. In embracing their grief in the presence of God, they embark on a spiritual pilgrimage which will take them on the way of the many ups and downs which may include of shock, isolation, denial, depression and finally, a form of acceptance and hope - acceptance in the sense of submitting to the sovereignty of God and hope in His covenantal faithfulness.

j) Significance of the normative principles from the book of Lamentations for the pastor as leader of a community of believers

The insights gained from the book of Lamentations in terms of the mourning process and the complexities and questions of each phase can equip the pastoral practitioner in addressing grief in their providing of compassionate individual pastoral care or in the communal worship setting (Allen, 2011:26).

From Lamentations it is clear that the poet played an important role in helping the community to come to terms with their affliction as he compassionately ministered to them and wept with those who wept. Priestly listening, especially in the initial phase of mourning, implies a willingness to listen without interrupting.

When working with adult deaf congregants, it is of paramount importance that the pastor realise that for believers who view themselves as culturally Deaf, their source of suffering is not in being deaf, but more so in the way the larger society views deafness and as a result, them and their culture.

4.5.2 Biblical perspectives pertaining to the attitude of hearing people towards deafness

“The Word of God is inclusive. Unfortunately, excluding is what many of us do to the Deaf”
(Hulteen, 2012:3:3).

As is the case with the general public, most hearing parents are totally ignorant when it comes to deafness and all it entails. Families may turn to a minister, pastoral practitioner and/or medical professional for support. These sources parents turn to have a great influence on the attitude parents' will assume toward their child's deafness. As was seen in chapter 3, medical professionals tend to have a pathological view of deafness, totally in contrast to the cultural view of Deafness, maintained by the Deaf. The decisions parents of deaf children make in terms of communication, language, education and hearing technology depend greatly on their attitude towards deafness and the guidance and advice they receive. Therefore, the pastoral practitioner plays a crucial role in providing reliable, accurate and helpful guidance and support.

The pastoral guidance is primarily aimed at the family with a deaf child, yet the pastoral practitioner also needs to be aware of his own attitude toward deafness before providing guidance to families of the deaf. Additionally the attitudes of both the faith community and, ideally, the greater community should also be addressed.

As this study indicated, there is a great need for normative principles from Scripture regarding the appropriate attitude toward deafness.

4.5.2.1 Motivation of the book of Lamentations in order to address attitudes toward deafness

The discussion in 4.5.1.3 explained the sociohistorical contexts of the book of Lamentations. The presence of the book of Lamentations in the liturgy of Israel's communal worship is in all probability an indication that the poems played a significant role. The poet might have written Lamentations as a personal expression of his feelings (Boda, 2003:57), but in the process he immersed himself in the situation of the people in such a way that these poems could be used in the people's public worship. The poems are mainly concerned with human suffering and with grief over human loss (Allen, 2011:24; Boda, 2003:72) and echoed Israel's own feelings of despair and separation from God and in effect reciting these poems therefore assisted the worshippers to articulate their own emotional states, similar to the way believers might sing Psalms of Lament during public worship. Psalms of Lament also create room for

a grieving description of a crisis. The honest, sincere and deeply emotional poems of Lamentations suggest that the believer can wrestle with God and it also reminds the believer of the faithfulness of God, even in the face of affliction. Allen (2011:6) elaborates:

Lamentations allow the human side of life to be fully explored. When lives are shattered by change, their range of human interactions is fragmented. The dirge gave permission for broken piece after broken piece to be picked up and wept over.

a) The poet of Lamentations' attitude towards his people

The poet plays a dominant part in Lamentations. Not only is he is very serious about the wrath and sovereignty of God, but also associates with the pain of the city and the people and gives expression to their coming to terms with their suffering. *"Is it nothing to you, all you who pass by? Look and see"* (1:12a).

He cries with those who cry. *"My eyes are spent with weeping; my stomach churns; my bile is poured out to the ground because of the destruction of the daughter of my people..."* (2:11a). He helps them to articulate their emotions and guides them to voice their feelings (Allen, 2011:26). Job's friends initially also showed compassion for their friend in his affliction (Job 2:12-13).

The poet places himself in the shoes of the people and looks at the situation through their eyes. *"...but hear, all you peoples, and see my suffering"* (1:18b). Allen (2011:27) defines this kind of empathy as 'the capacity to gain a sensitive understanding of another's pain that has not first been one's own' and elaborates that reading (and listening) to any text without compassion and empathy leads to shallow interpretation.

He intercedes for the afflicted people in prayer and pleads on their behalf. He also holds on to God's covenantal faithfulness and in this way provides the necessary hope to those in need. He calls the people to repentance, perseverance and introspection but also to strong hope in God (Helberg, 1984:9).

b) Normative principle:

Scripture contains material on the deepest feelings, struggles and emotions of afflicted believers. Reading these detailed and unmitigated expressions and emotions can enable believers to articulate and work through their own feelings during times of severe loss and grief. In this way Lamentations can be applied as a tool in a model of pastoral guidance to families with deaf children in assisting them in giving expression to their innermost feelings.

Compassion goes a very long way in supporting others. Compassion does not only imply sympathy, but it implies a deeper sense of listening and understanding, even if one has not personally lived through the same experience. It entails a 'standing in the shoes of the other' and truly having commiseration.

- **Significance of normative principle for a pastoral model for the guidance of families with deaf children:**

- These poems in Lamentations can be used by the pastoral practitioner in his guidance of people going through the process of grief. In times where words fail the mourners, these poems can be significant too in providing the articulation of the emotions and feelings they are struggling to bring to words.
- The attitude of the poet of Lamentations towards the people was one of associating with their suffering. Priestly listening in terms of the guidance of families with deaf children implies immersing oneself into the life and situation of the other. The dual implication this has for the pastoral practitioner, is that he attentively listens to and empathises with the loss the family might experience, but also that he has compassion for the culturally Deaf community and their view of deafness, the result of which would be that he would provide accurate and unbiased practical information about deafness to the family.
- In practical pastoral counselling the book of Lamentations could serve as a foundation for the discussion and conversation in the pastoral process.

- **Significance of the normative principle for the pastor as leader of the community of believers**

- The pastoral practitioner should attempt to verbalize and reflect the emotions he/she picks up from the counselees. This verbalization of counselees' emotions should not merely be limited to the pastoral conversation but can also be reflected in the liturgy, sermons and prayers as a means of reflecting with counselees on their situation and emotions.
- The book of Lamentations can be incorporated as pastoral care via the liturgy of the community of believers. The pastor can express his compassion during the worship service in his prayers, etc. God brings people together as communities of believers and since liturgy has shared aspects with pastoral care, it serves as way believers can and ought to pastorally care for one another (De Klerk, 2015:2). The liturgy can

be utilized as an aspect of the pastoral care of the family with the deaf child. It can enable the family with the deaf child to express and work through their loss in public worship and in the space of the liturgy of the community of believers.

- Priestly listening involves immersing oneself into the experiences of others and therefore can be applied to an attitude towards deafness in which there is an intentional attempt to understand and have compassion for the way the Deaf view deafness and to therefore appreciate that which is dear to them – their culture and language.

4.5.2.2 Motivation of 1 Corinthians 12:1-31 as focus verses to address attitude toward deafness

In this passage Paul provides guidance regarding community worship, since the congregation in Corinth was characterised by disorderly and self-centred worship which was not to the edification of the church as a whole (Hays, 1997:206). Since the focus of 1 Corinthians 12 is on the variety of spiritual gifts in the congregation, it is key to an understanding of the implications of a Christian identity for the believer's attitude toward those who are different from him or her.

In 1 Corinthians 12:12-26 in particular, Paul compares the church of Christ to a human body made up by parts that are not only diverse, but also interdependent (Hays, 1997:206; Morris, 1989:170).

4.5.2.2.1 Exegesis of 1 Corinthians 12:1-31 and comparison with the rest of Scripture

a) Textual context of the pericope

Place of the pericope within the book of 1 Corinthians (Bybel, 2007:1757; Hays, 1997:13; Morris, 1989:33):

- Introduction (1:1-9)
 - Salutation (1:1-3)
 - Thanksgiving (1:4-9)
- Paul addresses certain problems in the church community (1:10-6:20)
 - Division in the church community: factions (1:10-4:21)

- Dissension and moral laxity in the church community. A call for discipline (5:1-6:20)
- Paul responds to disputed questions and issues in the church community in Corinth (7:1-15:58)
 - Guidance regarding sex and Christian marriage (7:1-40)
 - Guidance regarding Christian freedom: meat sacrificed to idols (8:1- 11:1)
 - Guidance regarding good order in public worship (11:2-14:40)
 - Guidance regarding the resurrection (15:1-58)
- Conclusion (16:1-24)
 - The collection for Judaea (16:1-4)
 - Paul's travel plans (16:5-12)
 - Final requests and greetings (16:13-24).

b) The place of the pericope in the Bible

The first epistle to the Corinthians forms part of letters written by Paul to various congregations. With this letter Paul teaches the church community how to love Christ and one another in the midst of a depraved society (Bybel, 2007:1755).

c) Sociohistorical context of 1 Corinthians 12:1-31

This congregation in Corinth was established by Paul during his second missionary journey (see Acts 18:1-20) around 3-5 years before the writing of this letter approximately 55AD (Bybel, 2007:1755; Hays, 1997:6).

The physical location of the city of Corinth as a trade route between Asia and Western had many benefits but also led to increased syncretism. Since this is the lifestyle from which the young Christians in Corinth were called, they remained confronted by it daily.

The faith of the believers in Corinth was being tested by a rotten society and they struggled to fully understand what freedom in Christ truly meant to them (Bybel, 2007:1755).

Paul then responds to these disputed issues and problems by writing this letter to them in which he provides honest and candour advice and guidance.

d) Analysis of the thought-structure of the pericope

This pericope forms part of a larger unit (chapter 11-14) in which Paul emphasizes respect and understanding for one another and in which he provides guidance related to good order in public worship. Chapter 12 consists of mainly two parts (Bybel, 2007:1776; Morris, 1989:164; Thiselton, 2000:907):

- a) The variety of spiritual gifts of the Spirit (12:1-11)
- b) Diversity in unity: one body with many interdependent members (12:11-31)

e) The genre of the pericope and the book in which it is found

1 Corinthians 12 as well as the whole book of Corinthians falls within the genre of a personal letter of exhortation and instruction, since it was written to address specific issues within a congregation.

f) Revelation historical placing and significance of the pericope

Paul introduced this chapter by referring to 'spiritual gifts' (12:1). In the Greek text the word πνευματικῶν (pneumatikon) is translated here with 'gifts', but it might also be understood as 'men' in its masculine form or 'things' in its neuter form. However, since all spiritual people are those people who have spiritual gifts, the difference in meaning is not important (Morris, 1989:163; Thiselton, 2000:910).

Thiselton (2000:930) as well as (Hays (1997:208) explains Paul's change from using the above Corinthian term for 'spiritual things' in verse 1 to 'charismata' (spiritual gifts, gifts of grace) in verse 4 as a means to shift the focus from personal claims of status or individual achievement to more humble realities about gifts of grace from God. In verses 1-7 Paul acknowledges the diversity of spiritual gifts, proclaims that all the gifts are grounded in unity since they are all from a common source (the Spirit) and explains that all the gifts serve God's purpose for the common good (Thiselton, 2000:932). These spiritual gifts are given to be utilised and utilised in a manner that is edifying to not merely the person who received it, but to the whole community (Hays, 1997:211; Morris, 1989:166). The emphasis in verses 1-11 is thus the sovereign initiative of God in freely giving and activating all spiritual gifts in the community (Hays, 1997:208; Thiselton, 2000:936).

In verses 12-31 Paul uses an analogy of the human body to indicate that because all believers are 'in Christ' they are one body. *"For just as the body is one and has many members, and all the members of the body, though many, are one body, so it is with Christ"*

(12:12). Although the members differ they share a fundamental unity, thus demonstrating unity in diversity (Morris, 1989:170).

The necessity of diversity is elaborated upon in verses 14-20. The diversity of the body is not accidental, but created according to God's design. "...*God arranged the members in the body, each one of them, as he chose*" (12:18). Each member has a specific purpose and is necessary for the body to function properly and no member should therefore regard him/herself as unimportant or without worth (Hays, 1997:215; Morris, 1989:171).

In verses 21-26 the attention moves to the interdependence of the members. "*If one member suffers, all suffer together; if one member is honoured, all rejoice together*" (12:26). One member may execute his own function well, but that does not make other members with different functions dispensable. In the same way, just as is the case with a human body, it is impossible for the rest of the body to remain unaffected if one member suffers the whole body is inevitably affected (Hays, 1997:215; Morris, 1989:173).

From this pericope it is clear that the matter addressed here is the variety of spiritual gifts and the importance, necessity and indispensability of all the members to the community. The 'stronger' members of the community should not ignore the apparently 'weaker' members of the body or exalt themselves above them. If they do so, they are doing it to their own peril. In fact, Paul exhorts the 'more honourable' members of the community to delight in showing honour to the 'less honourable' members (Hays, 1997:215-216). Thiselton (2000:900) aptly states that if the church of God does not keep on being inclusively mutual and reciprocal, it ceases to be the church.

God's will for the church community is consequently for all the members to work together harmoniously for the good of the whole body, a body in which there is individual freedom (14-20) as well as equality and concern, love for and support of one another (21-26) (Hays, 1997:220; Morris, 1989:173).

In addition to this revelational theme elaborated upon by Paul, 1 Corinthians 12 also provides an underlying idea. Paul aims to address the haughty attitude of some of the members of the community which results in the apparently less honourable members feeling despised and excluded from the rest of the body because of these differences in spiritual gifts (Hays, 1997:220). A challenging conversion of the imagination and attitude would be required for some members to truly view themselves as bound in one body, with the apparently 'weaker' members.

g) Comparing the pericope with the rest of Scripture

- **Believers to have an attitude of unity in Christ:**

The theme of having an attitude of 'one in Christ' is referred to in a number of places in the Bible. In Romans 12 Paul once again encourages the believers to be living sacrifices and to be totally transformed by the renewal of their minds, *"Do not be conformed to this world, but be transformed by the renewal of your mind"* (12:2a), indicating the effect of grace on various spheres in the believers' life. It implies a whole new way of thinking about everything and doing everything in accordance with the transformation of their lives in faith (Achtemeier, 2010; Moo, 1996:756) in order for believers to comprehend what God wants of them (Moo, 1996:757). Paul then continues to again use the metaphor of the human body to indicate the place each one has in the unity in Christ *"...so we, though many, are one body in Christ, and individually members one of another"* (12:5).

In correspondence with the above, we also find this motif on unity and equality in Christ in Galatians 3:28. *"There is neither Jew nor Greek, there is neither slave nor free, there is no male and female, for you are all one in Christ Jesus"* (3:28). The place of this in the revelation history is clear: God's faithfulness to His promise to Abraham in Genesis 12:3 forms the basis of this unity and liberated existence (Bruce, 1982:183; Cousar, 1982:83).

In view of the discussion of Romans 12 together with elucidation from other passages in Scripture it is evident that all believers are equal before God; each and every member has a gift and a function to fulfil and absolutely no member if the body is redundant or unimportant.

Formulated differently: if members fail to recognise the importance and necessity of all the other members and their gifts, they would be doing so to the detriment of the whole body.

- **Jesus Christ's humble attitude**

In Philippians 2:1-5 Paul characterises a community of believers in Christ and does so by using keywords from the preceding chapter as foundation (Craddock, 1985:35). *"So if there is any encouragement in Christ, any comfort from love, any participation in the Spirit, any affection and sympathy..."* (2:1). The opening word "so" used in this translation indicates an assumption that these experiences listed after it are already truly the believers'. Other translations translated this word with "if" and "since", all indicating a conditional clause used to lay a foundation for a request or instruction (Craddock, 1985:35; Hawthorne, 1983:224; O'Brien, 1991:165). The realities (indicative) listed in

verse one can be phrased as: *“Since there is encouragement in Christ, comfort from love, participation (fellowship) in the Spirit and affection and compassion...”* and is followed an elucidation of the humility of Christ and believers are exhorted or instructed (imperative) to follow His example and to have the same attitude of *“...having the same love, being in full accord and of one mind...”* (2:2). He urges them to do nothing out of selfishness or to disqualify other members on the grounds of their social standings, but to rather reflect true humility and to be ready to regard others more significant than themselves and to rejoice in them (O’Brien, 1991:603). Selfishness is avoided when one is willing to serve others and unity is maintained when members have each other’s interests at heart: *“Let each of you look not only to his own interests, but also to the interests of others”* (2:4). Jesus Christ was humble, obedient and willing to serve others; He *“...emptied himself, by taking the form of a servant, being born in the likeness of men...”* (2:7). The verb emptied used here is from the Greek κενόω (kenóō) literally meaning ‘to empty’ and then metaphorically meaning ‘to make to no effect’ (O’Brien, 1991:217). O’Brien (1991:217) suggests that the expression is used here as a way of saying that Jesus Christ poured out himself and placed himself totally at the disposal of people. Furthermore, Christ voluntarily took on the form of a slave, adopting both the nature and the characteristics of a slave in order to execute God’s plan of salvation (O’Brien, 1991:218; Vorster, 2014:95). He came down to earth and truly entered and immersed Himself into the lives and situations of other people. Vorster (2014:112) elaborates on the ethical implication of the form of a slave and explains that it entails that believers have to adopt Christ’s sincerity, love and compassion in their testimony and militate against unjust social structures and work towards the promotion of peace, justice and good relationships among all people.

Paul’s instruction in Philippians 2 is direct and clear: adopt the attitude of Christ (O’Brien, 1991:203). Christ suffered with people and for people; He showed compassion and love for the marginalised in society and His attitude of involvement, love and compassion ought to be reflected in the lives of believers (Vorster, 2014:111): *“...love one another as I have loved you. Greater love has no one than this: that someone lay down his life for his friends...”* (John 15:12, 13). With the above as the measure of love, Broesterhuizen (2007:11) argues that this love would also mean that the believer would be willing to share ideas and experiences, additionally implying a willingness to renounce or at least reconsider one’s own viewpoints, ideas and wishes out of love for the other; to enter the world of the other person and seeing the world from his perspective and experience. It entails a willingness to be convinced of the other person’s view, yet always judging it in the light of Scripture.

Christ's attitude transformed people and in turn transformed societies (Vorster, 2014:111). This attitude of Christ is exemplary to the believer. The believer ought to be guided to comprehension of how Christ encourages him; what the implication of God's love for him entails as well as what the significance of the fellowship of the Holy Spirit is. Only then, when this grace of the Triune God is a reality to the believer, will he be able to adopt the attitude of Christ in his life.

In Philippians 2:12-13 Paul urges the community of believers to not only focus on their individual lives but particularly to continuously work on their communal spiritual well-being with godly fear and more zeal than before, until all the community of believers fully develop spiritual health and wholeness (Hawthorne, 1983:99; O'Brien, 1991:274). They are also comforted and encouraged that they are not alone in this process and don't have to rely on themselves. In fact, as a result of the powerful work of God in them they are enabled to and ought to work towards achieving these spiritual objectives (Hawthorne, 1983:100).

h) Choices of faith that the first readers were confronted with

As already mentioned in the preceding passages, the young believers in Corinth were faced with decisions related to Paul's explanation in 1 Corinthians 12:1-31 that the diversity in the gifts among the community of believers is equally necessary. Additionally, they are all indispensable members of the same body of Christ and should deem each other as such.

i) Conclusion

God sovereignly freely provides the community of believers with a variety of indispensable, equally important spiritual gifts (12:4-6). God is also the common source of all these gifts serve the purpose of being used in a way that serves the common good, i.e. edifying and to the benefit of the whole community of believers (12:7). Even the seemingly 'weaker' members are important and should be included and honoured (12:22).

The community of believers is comparable to a human body in which each member has a specific task and function and without which the body would not be able to function effectively (12:14-20). This unity with its diverse and interdependent members is not accidental, but designed as such by the Holy Spirit (12:7-11). No member should be regarded by himself or by others as unworthy or insignificant in the functioning of the remainder of the body. If any of the members suffer in any way, the whole body inevitably suffers with it and therefore members are to have an attitude of care for one another, be

concerned about each other and support and love each other for the good of the whole, unified body (12:24-26).

God can change a believer's way of thinking by renewing the believer's mind. The result being that the believer can think differently about everything and do things in correspondence to God's will. Since the community of believers have unity in Christ the renewal of their minds should also include that they will truly have an attitude of unity in Christ and that they are all equal before God.

The members of the community of believers are one in Christ and together form the body of Christ (12:12). Additionally believers ought to also follow Christ and resemble Him in the way that they think and behave. Christ voluntarily took on the form of a slave and served others. He was humble and sincere and showed love and compassion for the marginalised people. He suffered with others and was truly involved. The community of believers should reflect this attitude of Christ in their lives, act against unjust social structures and promote justice and good relationship among all.

Adopting the love of Christ implies a willingness to truly listen to others, to learn to appreciate their otherness and to really view them as part of the unity in Christ. In this way people are transformed, bridges are crossed, distances in relationships are decreased by love and in turn societies can be transformed.

j) Normative principle

- The variety of spiritual gifts in the community of believers is all of the same Source. God sovereignly allots the spiritual gifts freely and these gifts, although they vary greatly, all equal. None are more important than the other.
- The community of believers is unified as the body of Christ. Each member, from the apparently 'stronger' to the apparently 'weaker' members has a specific function in the body. God designed the body to be interdependent and therefore all members are necessary for the effective functioning of the whole body. Subsequently, if one member suffers, all the members are affected. Members of the body have an obligation to care for each member of the rest of the body, be concerned for one another and love each other for the benefit of the whole body.
- As the body of Christ believers ought to adopt Christ's attitude and follow His example of involvement, humility, sincere compassion and love for all, also the

‘weaker’ members (marginalised) in society and in this way encourage justice and good relationships among people.

- Adopting the attitude of Christ means being willing to place others’ interests above one’s own; to be prepared to renounce one’s own perspective and ideas out of love for the other. It suggests seeing those who are different from you as part of the unity in Christ. Boundaries between people who differ from each other are not bridged by “undoing” the “otherness” of one party, but by a love that has learned to recognise and appreciate the uniqueness, otherness of the other person.
- The above-mentioned uniqueness (otherness) of each member of the body should not merely be recognised and appreciated but additionally be actively discovered and utilized.
- **Significance of normative principles deduced from 1 Corinthians 12 for a model of pastoral guidance of families with deaf children**
 - Families with deaf children characteristically view deafness, at least initially, as a disability, which in turn impacts on the way they might look at their child. Pastoral guidance of a family with a deaf child ought to focus on the importance of the child in the larger body of believers. God has also placed this child in their family with a function to fulfil. This might assist parents to gain hope and to view their child as a healthy child, a child with potential and a future, a child who is a unique gift to the community of believers and who has an important role to play in the body of Christ and in society.
 - Adopting the attitude of Christ in this application would mean that the pastoral practitioner would emphasize the interests of the deaf child. The pastoral practitioner ought to be fully informed in order to guide the families in decisions which would impact the mental, emotional and spiritual well-being of their deaf child (Burke *et al.*, 2011:277).
 - The pastoral practitioner guides parents to discover and apply their own gifts in practising their diakonia. Their gifts will potentially be honed by their current situation and provide additional, unexpected opportunities for diakonia.

- **Significance of normative principles deduced from 1 Corinthians 12 for the congregation and the pastor as the leader of the congregation**
 - Certainly the pastoral practitioner and faith community will have compassion with the family with the deaf child. But compassion with the deaf child necessitates the believer to also have compassion with the Deaf community and the way they understand and experience their deafness. Kenosis implies “being Deaf with the Deaf”, by ridding oneself of the “empowerment” that causes separation in the relationships between hearing and Deaf people (Broesterhuizen, 2005:328). This separation can be bridged, not by simply “removing” or “undoing” the other’s ‘otherness’ but to bridge the distance by love. A love which views others as part of the unity in Christ, and a love that learns to be amazed by the other person’s individual qualities (Broesterhuizen, 2007:12).
 - The eye and the ear must be appreciated for what they are – eyes and ears. Eyes cannot hear and ears cannot see. In the unity of the body the eye and the ear need each other and are interdependent on each other. The deaf child must therefore be accommodated by the other members of the body. The deaf child is a unique and indispensable being and has a function to fulfil in the wellness of the body. Consequently the rest of the body suffers when the deaf suffer and rejoice in the things they rejoice in. The culture of the entire pastoral care of and ministry to the deaf (and therefore also families with deaf children) should be viewed in this light.
 - An attitude as described above would not only increase compassion between the hearing and the deaf. All members will be enriched and by reaching out to each other a space is created where dialogue can take place and strangers can move closer to each other, be enriched by each other and confirm each other’s unique place in the body of Christ. By discovering and appreciating each other’s differences and functions a process of growth is encouraged: Growth toward each other as well as spiritual growth toward reflecting God in their relationship (Broesterhuizen, 2008:116).
 - The parents of deaf children (and later in their lives, deaf children as well) have a responsibility to not only discover but actively apply and utilise their gifts to serve others. Parents (and later their deaf children themselves) should therefore accept that the unique position they are in enables and hones them to make a unique contribution in the life of others. The same applies to the deaf child.

4.5.3 Biblical perspectives regarding ethical questions related to deafness

4.5.3.1 Introduction

The initial emotions most likely experienced as parents move through the various phases of the grieving process toward acceptance might give rise to various ethical questions and dilemmas parents find difficult to deal with (2.5).

Spiritual questions related to the relationship with God might arise:

“How do you explain to a young child that God is almighty, that He can heal her, but sort of chooses not to do so?” (Participant H).

“And you don’t understand; and I cried and said ‘Lord I can’t, I can’t believe in you anymore’. I struggled with the Lord in the process...You know, you feel guilty because you feel the way you do, and because I fought with the Lord so much. But yet, when the full...realisation of everything, in working through it...you know... the Lord was actually so good to me...Really....” (Participant B).

Initially, parents are most likely totally unaware of the contrasting views of deafness, oralism versus sign language (3.4.2), the sensitivity regarding deafness versus Deafness (3.4) and the cochlear implant controversy (3.6.1.3.1). Apart from wrestling through the phases of grief and coming to acceptance of their child’s deafness, parents have to cope with an overwhelming amount of new information and with difficult decisions they have to make (3.6.1.3).

The previous chapters of this study indicated a great need for normative guidelines from Scripture in addressing this variety of issues related to the sovereignty of God on the one hand and the more practical ethical questions and difficult life-altering choices families are faced with on the other.

Space does not permit an elaborate discussion of all the practical choices in terms of deafness; however, the ethical questions about the sovereignty of God will be briefly discussed and serve as an example of how other ethical questions can be addressed in the model of pastoral care of the family with the deaf child.

4.5.3.2 Practical ethical choices

The full scope of particularity the more practical ethical choices is not exhaustively discussed in this section since the goal of this thesis is not to adjudicate all the ethical choices as essentially either ‘right’ or ‘wrong’. The researcher strongly judges that an attitude of humility,

other-centeredness and love is adopted, a basis for continued conversation is created in which deafness can be viewed as an opportunity to gain access to an additional culture and the opportunity to learn a second language (Broesterhuizen, 2008:123; Burke *et al.*, 2011:277). If the interests of the deaf child are placed above all else, the pastoral practitioner will emphasise the importance of early access to language etc. and the advantages of exposure to Deaf culture. If the plea of the deaf community for a bilingual-bicultural approach to deafness is thus respected, this attitude will largely determine the ethical choices parents will make for their deaf child. It is in this process that the pastoral practitioner has a crucial task in entrenching and equipping himself sufficiently in all aspects of deafness and to be in a position to place all the relevant information on the table, create awareness and pastorally guide parents in their wrestling through these difficult choices and questions including:

- Questions related to faith healing
- Questions related to the cochlear implant controversy
- Choices regarding the mode of communication (1 Cor. 14:10-11)
- Choices regarding education

4.5.3.3 Biblical perspectives related to the question of the sovereignty of God

The ethical question parents might struggle with, specifically in the early stages of the process of grief, is the whole matter of whether it was the will of God for their child to be deaf. If it was not the will of God, then the question arises of how He was involved and if this would imply that He is not truly in control of everything that happens. In times like these believers might wonder if there are things against which God stands powerless. The children of God have been struggling with the difficult question about suffering in this life for centuries (Coetzee, 2015:5).

In essence this question is about the sovereignty of God, our relationship with God and it is a result of how we see God. The will of God is sovereign and independent of man. Yet at the same time, the will of God is perfectly just and wise. Paul testifies to this in Romans 11:33-36: *"Oh, the depth of the riches and wisdom and knowledge of God! How unsearchable are his judgments and how inscrutable his ways!"*

The ways of God cannot and will never be fully comprehended in this dispensation. The answers to many questions will never be found. The goal of pastoral care with regards to the sovereignty of God can therefore not be to provide believers with definite answers and to explain the mysteries of God to them, but rather to compassionately join them in their

wrestling to comprehend the things of God. Romans 1:34-36: *“For who has known the mind of the Lord, or who has been his counsellor?” “Or who has given a gift to him that he might be repaid?” For from him and through him and to him are all things. To him be glory forever. Amen.”*

The normative insights gained from Lamentations provide principles with respect to this cooperative wrestling together with others about with the mysteries of God and the things not to be comprehended in this life. Lamentations 3:22-25 indicates a turning point, where the transition from affliction to reflecting on the attributes of God is clear. The focus is shifted from being perplexed in terms of the affliction to reflecting on the attributes of God that are known and which can be understood. The unchanging attributes of God include: God is wise; God is good; God is righteous; God is merciful; God is omnipotent; God is faithful.

The concept of remembrance and reflection plays an important role in working through grief after great loss and has important implications for pastoral care to a person who experiences great loss. This change in perspective can be a great source of comfort. Examples from Scripture of people in despair coming to this turning point in perspective include Habakkuk, the psalmist of Psalm 73 and 79 as well as Job, in chapter 42.

From Lamentations it is clear that the poet went through the emotional turmoil of the ups and down of the process of grief during which his emotions fluctuated between the lows of depression, anger and wrestling with God, to the highs of finding rest and comfort in the Lord, only to fall back into despair again.

The pastoral practitioner must be equipped to pastorally care for believers who are struggling to understand and accept the sovereignty of God. His role is not to merely provide an explanation of the definition of the sovereignty of God but to guide believers to make this intentional transition to focus on the attributes of God and remembering God’s covenantal love which implies that everything that happens stems out of His covenantal love. He guides them to enter into conversation with God. God’s covenantal love and faithfulness surpasses everything and His providence our only source of comfort in this life (Coetzee, 2015:6).

- **Significance of normative principles related to the sovereignty in a model for the pastoral care of families with deaf children**

Although parents of deaf children might initially be desperate for answers in terms of why their child was created or became deaf, the pastoral practitioner’s role will not be to try and provide an explanation. However, he can compassionately join the parents in their wrestling with God and guide them to focus on things they as believers can understand and hang on to.

If each passage is read, expounded and applied with care and empathy in its greater context in Scripture the following passages from Scripture could be used in pastoral care to affirm God's personal involvement include:

- **Exodus 4:11:** *"Then the Lord said to him, "Who has made man's mouth? Who makes him mute, or deaf, or seeing, or blind? Is it not I, the Lord?"*
- **Psalms 139:** Focusing on the omnipotence (7-12) and the omnipresence of God (13-18) draws attention on the fact that God is in control, knows us through and through and that He determines absolutely everything. *"For you formed my inward parts; you knitted me together in my mother's womb. I praise you, for I am fearfully and wonderfully made. Wonderful are your works..."* (Ps. 139:13-14).
- **John 9:3:** Specifically when parents struggle with the 'why' and feelings of guilt because of their child's deafness, parents can find comfort in Jesus' reply to his disciples when questioned about the cause of a blind man's blindness: *"Jesus answered, 'It was not that this man sinned, or his parents, but that the works of God might be displayed in him'."* This additionally emphasises the important function of the apparently 'weaker' members in revealing the works of God.
- Finally, the reassurance can be gained from **Jeremiah 29:11** that God has a plan for everything that He does, including (and it is not necessary for the believer to necessarily understand the what, how and when of His plans) (Wright, 2000:136). Parents of a deaf child can find solace in the fact that this is also true for their deaf child: *"For I know the plans I have for you, declares the Lord, plans for welfare and not for evil, to give you a future and a hope"* (Jer. 29:11).

The sovereignty of God cannot be explained or completely understood. The pastoral practitioner cannot provide parents with all the answers to the questions that they are struggling with. Yet, he can use passages from Scripture to time and time again guide them back to Coram Deo, to guide them to bring their question to the Lord and to lament: "Oh Lord, we do not understand", and additionally make the choice to add "We choose to focus and believe in Your attributes and intimate involvement in our lives, as revealed to us in Scripture". The passages above can therefore serve as examples of passages to reflect on remind oneself of in times of perplexity.

4.6 CONCLUSION: NORMATIVE AND ETHICAL PERSPECTIVES FROM SCRIPTURE FOR A MODEL FOR THE PASTORAL CARE AND COUNSELLING OF FAMILIES WITH DEAF CHILDREN

This chapter set out to determine what normative and ethical perspectives Scripture provides regarding the desired situation of pastoral care and counselling of families with deaf children. The normative perspectives gained were compared with the interpretive perspectives in order to determine the significance of the Wisdom of God in its interaction with worldly wisdom.

The book of Lamentations would be particularly valuable to the pastoral practitioner in the pastoral care of a family with a deaf child. By using Lamentations the pastoral practitioner would not only be validating the process of grief but also be able to encourage the family to embrace their grief and wrestle through this spiritual pilgrimage with God.

The pastoral practitioner can utilise the poems of Lamentations as a tool in assisting the parents of the deaf child in articulating their feelings of loss. Additionally Lamentations can also be used in the liturgy of communal worship as it provides a way of publicly working through their loss in the space of the loving community of believers.

In the light of 1 Corinthians this study confirms the shift in literature in the way deafness is not viewed as a disability but respected as a minority socio-linguistic culture. From 1 Corinthians 12 the pastoral practitioner can encourage both the parents of the deaf child and the rest of the community of believers to view all members as equal and to be cautious not to view the deaf child or other deaf members as less important. The unity of all the members in Christ implies that the deaf child is to be recognised and appreciated as an element of variety in the unity, as a gift and as having a unique role to play in the proper functioning of the whole body. The child's deafness provides him with distinctive gifts and opportunities, which should be developed and applied.

In the light of Philippians 2:4 and John 15:12-13 specifically, believers ought to be urged to adopt an attitude of Christ, by immersing themselves in the life and experiences of others. By loving others and also by looking after the interests of others, in this case, the deaf.

In practice this would imply listening to their needs, their perspectives and being willing to reconsider their own perspectives of deafness as a disability to deafness as the way culturally Deaf people view it - a socio-linguistic minority culture. The hearing community (family, pastoral practitioner, faith community and greater community) ought therefore to be called up to an attitude of compassion and understanding toward the deaf, Deaf culture and

the Deaf way of life. Furthermore, the deaf members of the congregation must be accommodated and their interests looked after.

However, characteristically the medical view of deafness is maintained by the majority of medical professionals and therefore the needs and interests of the deaf are often not heard. The pastoral practitioner has a crucial role to play in being fully informed of all aspects of deafness in order to be able to provide accurate and reliable information and to similarly provide parents with the Deaf perspective of deafness, thereby also personally practising the principle of Philippians 2:4 and John 15:12-13.

The pastoral practitioner working with families with deaf children must be prepared for a wide variety of ethical questions that might arise and be able to compassionately guide families in their wrestling with comprehending, for instance, the sovereignty as well as other more practical questions in terms of important life-altering choices to be made. He should also equip members of the congregation to minister to and serve deaf and their families.

If the pastoral practitioner himself adopts an attitude of Christ in this personal view of deafness, he would be considerably better equipped to guide the family of the deaf child as well as the rest of the community of believers and possibly even the larger society to adopt similar attitudes. He would also be in a better position to minister to the deaf child in his context. Burke *et al.* (2011:272) conclusively state:

The community needs to understand deafness as primarily a condition of gaining a culture and language rather than sensory loss, so that family and others evolve from grieving the loss of their expectations of what their child's life might be like to looking forward with hope to the unique contributions that child can bring to the world.

4.7 INTEGRATION OF NORMATIVE PERSPECTIVES WITH THE PERSPECTIVES FROM THE EMPIRICAL AND INTERPRETIVE CHAPTERS

Integrating the perspectives gained from the empirical, interpretive and normative tasks presents the pastoral practitioner with quite a challenge: *"How can they remain open to the world and learn from the knowledge it offers, while placing this knowledge in a theological context based on the redemptive Wisdom of Christ?"* (Osmer, 2008:100).

Cross-disciplinary dialogue is defined as “a special form of rational communication in which the perspectives of two or more fields are brought into conversation” (Osmer, 2008:163) and is necessary to relate the empirical findings and the ‘worldly wisdom’ of the auxiliary sciences to the Wisdom of God. Cross-disciplinary dialogue guides the pastoral practitioner in determining what ought to be done, before moving over to the next task of pragmatic theological interpretation with the aim of a strategy in order to move towards these desired “ought to issues”.

CHAPTER 5

PASTORAL CARE AND COUNSELLING OF FAMILIES WITH DEAF CHILDREN: THE PRAGMATIC TASK OF SERVANT LEADERSHIP

5.1 INTRODUCTION

With the inception of this study (chapter 1) the central theoretical argument was formulated that families with deaf children could greatly benefit from a pastoral practical theological counselling model for much-needed pastoral care and counselling.

In the subsequent chapters the focus in chapter 2 was on embarking on an empirical study in order to investigate the current situation regarding pastoral care and counselling of families with deaf children; in chapter 3 on gaining meta-theoretical perspectives from auxiliary science, in order to interpret the current situation and in chapter 4 on finding normative principles from Scripture for relevant application in the pastoral care and counselling of families with deaf children. The last remaining task for practical theological interpretation according to Osmer's model (Osmer, 2008:4) is the pragmatic task, as indicated in the diagram below:

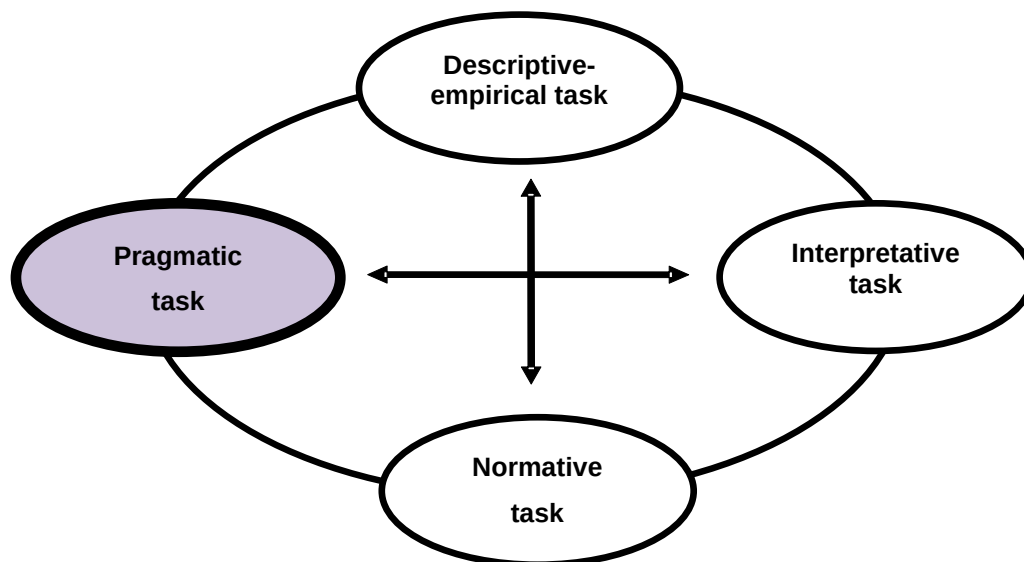


Figure 5-1: The pragmatic task (Osmer, 2008:11)

The pragmatic task entails the formulation and implementation of a strategy or action plan for the solution of the problem formulated in the empirical-descriptive task (*"How might we respond/how should we act?"*). This pragmatic task further implies change towards desired goals. Therefore, synthesis established by a hermeneutical interaction between the research

results of the descriptive, interpretative and normative tasks will be utilized in order to propose perspectives and guidelines for a model for pastoral practitioners in the pastoral care and counselling of families with deaf children.

5.2 OBJECTIVE

The aim of this chapter, as already mentioned, is to make the transition from theory to practice by formulating and discussing strategic perspectives and guidelines from the findings of the current research in order to finally propose a model for pastoral practitioners in the pastoral care and counselling of families with deaf children.

In order to execute the above aim, it is necessary to integrate the results of chapters 2, 3, 4 of this study, as the synthesis established by hermeneutical interaction between the research results of the descriptive, interpretative and normative tasks will be utilized.

5.3 ELUCIDATION FROM THE VARIOUS CHAPTERS OF THIS RESEARCH AND ITS SIGNIFICANCE FOR A PRACTICAL THEOLOGICAL MODEL:

The following discussion was done by considering the results of the preceding chapters of this study for the subsequent significance and application thereof in the current chapter, as shown in the diagram below:

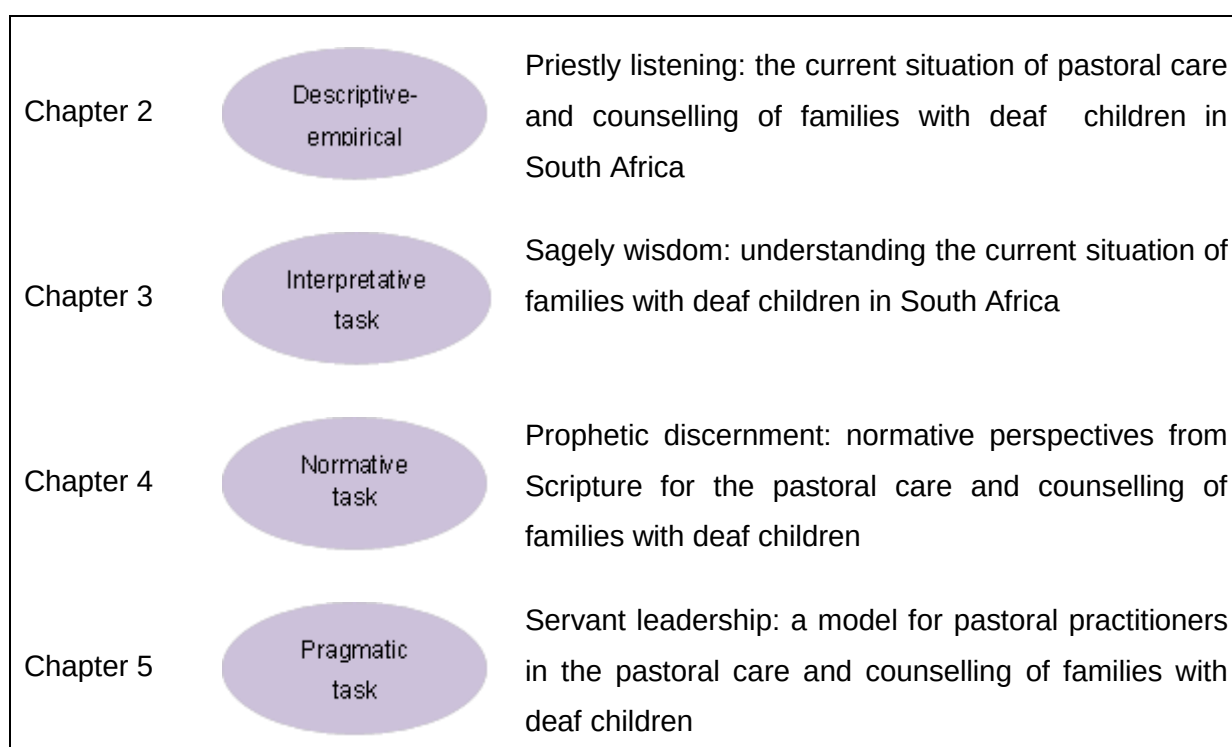


Figure 5-2: Summative view of discussion plan

5.3.1 Elucidation provided by the descriptive-empirical task of priestly listening

The qualitative inquiry revealed that parents of deaf children typically have very little prior knowledge and exposure to deafness. Consequently learning of their child's deafness triggers a process of grief characterised by feelings of shock, being overwhelmed, frustration and struggling with the diagnosis, sadness, fear of the future and finally acceptance.

Families in the process of adapting to deafness in the family are faced with numerous educational, communicational, spiritual and practical challenges.

The guidance families have mostly received from professionals in the medical field could mostly be characterised as pathological in approach and as a result little to no information in terms of the other approaches to deafness was provided to families.

The support families enjoyed from family and friends was described as accommodating, understanding, supportive and encouraging. Although some felt supported by their spiritual community, none reported being provided with any formal pastoral counselling or broader pastoral care during this particularly challenging time in their lives.

The need for pastoral care and guidance was emphasised by the impact deafness had on the spirituality of the family and the difficult ethical questions it brought to the fore. Participants' needs and expectations serve as recommendations to religious communities in this regard.

The significance of the above elucidation for a pastoral model is firstly that pastoral practitioners faced with families with deaf children should have a spirituality of presence and truly attend to the experiences, needs and expectations of the families. Priestly listening implies truly listening to people and having compassion with them. Pastoral practitioners must increase their understanding of issues emanating when working pastorally with families with deaf children in order to develop their ability to lead the family and also the community of believers more effectively.

5.3.2 Elucidation provided by the interpretative task of sagely wisdom

The literature study yielded insight into the various aspects of deafness including levels, age of onset and aetiology of deafness as well as types of deafness. It also confirmed the difficult emotional process of grief (from the empirical study) parents of deaf children typically go through when first learning about their child's deafness.

Additionally to the two traditional approaches to deafness, i.e. the medical (pathological) model and the socio-cultural model of deafness, the literature study revealed a development in terms of a bilingual-bicultural view which creates room for conversation between the two traditional views.

The results from the literature study confirmed the results from the empirical study, these being that the guidance generally provided by specifically medical professionals tends to be from a one-sided, pathological view of deafness. Overwhelmed and uninformed parents rely greatly on the advice of the medical professional in their choices about treatment, education and language.

Parents and professionals can play an important role in the deaf child's social and emotional abilities and therefore the bilingual-bicultural approach could be a great tool in addressing both the needs of the child and assist parents in making informed decisions for their deaf child. Researchers additionally place emphasis on the significance of early identification of deafness, followed by early intervention and full access to a comfortable language as influential to the outcome of the communication abilities and overall development of the deaf child.

In terms of spirituality of deaf children, it became clear that the choice of communication and education can influence the spiritual development of the deaf child and therefore the language needs of deaf children should be a high priority on any professional's agenda.

The insights gained from the interpretive study came down to the fact that, if parents and professionals were to make a paradigm shift from the pathological view of deafness to adopt a bilingual-bicultural dialogue approach their understanding deafness as a condition of gaining a culture, progression from grieving to acceptance could be facilitated by hope for their child's future. This approach would subsequently impact the decisions to be made in terms of hearing technology, communication and education.

This inquiry also highlighted the challenges of terms of Deaf pastoral ministry and the deficit in terms of spiritual and religious resources on deafness readily available to pastoral practitioners, in order to ensure optimal pastoral care and counselling of these families and optimal development of deaf children.

5.3.3 Elucidation provided by the normative task of prophetic discernment

The normative perspectives gained from the exegesis were compared to the interpretative perspectives thereby determining how worldly wisdom appropriately relates to and interacts with the Wisdom of God (Osmer, 2008:162).

Exegesis of the book of Lamentations confirmed the process of grief referred to in both the empirical and interpretive studies. Lamentations validates the process of grief and can therefore be used to assist the parents of the deaf child to articulate their grief and to encourage the family of the deaf child to wrestle through this process with God. Lamentations can also be used in the liturgy of communal worship as a way of publically working through grief in the sphere of the community of believers.

In view of the exegesis of 1 Corinthians 12 and additionally considering Philippians 2:4 and John 15:12-13, this research supports the shift in literature in the view of deafness. All members of the community of believers are equal and unity in Christ implies that the deaf is to be recognised and appreciated as an element of variety in the unity, as a gift and as having a unique role to play in the proper functioning of the whole body. The child's deafness provides him with distinctive gifts and opportunities, which should be developed and applied.

The personal attitude of the pastoral practitioner will determine his pastoral care of and guidance for the family with the deaf child and he should therefore recognise and assess his own attitude first. He should be fully informed of all aspects of deafness, which will enable him to pastorally care for the family with the deaf child, to provide accurate and reliable information about all views of deafness and provide normative advice in terms of ethical issues.

All believers in the community of believers ought to be urged to adopt an attitude of Christ, by immersing themselves into the life and experiences of others. By loving others and also by looking after the interests of the deaf. This would be congruent with the bilingual-bicultural dialogue approach to deafness, which emanated from the interpretive task of this study.

5.3.4 Integration of attained results for a strategy for the pragmatic task

The fourth of Osmer's (2008:10) tasks of practical theological reflection focuses on identifying action strategies in order to adjust the current situation (as described by the empirical task) to the ideal renewed situation or goal (as described by the normative task). It asks: *"How might we respond in ways that are faithful and effective?"*

Applied to this study, the essence of the pragmatic task would be to determine strategies of action that will shape the current situation of the pastoral care and counselling of families with deaf children toward desired the ideal situation.

The model to be proposed will be aimed at: *“Determining strategies of action that will influence situations in ways that are desirable and entering into a reflective conversation with the ‘talk back’ emerging when they are enacted”* (Osmer, 2008:4).

Van Wyk (1995:85–101) explains a model as referring to the way or the procedure by which certain aims and objectives are attained. In accordance with Osmer’s understanding of the pragmatic task, practical theology entails the dynamic process of critical and constructive theological reflection on the praxis of the church in the world, carried out in the light of Christian Scripture and tradition. It implies critical dialogue with other sources of knowledge in response to their interpretations of the challenges and situations they face. This dialogue leads to ongoing modifications and transformations of the church’s practices in order to be more adequately responsive to their interpretations of the character of God’s call to partnership. The primary purpose of a practical theological model would therefore propose a way to ensure that the church’s public proclamations and praxis in the world authentically address the contemporary contexts into which the church seeks to minister by faithfully reflecting the nature and purpose of God’s continuing mission to the world (Anderson, 2001:22; Fowler, 1999:75).

5.4 A BIBLICAL MODEL FOR THE PASTORAL CARE AND COUNSELLING OF FAMILIES WITH DEAF CHILDREN

Various authors published literature on pastoral care and counselling and have proposed models, phases and processes for pastoral care and counselling, and some of the more prominent include Jay E Adams’ nouthetic counselling model (Adams, 2009), Howard Clinebell’s holistic growth model (Clinebell, 1984:25), Daniel McKeever’s narrative model (Louw, 1998:365), Lawrence Crabb’s rational-analytical / Biblical model (Crabb, 1978), Gary Collins’ Christian counselling model (Collins, 2007), Daniël Louw’s conversation model (Louw, 1998) and Donald Capps’ thematic metaphor model (Capps, 1979:79-107).

Breed (2015) proposes a Biblical model for pastoral counselling in which he incorporates elements and principles from the work of various authors including Larry Crabb, Richard Osmer, Tim LaHaye, John MacArthur, Craig Groome, William Backus and Paul Tripp. This model essentially centres on believers’ relationships (and conversations) with God and convictions believers have formed from experiences in their lives. These convictions are explored to identify them as either true or false; after which false convictions (lies) are then

addressed with God's eternal truths as found in Scripture. This model is very appropriate for an array of pastoral situations ranging from marital counselling, trauma counselling, addiction counselling etc.

Without elaborating on the various pastoral processes and models that exist for pastoral care, the Biblical model for pastoral counselling (Breed, 2015) is used as framework for a practical theological model for the pastoral care and counselling of families with deaf children. Since Breed's model is used in trauma counselling it could also be helpful in addressing the mourning process parents of deaf children go through (as indicated in the descriptive-empirical study). Throughout this study the effect of parental attitude towards deafness has surfaced as playing a crucial role in the overall well-being and development of the deaf child. Breed's model would be particularly applicable in evaluating and addressing the beliefs especially hearing people have towards deafness.

The model of Osmer, which was utilized to conduct the current study, is also incorporated in Breed's model.

Therefore, since Breed's Biblical model for pastoral counselling incorporates the same model used for this study and appears to be relevant in addressing essential issues raised in this study, the researcher considers it to be an appropriate model to utilize as a framework or foundation in developing the researcher's own model for the pastoral care and counselling of families with deaf children.

5.4.1 Important points of departure

5.4.1.1 Relationship between practical theology and psychology

Pastoral care consists of two dimensions, being the horizontal and vertical lines, where the vertical line emphasises man as an integrated being within a social context. Psychology is based on principles including making sense of life, accepting oneself and optimal self-actualisation. The focus is on the needs and the emotions of the individual and how he can find help and joy within himself, and come to independent answers as solutions. Since pastoral care works from the principle that God is the creator of everything and reveals Himself in nature, it can utilise insights discovered in psychology. However, pastoral care additionally provides the will of God for man as the norm, the *"what ought to be going on"* (Breed, 2015).

The pastoral practitioner will therefore not only actively provide advice and knowledge of deafness but also focus on norms in terms of deafness and guide the family to God.

An overemphasis of either knowledge, emotions or actions of the counselee on the horizontal dimension is less than ideal and the model of Osmer can assist in maintaining balance in pastoral care.

5.4.1.2 Goal of pastoral counselling

In his book, Crabb (1978:29) explains that the goal of pastoral counselling is "...to promote Christian maturity, to help people enter into a richer experience of worship and a more effective life of service". Breed (2015) confirms this and adds that pastoral care aims to guide people to a deeper knowledge of God and themselves, through the powerful work of the Holy Spirit, so that they may grow in their faith. Maturity in faith will aid believers to deal with crises in their lives and enable them to live a life which honours God, with peace in their hearts.

Pastoral care aims to bring man to a closer relationship with his Creator and to guide him to conversation with God. Man is a being in conversation; conversation with God, conversation with his fellow man and also with himself. Stressful or traumatic life events trigger a conversation between man and the specific situation. During the pastoral conversation the practitioner joins this conversation of the counselee. He should then try to "come into the conversation". The question of Osmer "*what is going on?*" is relevant here. What is the counselee telling him- or herself? How does he/she interpret the things that happened to her? In the end the practitioner should facilitate a conversation between the believer and God. He joins the conversation temporarily and then exits the conversation again. The essence here is that the pastoral practitioner merely acts as the facilitator in the conversation between God and man (Breed, 2015). The traumatic experience of learning of their child's deafness similarly triggers a conversation in the parents' minds; not only a conversation with God, but also a conversation with deafness, their deaf child, themselves and other people. The pastoral practitioner enters these conversations to comprehend the conversations already taking place.

The family with the deaf child can then be assisted in their adaptation to a life with deafness via the pastoral process. The pastoral process is the ideal place to receive guidance, sound practical advice, comfort and equipment in terms of deafness and all the challenges it brings. Pastoral counselling therefore joins the existing conversation and is involved in the conversation for a limited period after which it exits the conversation again for the conversation between the parents and God to continue independently from the pastoral practitioner. Essentially pastoral counselling is, according to Breed (2015), the facilitation of the conversation between a believer and God.

The pastoral practitioner cannot guide believers to a conversation with God if he does not fully understand God's conversation with man and man's conversation with God. The basic principles that underlie Breed's Biblical pastoral model provide insight into this conversation.

5.4.1.3 Guidelines in terms of the role of the pastoral practitioner

Being called in to stand in the service of Christ and being in a living relationship with Christ, the pastoral practitioner should radiate the attitude of Christ. This attitude implies a total pouring out of one's one life in serving others and forms the foundation upon which the pastoral relationship will be built (Breed, 2015; De Wet & Breed, 2014b:17).

Before each encounter the pastoral practitioner prays for wisdom and insight and also for the Holy Spirit to comfort the counselee and to give him peace. In this way the pastoral practitioner also reminds himself that it is not him/her doing the work or who works in the counselee but the Spirit of the Lord who works in the life and heart of the counselee.

With this in mind the pastoral practitioner can focus on creating a trusting environment where the counselee feels truly listened to and cared for. The focus of gaining access to the story of the counselee's life is about much more than bringing the normative will of God to the table, it is also about bringing the person in conversation with the Triune God, so that he/she can be comforted, encouraged and taught through that relationship; it is about proclaiming the grace of the Lord. It is an attempt to understand and to determine what the grace of God the Father, Son and Holy Spirit means in this particular context and to speak God's Word into this situation (Breed, 2015)

In the broader sense of the pastor's role as leader of a congregation, Osmer (2008:192) explains the pastor as follows: *"Servant leadership is leadership that influences the congregation to change in ways that more fully embody the servanthood of Christ"*. Pastoral practitioners, though not limited to only being leaders of congregations, ought to lead the community of believers to change in ways that more nearly reflect its mission as a contrast to society and social catalyst.

5.5 THE BASIC FOUNDATION UNDERPINNING BREED'S BIBLICAL PASTORAL MODEL

Man is a being in conversation. He continually converses in his mind with himself, his convictions and his environment to try and make sense of life, life events and in trying to figure out a way to diminish pain and find solutions for problems in his life. This conversation in man's mind determines man's reaction in life situations.

The depiction below is a summary of Breed's (2015) understanding of the flow of the conversation in man's mind:

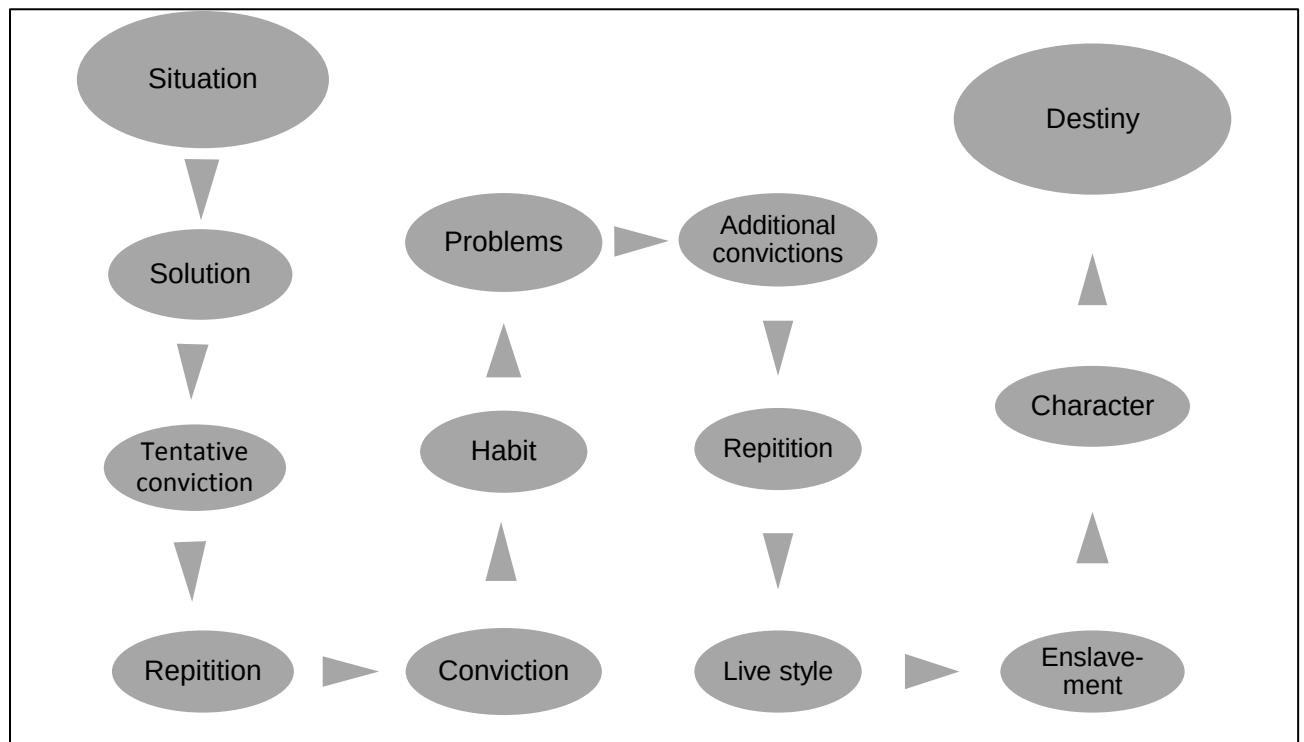


Figure 5-3: Summary of conversation in man's mind (adapted from Breed, 2015)

An event or situation in life may lead to a crisis situation in which the believer is faced with decisions in terms of how to respond to the specific situation. This decision that a person makes can become a conviction if applied and confirmed repeatedly in similar situations.

These convictions are difficult to change and are not necessarily all based on truths and realities, but often stem from incorrect understandings and lies. The consequences of decisions, actions or feelings based on these convictions in turn can create problems and eventually determine a person's character, which ultimately determines his destination. Man's life is therefore greatly influenced by his decisions and convictions (based on truths and/or untruths).

These convictions are formed either by repetition (habit) or by trauma (life events which have a great impact on one's life) and once established, are difficult to change (Breed, 2015).

Characteristically, believers turn to a pastoral practitioner with the consequence of this process - problem or problematic behaviour, as a result of problematic emotions, caused by problematic convictions (lies). Only addressing the problematic behaviour will not be effective long term, it is crucial for the pastoral practitioner to address the root (convictions)

of problematic behaviour to bring about permanent behavioural modification (Breed, 2015). The pastoral practitioner working with families with deaf children must consequently make sure that the pastoral process and conversation are based on correct convictions from the very start.

5.5.1 The principles of Breed's Biblical pastoral model

- **God created man to live in relationship with Him, his fellow man and with creation.** Yet as a result of the fall of man, these relationships are distorted and destroyed. Where the relationship between man and God was intended to be an intimate relationship in which man experiences the closeness, providence and love of God, man now tries to provide for himself and experiences fear and emptiness since he cannot love and obey God as he had been intended to and also cannot experience God's love (Breed, 2015). The relationship between man and his fellow man was designed to be characterised by trust, honesty and closeness in which people serve each other and build each other up, but now people distrust each other, use each other and as a result relationships are full of pain and bitterness. Similarly, man was created to cultivate and protect creation and creation was to answer with fruit so that man could receive and benefit from the result of his work, but now creation does not respond as intended and brings forth thorns and thistles which once again leave man feeling defeated, disappointed and acutely empty (Breed, 2015).
- **Attempts to cure the pain and fill the void on the inside.** Whenever man experiences this emptiness, pain or frustration he desires to cure the pain and attempts to fill this cavity. If an attempt appears to be successful man will repetitively use it to numb the pain. As was seen above, this repetition causes habits which in turn result in convictions (based on either lies and/or truths) in man's subconscious. Convictions based on lies provide only temporary relieve problems and may cause more problems and enslave man in the process (Breed, 2015). Breed explains this temporary nature of solutions based on lies by referring to Jeremiah 2:13 *"...for my people have committed two evils: they have forsaken me, the fountain of living waters, and hewed out cisterns for themselves, broken cisterns that can hold no water"*; God is like a fountain of living water. He is always there and I can always go to Him to receive grace, but if man searches for solutions in the wrong places, it is similar to trying to keep water in a cracked pot which cannot hold water (Breed, 2015).

- **God-shaped cavity.** The conclusion Breed comes to in terms of the emptiness man experiences as a result of the fall of man, is that the solutions based on false convictions may bring brief relief, but man remains unfulfilled and without life in abundance; ultimately, this void is God-shaped, and therefore nothing else but the Triune God can provide permanent relief (Breed, 2015): *“Come, everyone who thirsts, ... come to the waters; and he who has no money, come, buy and eat! Come, buy wine and milk without money and without price”* (Isa. 55:1).
- **The formation of habits.** In reaction to specific situations, the convictions established in man’s heart are used to react in situations. Breed (2015) explains that God gave man the ability to form habits (habit capacity) and that it enables man to store the repeated solutions (convictions) so that recalling the solution and acting on it becomes semi-automatic and does not require active decision-making anymore. So the solutions (true and /or false) to specific situations are stored in man’s brain and they determine behaviour. Breed differentiated between the convictions stored in the brain as either being lies, un-integrated truths, partially integrated truths and integrated truths and emphasises the importance of identifying the problematic convictions and replacing them with the truth and/or developing the un-integrated and partially integrated truths to become completely integrated into the believer’s life. This is not merely done through the modification of behaviour (breaking the habit), but by conviction of the truth and to repetitively and consciously making this commitment to the new truth until a new habit is formed (Breed, 2015).

5.5.2 Theoretical framework for pastoral counselling: three anchor points

It is crucial for pastoral practitioners to have a strong theoretical framework from where they can provide pastoral care and counselling to believers in a theologically justified manner.

As briefly explained earlier on, man is left with emptiness after the fall of man (which he tries to fill, a thirst he tries to quench, by various temporary means) which can only be filled by the Triune God. This means that the believer should be guided pastorally to know the Triune God and what the grace is that he receives from God (living water - John 4:10-14) increasingly more. Only when believers are guided to accept this living water (grace) of God, can the believer truly experience fulfilment, peace and joy in their lives (Breed, 2015). The three persons of the Trinity form theological anchor points which frame the life of the believer, and also the pastoral model:

i. Knowledge of God the Father

Among the many basic human emotional needs, Breed (2015) highlights security, unconditional and undeserved love as the human needs that, if met, lower anxiety and defensive behaviour. Knowledge of the Father's grace and undeserved love is essential in living a life of victory, since the cause of unfulfilled longings is not knowing God and His love fully and not living fully from His grace. Guiding the believer to sincere confession that God is his shepherd and security and that he genuinely does not need anything else is therefore an important goal of pastoral care and counselling (Breed, 2015). Breed (2015) explains the value of Psalm 23 in guiding believers to the same confession as the David in Psalm 23:1: *"The Lord is my shepherd; I shall not want"*.

Already in the first verse one finds a personal confession where the poet refers to the Lord as his shepherd and that he has everything that he needs. When counselees get to know the Father in his grace and love, they can eventually sincerely come to a similar confession, which is what the pastoral practitioner wants to guide him to. From verse 2, the poet elaborates on the reasons why he is able to make such a confession:

- **Psalm 23:2:** *"He makes me lie down in green pastures. He leads me beside still waters"*. Like a shepherd knows his sheep, the Lord also knows his children and knows when they tire and feel hunger and thirst. During the baptism, the Lord promises to be that child's God, in accordance with the covenant. The God also became our Father through Christ and like a Father He knows His children each by name. This comfort is what people in trauma need when everything around them seems broken - God knows them and understands them, and He will provide rest, in His time (Breed, 2015).
- **Psalm 23:3:** *"He restores my soul. He leads me in paths of righteousness for his name's sake"*. The poet experiences that the Lord gives restoration in times when he is disheartened and that He guides him on the right path. Through His Word and the Holy Spirit, the Father teaches believers how to live and through the Holy Spirit the Word is opened up for the believers so that they may find renewed hope. In counselling, hope is essential and the counselee is guided to discover this renewed hope and encouraged that God is busy with him/her and that nothing can stop Him from reaching His goal in the counselee's life (Breed, 2015).
- **Psalm 23:4:** *"Even though I walk through the valley of the shadow of death, I will fear no evil, for you are with me; your rod and your staff, they comfort me"*. Here, the poet

does not attempt to find relief from his situation, nor does he only serve the Lord during prosperous times, but he trusts in the Lord and finds comfort in His presence, even in his time of deepest need. The Father sent His Son to be with believers (Immanuel) and after Jesus ascended to heaven, the Holy Spirit was sent to dwell in the hearts of believers. This is the promise counselees must be reminded of and guided to accept (Breed, 2015).

- **Psalm 23:5-6:** *“You prepare a table before me in the presence of my enemies; you anoint my head with oil; my cup overflows. Surely goodness and mercy shall follow me all the days of my life, and I shall dwell in the house of the Lord forever”.* Believer’s greatest enemy, Satan, was defeated by Jesus Christ and has no power over believers anymore. The Father then makes believers guests of honour at His table in this celebration of victory. Believers can therefore lead a life of victory over sin because the Father liberated them from their enemies by sending His Son. This act of love by the Father is often overlooked in the emphasis on the Son who died for our sin. By noticing the love of the Father, counselees whose pain is rooted in rejection or neglect by a parental figure, can be guided to meet the true and faithful Father who has adopted them and from whose love they can never be separated. As His children, they will dwell in the house of the Lord forever, where they are surrounded by goodness and unfailing kindness forever (Breed, 2015).

Through the confession of the poet, Psalm 23 therefore allows counselees to meet God as their Father who takes full responsibility for caring for them, being with them and honouring them in all circumstances.

ii. **Comfort of the work of the Son, Jesus Christ**

When believers are faced with their own baggage, sin and brokenness, they can become discouraged and ashamed. But man’s identity does not reside in his brokenness, his identity lies in serving Christ. Christ brought reconciliation between man and God and restores the relationship of man with his Father. Breed (2015) uses Ephesians 6 to illustrate the confrontation with hostile forces and the Triune God who gives believers strength through their knowledge of Him, in order for them to execute their calling according to His counsel.

Philippians 2:1-5 also serves to indicate what the comfort or encouragement is that is to be found in the work of Christ. The imperative in verses 2-4 (to have the mind and attitude of Christ) can be complied with because of the indicative in verse 1. Firstly, counselees must understand what the attitude of Christ was: that God sent Him to earth, and that He chose

not to hold on to His position in heaven, but to come to earth, be humiliated throughout His life and particularly at the end of His life on the cross. He did whatever was asked of Him in order to bring reconciliation with God, no matter what it required of Him. After He received the highest honour, God exalted Him again. He could do this because He has the assurance of God who He was with Him.

Secondly then, counselees are enabled to follow the example of Christ, since they have:

- This encouragement of Christ, which means that they have a Saviour who has gone through humiliation but who was also exalted above all and crowned with honour and glory and who can take care of them;
- The comfort of love, implying that they have an omnipotent Father in heaven, who loves them and provided for them;
- The participation in the Spirit and affection and compassion, because the Holy Spirit dwells in them and continuously brings them back to the promises of the Lord;

Counselees need the encouragement and comfort of Christ to realize that they are acceptable and to experience that they are acceptable to the Father. Apart from this, it serves to remind them that they have a particular purpose in this life.

iii. The work of the Holy Spirit

The Holy Spirit as Helper / Comforter. Before his crucifixion, Jesus comforts the disciples by promising to send a 'helper' (paraclete) - the Holy Spirit (John 14:16). In the Greek text the word παρακλητον 'parakleton' is translated with 'helper', 'comforter' or 'advocate' who assists, supports, relieves and guides (Breed, 2015; MacArthur, 1994:134).

The Holy Spirit as Guide in truth and understanding (insight). The Holy Spirit guides believers in the truth and brings peace into the believers' hearts so that they do not have to be afraid (John 14:26-27). He constantly points believers to the truth and also transforms their hearts to conform to the truth. The Spirit additionally reminds believers of specific truths from Scripture that are applicable to their specific situation (MacArthur, 1994:136). From 1 Corinthians 2:9-11: "What no eye has seen, nor ear heard, nor the heart of man imagined, what God has prepared for those who love him...to us through the Spirit. For the Spirit searches everything, even the depths of God. For who knows a person's thoughts except the spirit of that person, which is in him? So also no one comprehends the thoughts of God except the Spirit of God." believers can be brought to understand that the Spirit knows us

through and through. God sends His Spirit to dwell in us and to explain to us who God is so that believers may truly know Him (Breed, 2015).

The Holy Spirit empowers to love (Romans 5:1-5). Through Christ believers have peace and free access to God (Rom. 5:1). The Holy Spirit empowers believers to love and obey Christ: "...God's love has been poured into our hearts through the Holy Spirit who has been given to us." (Rom. 5:5) (Breed, 2015; MacArthur, 1994:139). God uses affliction and suffering to strengthen believers' faith (Rom: 5-3-4) since it is in these times of despair that believers are confronted with difficult convictions and must practise their faith. When believers go through this process of endurance and strengthening of their faith it ultimately produces hope because God's love has been poured out in their hearts. Confidence in God is cultivated since, if believers don't lose their faith when they endure suffering, they will have confidence in the fact that God will once again be with them and carry them through if they were to face suffering again (Breed, 2015). The Holy Spirit works in the hearts of believers and reminds them of their Father who loves them. Subsequently believers will be enabled to love others because they know the love of God.

The Trinity's acts of salvation are the various parts of the armour provided by God, which enable man to stand firm in this wrestling/battle (Eph. 6):

- **The belt of truth (Eph. 6:14).** What does it mean when Christ says that he is the truth (John 14:6)? Christ reveals God through his disposition towards others and in the way He lived (Breed, 2015).
- **The chest plate of righteousness (Eph. 6:14)** is Christ's work of redemption by standing in our place and paying for our sins. The implication of this for pastoral care is that the believer can be liberated from his shame and guilt over sin by accepting and appropriating this absolution each time he falls into sin (Breed, 2015).
- **Protective shoes (readiness given by the gospel of peace) (Eph. 6:15).** The gospel, the Good News, provides protection and is a source of strength to believers. The believer should be ready and willing to also proclaim the wonder of the Gospel to others. In proclaiming it to others, the gospel also becomes more of a reality to the believer and as a result the gospel is integrated into his life.
- **Shield of faith (Eph. 6:16).** The shield is used to deflect the flaming darts of Satan. Satan is constantly attacking believers and reminds us of our sin and mistakes in order to break us down. Man in conversation with his feelings of guilt and shame

should consciously take up the shield to deflect these arrows and be guided pastorally to do so in his conversation with himself and his feelings. As soon as the believer starts to doubt he runs the risk of falling back into old patterns of thinking, and this is why it is so important to actively put up the shield of faith by intentionally making a conscious decision to believe (Breed, 2015). Making this conscious decision is an important pastoral principle since counselees can return to this decision in times of doubt or when their faith starts to waver. Having this decision to return to prevents the believer from having to go through the whole process of wrestling with the specific issue again. As soon as they start to doubt or feel that they are slipping back into old patterns of thinking or that they are starting to wrestle with the specific issue again, they need to deliberately stop and intentionally cling to the decision they've made about the issue.

- **The helmet of salvation symbolises the victory of Christ.** A helmet protects the head, and therefore symbolically also the mind and thoughts. Believers are victors in Christ and not slaves or losers anymore. By actively putting on the helmet of salvation, believers protect their minds against Satan's accusation and attempts to make the believer feel that he can never conquer or be victorious (Breed, 2015).
- **Sword of the Spirit, which is the Word of God.** This piece of the armour goes hand in hand with the belt of truth. But here it is applied as both a weapon of defence and attack. Satan can be actively chased away by confronting him with the Word (as Jesus did in the temptation in the desert in Matthew 4:1-11) (Breed, 2015).

In conclusion, believers are guided to understand and believe what the comfort in Christ means to them in their situation - that they are acceptable to the Father, because of the work of Christ.

5.5.3 The role of prayer in the pastoral process

Prayer forms an indispensable part of the pastoral process and the pastoral practitioner can guide the family to pray that the Holy Spirit will fulfil them so that the joy and the peace of God may enter their lives and also to pray that the Spirit will grant them the wisdom to deal with specific situations. The Spirit realises the love and the presence of the Father and the salvation and victory of the Son in the lives of believers (Breed, 2015).

The aim of the pastoral practitioner entering the conversation between the counselees and God is to guide them to accept the grace of the Triune God and make it their own. The pastoral practitioner therefore guides the counselees to base their conversation with God as well as the truths from Scripture (Breed, 2015).

For the pastoral practitioner to have an intimate relationship with God and lives a life with God it is an important condition for being in a position to guide the counselee to a similar relationship with God. The pastoral practitioner needs to be fulfilled with the Spirit and let the Spirit guide him/her (Breed, 2015).

5.5.4 The place of the Bible in the pastoral process

It is important to note that Scripture plays an important role in each of the phases of the counselling process since all pastoral work is essentially from and through the Bible. Counselees are brought to the Bible and guided to understand and to apply it in their lives. In this way counselees grow in their reading, knowledge of and application of the Bible and can also lead others in the same way (Breed, 2015). God speaks through the Bible in the conversation.

5.5.5 The pastoral counselling process of Breed's Biblical pastoral model

The pastoral process is a journey that the pastoral practitioner joins the counselee on. There is a certain dynamic between the pastoral practitioner and the counselee and their joint journey consists of certain phases and steps that they move through. Although the process consists of steps, these steps are not necessarily completed one after the other, but often progress in a spiral fashion (Breed, 2015).

The phases of Breed's Biblical model for pastoral counselling correspond with the four tasks of Osmer's model for application of Practical Theological interpretation as follows:

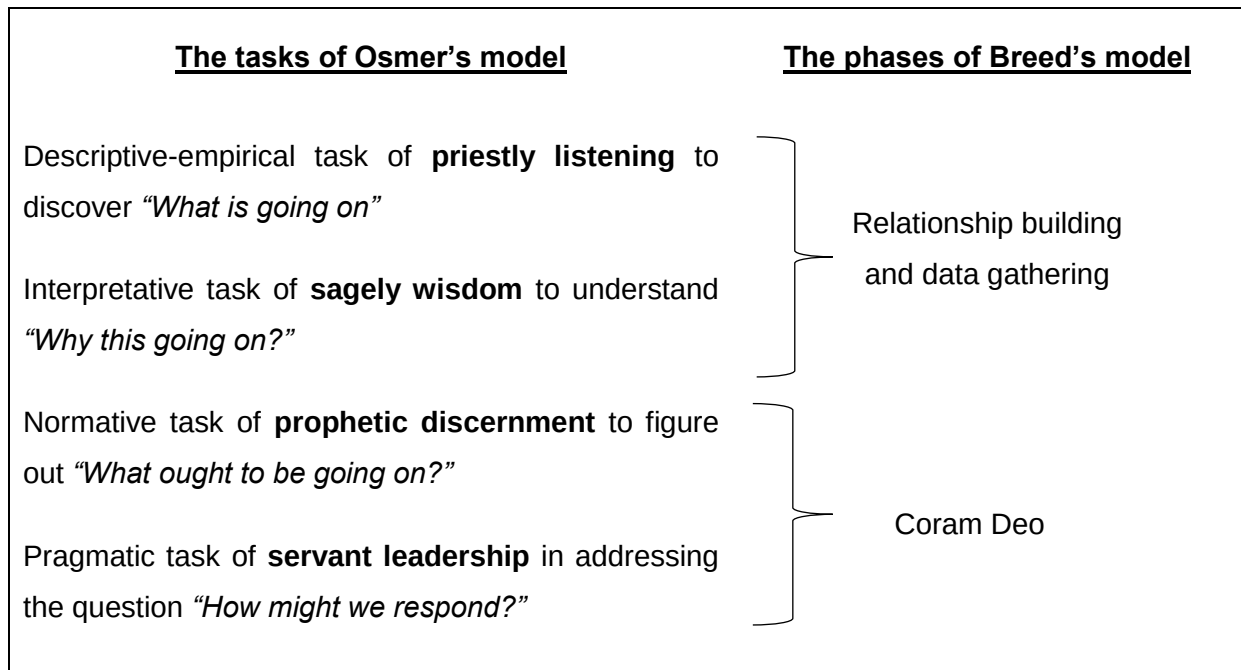


Figure 5-4: An illustration of Osmer's tasks of practical theological interpretation and the correlation with the first phases of Breed's model for pastoral counselling

5.5.5.1 The first phase of relationship building and data-gathering

- **Building relationship** – By the time counselees knock on the door of a pastoral practitioner, they might have been wrestling with a problem for quite some time already and it might not be easy for them to open up about all their deepest feelings and emotions from the word go. The pastoral practitioner must be cognisant of this and build a relationship (rapport) with them. Elements of love, understanding, trust, openness and acceptance are crucial in cultivating a trusting pastoral relationship. The pastoral practitioner accepts the counselee unconditionally because Christ accepted him. Additionally, the pastoral practitioner ought to truly place himself in the counselee's shoes to enable him to truly radiate and impart empathy to them (Breed, 2015).

Especially in the initial encounters, the pastoral practitioner must realise that he does not know and understand the conversation taking place in the mind of the counselee and therefore needs to ask many questions and use reflective techniques to come to a better understanding. The conversation which is already taking place in the mind of the counselee must be entered into by the pastoral practitioner. The pastoral practitioner temporarily becomes part of the counselee's conversation with his situation, God and himself by building relationship with the counselee in order to understand this conversation (Breed, 2015).

Once entered into this relationship, the pastoral practitioner can start to explore and discover what the lies and invalid convictions are upon which the counselee builds his life. From these convictions certain emotions result and specific behaviour follows. This behaviour leads to certain habits, which in turn lead to a specific way of living and finally to a destination. In exploring the lies and invalid/wrong/incorrect/false convictions the pastoral practitioner has the opportunity to then replace them with truths from Scripture. This process of replacing lies with truths consists of firstly confirming each time that the counselee believes the truth and secondly to practise and repeat it until it becomes a new conviction, based on truth (Breed, 2015). This relationship-building and data-gathering prepares the way for the next phase, that of Coram Deo.

5.5.5.2 The second phase of Coram Deo

The second phase of the counselling process is often referred to as the confrontational phase, since it is here where the counselee is confronted with the untruths in his life and called to repentance and conversion. Breed (2015) feels that the emphasis in calling it a confrontational phase would be placed too heavily on the vertical line (between God and man) and not enough attention is paid to the horizontal line (between man and man). Instead Breed chooses to refer to this phase as the “Coram Deo” phase (the Latin for living one’s entire life in the presence of and trust in the Lord) where there is equal emphasis on the horizontal and vertical dimensions. By bringing him/her to the Lord’s laws of grace, the counselee is not only confronted by the law but also receives the proclamation of the grace of the Lord. Coram Deo goes hand in hand with Sursum Corda, meaning to lift one’s heart up. The counselee is guided to stand before God, lift up his heart to God and to see his/her life in the light of God’s word (Breed, 2015).

Where the previous phase the emphasis was on the pastoral practitioner becoming part of the conversation via the building of a trusting and open relationship, this phase wants to pertinently bring God into the conversation. God is brought into this conversation:

By the word of God – the counselee is guided to go to the Word of God and compare the lies he or she believes, his/her own convictions with truths from Scripture. Here the lies are explored to expose false convictions which are then replaced with the truths by repeatedly committing to the truth, and committing to God. Counselees are reminded of what the three anchor points (5.5.2) mean to them and how it applies to their situation (Breed, 2015);

By the Holy Spirit who works in people through the Word. He guides them and affirms the word to them as the truth. The Holy Spirit can eventually replace the false convictions with

the truth to form a new habit and in order to break the old habit under the guidance of the Holy Spirit (Breed, 2015);

By the pastoral conversation – additional to the Holy Spirit, the pastoral conversation in itself as well as the example of the pastoral practitioner's life can serve as a means of bringing God into the conversation. If the counselee sees that the pastoral practitioner accepts the word of God, lives by the word of God and that the word of God brings peace and joy to the pastoral practitioner, the Holy Spirit can work even more powerfully through not only the Word that the pastoral practitioner brings, but also through the example the pastoral practitioner sets to the counselee (Breed, 2015);

Directly - God can work through the Word, Holy Spirit and the pastoral conversation but also directly through the Holy Spirit.

The Coram Deo phase consists of bringing the counselee to both the law (commandments) and the grace of the Lord. The counselee is guided to understand the three anchor points (5.5.2), and to comprehend the implications of the love of the Father, the comfort of Christ and the communion with the Holy Spirit in their current situation. Breed (2015) argues that John 15:8-11 illustrates two sides of the care of God the Father. God does not only provide for believers but also indicates boundaries (commandments) within which believers are to live. These boundaries do indeed limit, but are given because God loves believers. When the counselee understands the grace of the Lord, the laws (commandments) become laws of love which help us to remain in the love of God.

Prayer as conversation with God

Prayer plays a fundamental role in bringing the counselee to and in conversation with God. Not only does the pastoral practitioner continuously pray for the counselee, but he also guides the counselee to talk to God personally. Only the Holy Spirit can make a true conversation with God take place and He works in the believer's heart. Counselees often view prayer as something formal, or a duty to fulfil. The pastoral practitioner refutes this view of prayer and brings awareness to the wonderful gift of prayer. In prayer, security in God can be found in the presence of God (Ps. 16) as the believer's refuge; and in prayer the believer finds strength in His might (Eph. 6:10). Prayer is also communion with God and believers can freely talk to God and pour their hearts out to Him. By giving themselves as living and holy sacrifices, believers seek to determine the will of God, can wrestle with God about the things they do not understand and in this process come to an intimate closeness to God.

To pray to God and to express his feelings, talk about the conversation he used to have with his circumstances, the new truths they've discovered and ask God to assist them in committing and staying committed to the newly-discovered insights.

Accountability partners

Once the counselee has discovered the lies and false convictions, learned what the truths are, replaced the lies with truths and has committed to the truths an accountability partner (especially in cases of addiction) to turn to when he/she has fallen. The accountability partner's role is then to remind the counselee of both the grace of God and the commandments of God time and again, thereby assisting the counselee to fall less deeply than he did previously (Breed, 2015).

5.5.5.3 The third phase of obedience and perseverance

Where the previous phases focused on entering the conversation via relationship-building and data-gathering; and on bringing the counselee to discover and replace false convictions with truths from Scripture, the third phase of Breed's pastoral model is focused on assisting the counselees to practically break the habit of living according to the false convictions and to integrate the truths into their lives, to persevere in the decisions they've made to eventually form new habits based on truths (Breed, 2015).

Breed uses the 'addictive cycle' to illustrate the process of addiction (the sin cycle), attempts to break from addiction by confrontation with the law (the law cycle) and the proposed way of breaking addiction by focusing on both the laws and the grace of the Lord (the grace cycle) (Breed, 2015). The principle of the grace cycle is that healing does not result from forcing a counselee or by causing him/her to experience guilt (the law and sin cycle); rather, healing comes about by bringing the counselee to the grace of the Lord (the grace cycle) and in this way cultivating love and gratitude. Love and gratitude then become the driving force for obedience. This causes a sense of boldness in the counselee which enables him/her to repeatedly go to the Lord, even when he/she has fallen. In this way loneliness and withdrawal are avoided and the cycle of falling and getting back is shortened over time.

In the grace cycle red flags (for example loneliness, anxiety, fear and feelings of worthlessness) which usually trigger a conditioned response (the reflex) are identified and addressed. The counselee is guided to, instead of continuing on the sin cycle or the law cycle, consciously saying no to the conditioned reflex and choosing the new grace cycle. That which was discovered in the Coram Deo phase (the false convictions, the truths, God's

grace and the three anchor points) is confirmed once again. From here the counselee then makes the decision to walk away from this pain, by saying “no” to the false convictions and wrong actions, and to fill this void and emptiness on the inside with the grace of the Lord, by saying “yes” to the grace of God (Pss.16 and 23). The danger of falling back into old patterns is real and therefore other people play a significant role. When counselees become aware of a ‘red flag’ situation, they can contact their accountability partner who can bring God into the conversation again; remind them of and assist them to fill their emptiness with of the laws and the grace of the Lord (Breed, 2015).

In particularly addiction to any kind of sin, it is important to confess this sin before the Lord, realise once again that He knows the counselee by his name, that he is His and then to accept the forgiveness of the God. From here the counselee again chooses to life from/out of the love of the Lord. The counselee then again commits to the truths learned during the Coram Deo phase and confirms and reiterates that he believes that these truths are the Words of Life. Breed (2015) adds to this commitment to the truth and suggests additionally to committing to the truth, guiding the counselee positively to also do works of service.

Going through the grace cycle successfully, even just once, is to create hope, which is a crucial part of the pastoral process. The counselee then experiences first-hand how perseverance creates hope. The counselee will probably go through this process over and over again and fall every now and then, but the goal is to fall less deeply each time, and to always return to the Lord who is the only solution and answer to the emptiness and pain in the counselee’s life. Applied to families with deaf children this would imply persevering in the newly-discovered truths related to alternative views of deafness on the one hand and the truths related to the grief process and attitudes towards deafness on the other. The goal is to bring parents to a point of not only tolerating their situation, but to gain renewed hope each time they go through the grace cycle.

5.5.5.4 The fourth phase of support and follow-up

To an extent, this fourth and last phase of Breed’s Biblical model for pastoral counselling is a continuation of the previous phase of obedience and perseverance. The pastoral practitioner cannot work intensively with the counselee indefinitely, nor is it God’s complete plan for ministry, thus the focus shifts more to the community of believers in which the counselee is involved for continued support and spiritual growth (Breed, 2015; Goode, 1994:306).

Breed (2015) bases this phase on the “one another” texts in the Bible which serve to indicate the emphasis God places on the role believers have in each other’s lives and in support of each other.

- **James 5:16**, for example, reads: *“Therefore, confess your sins to one another and pray for one another, that you may be healed”*. Breed (2015) views this as the essence of what a church must be. Contrary to what is often experienced, a community of believers is not supposed to be a place where people hide behind masks of ‘we are all okay’. A congregation is in fact a gathering of self-admitted sinners who come to church precisely because they know that they are sinners and that they know that they need the Lord and one another. All the people in the community of believers need the Lord, the salvation of Christ, the grace of God and the strength of the Holy Spirit. Believers (sinners) therefore join a community of believers to receive the grace of God and to praise Him through it.

The community of believers should therefore be the environment where people can have the confidence to confess their sins to each other, to ask for assistance and to be prayed for, in order to find healing. For the cycle of grace therefore, counselees need other people to pray for them, to tell them and remind them of the grace of the Lord and to support them and carry them through this process.

- **Ephesians 4:32** reads: *“Be kind to one another, tender-hearted, forgiving one another, as God in Christ forgave you”*. Clearly the community of believers is not intended to be a place for pointing fingers, nor is it a place where sin is ignored. Since believers know that sin breaks down and causes pain, they want to help each other break with sin. Regardless of who the fellow believer (sinner) is or what his circumstances are, the Lord commands believers to be friendly and tender-hearted towards each other and to assist and support each other. A newcomer in a community of believers should experience warmth and acceptance and a feeling of being embraced and pulled closer, regardless of who he/she is, because that is what God has done for them (Breed, 2015).
- **1 Thessalonians 5:14**: *“And we urge you, brothers, admonish the idle, encourage the fainthearted, help the weak, be patient with them all”*. This verse stipulates the attitude believers are to have towards each other. Not only should the emphasis be on addressing sin and supporting the weak, but also on encouraging those who are discouraged or feel like they cannot go on. This kind of support cannot only be the

responsibility of the pastor and/or pastoral counsellor and therefore the rest of the community of believers are also needed (Breed, 2015). In relation to families with deaf children this places emphasis on the pastoral practitioner to facilitate dialogue between the opposing worlds of the deaf and the hearing. Additionally the pastoral practitioner can activate the community of believers by equipping them through creating awareness in terms of deafness. The community of believers, after evaluating and adjusting their own convictions of and attitudes towards deafness, are then in a much more favourable position to support the family through their loss and particularly to accommodate the needs of the family and the deaf child.

5.6 PRACTICAL THEOLOGICAL MODEL FOR PASTORAL CARE AND COUNSELLING OF FAMILIES WITH DEAF CHILDREN

By integrating the research results of the empirical, interpretive and normative tasks of the addressed in the previous chapters the challenge is now to merge these results with that of the current pragmatic chapter's findings to construct a new practical-theological model in order to address the need identified at the start of this study.

5.6.1 Guidelines in terms of the role of the pastoral practitioner in the pastoral care and counselling of families with deaf children

Before embarking on the journey of pastoral care and counselling of families with deaf children the pastoral practitioner needs to comprehend his/her unique role in this context.

"The harvest is plentiful, but the labourers are few" (Matt. 9:37).

The need of pastoral care and counselling to families with deaf children, as well as Deaf ministry, is great and therefore it is of paramount importance that the pastoral practitioner working with families with deaf children be culturally competent and understands the diversity and complexities related to deaf children and their families.

Priestly listening implies immersing oneself in the life and situation of the other and in this context it has a dual implication for the pastoral practitioner. Not only does he/she attentively listen to and empathise with the loss the family might experience, but also has compassion for the culturally Deaf community and their view of deafness, the result of which would be that he would provide accurate and unbiased practical information about deafness to the family.

Emphasis on the importance of parental acceptance of deafness as well as the essentiality of early access to a comfortable language should receive ample attention.

The pastoral practitioner enters into conversation with the family with the deaf child with the aim to assist them in working through the process of grief as a result of their experience of loss. In assisting the family to work through their grief (3.6.1.2) and to pastorally guide them through this transitional period in their lives, the pastoral practitioner must ensure that he is well informed about the different models of deafness and be able to bring these contrasting models not only in conversation with each other, but also with the Word of God (3.6.1.3 & chapter 4).

The pastoral practitioner should be aware of his own assumptions about and attitude towards deafness in order to be able to address the misconceptions and questions surrounding deafness and guide the family to awareness and growth.

Additionally, he/she should ensure that the pastoral process and conversation are based on correct convictions for the start.

In the broader sense of pastoral care, the pastoral practitioner, as the servant leader, is to lead the community of believers and eventually also the broader society to awareness in terms of deafness and support an involvement with the family with the deaf child.

It is crucial for the pastoral practitioner to keep the bigger picture in mind. This model is mainly aimed at pastoral care and counselling of the parents of deaf children, but ministry of the child starts by ministry to the child's parents. Thus, the pastoral practitioner does everything he does with the child in mind. By providing responsible pastoral care and counselling to the parents, the pastoral practitioner is also preparing the way for pastorally caring for the deaf child as he/she grows up.

For this reason it is crucial that the pastoral practitioner be cognisant of the spiritual challenges of deaf people (3.8.1) as well as the recommendations of the role, competency and attitudes of pastoral practitioners working with families with deaf children (3.9.2).

5.6.2 Pastoral model for pastoral care and counselling of families with deaf children

With Breed's model for Biblical Counselling as foundation, and the application of Osmer's model of practical theological interpretation to this model, the researcher incorporated the research findings of this study and proposes the following pastoral model developed for the pastoral care and counselling of families with deaf children:

This model supports the multicultural approach of a bilingual-bicultural dialogue and consists of two dimensions. In the first dimension the focus is on the pastoral counselling of the family of newly-diagnosed deaf children and in the second dimension on the broader support and pastoral care of the family of a newly-diagnosed deaf child.

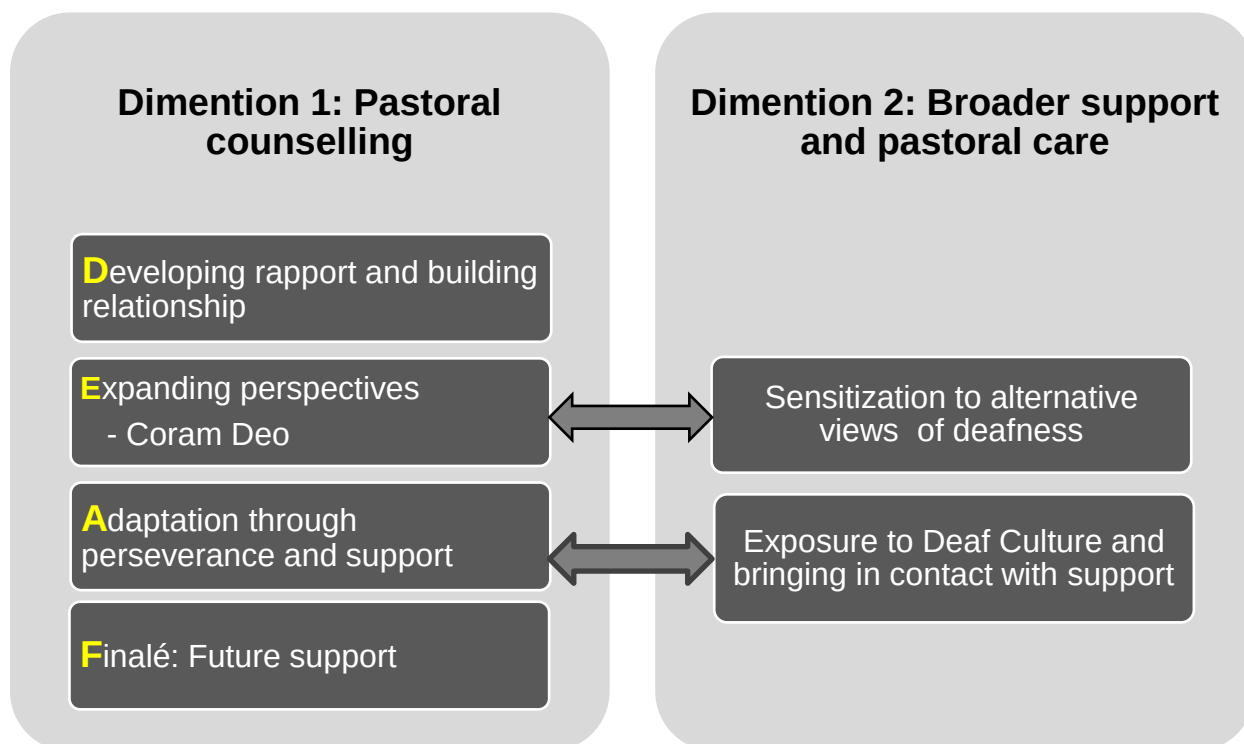


Figure 5-5: Pastoral counselling and broader support and pastoral care as two dimensions of the **DEAF model for pastoral care and counselling of families with deaf children**

These above two dimensions do not follow on each other sequentially, but rather take place simultaneously in a parallel fashion. The pastoral counselling dimension comprises the counselling process by which the family is pastorally counselled by the pastoral practitioner. The first letters of the various phases of the first dimension form the acronym DEAF. The pastoral care dimension on the other hand entails the broader support and pastoral care of the family by exposure to Deaf culture and the involvement of the broader faith community.

5.6.2.1 Phase 1: Developing rapport and building relationship.

During the first phase the pastoral practitioner faced with a family with a deaf child establishes a trusting relationship with the family and listens with compassion and empathy to everything they share about their journey. A spirituality of presence is necessary to truly attend to the experiences, needs and expectations of the family. The parents are

encouraged to share their emotions and experiences of loss in a trusting and accepting environment. This phase may take place over several sessions as the pastoral practitioner attempts to understand the loss, questions and struggles the family with the deaf child is facing.

Together the pastoral practitioner and the parents of the deaf child can then explore these feelings and their underlying convictions together.

5.6.2.1.1 Determining the challenges and questions parents of deaf children might be faced with

The parents of a newly-diagnosed deaf child tend to be uninformed about deafness and all its facets. They might go through a process of intense loss before coming to acceptance of their child's deafness (2.5).

In essence the pastoral practitioner seeks to understand how parents' evaluate their situation and their deaf child. How do they evaluate challenges brought on by deafness and what perceptions have they formed as a result of thereof? Parents need to feel secure enough to open up to the pastoral practitioner. The more they open up the more they will have an opportunity for growth. Parents might feel hesitant to truly admit what their emotions toward God, each other, their deaf child and themselves they have since they might fear rejection or feeling judged because of these emotions. Parents are reassured of confidentiality and a safe space is created in which they can freely express their deepest emotions and experiences.

Here the focus is on what their questions, issues and struggles are. Typically the following might emanate from during the initial phase (2.5; 3.6 and 5.3.1):

- Families are going through a process of intense loss as they learn about their child's deafness;
- Families might have little or no prior exposure to and thus comprehensive knowledge of deafness;
- Families might struggle with communicational hindrances in the communication between the hearing and deaf members of the family as well as the challenge to decide which communicational route to follow;
- Families are often uninformed about the various models of deafness and subsequent implications of the various approaches to education and communication.

Issues arising from the above might include:

- Questions about the goodness of God (Why God has allowed their child's deafness);
- Questions about the sovereignty of God (Why God isn't restoring their child's hearing);
- Questions about why their child is deaf (As punishment for parental sin);⁴
- Making decisions regarding mode of communication and education;
- Concerns about their child's future and the challenges that lie ahead;
- Parents' pathological views of deafness as disability and subsequently as having a pathological view of their deaf child as disabled; and
- Parental need for support from community and religious community.

5.6.2.1.2 Determining the underlying convictions maintained by the parents

Parents' reaction to their great loss and deafness is determined by their convictions. The pastoral practitioner seeks to understand what the beliefs are which are at the core of these issues and therefore attempts to determine what they believe about God, their situation and also their deaf child. What do they believe about deafness? In his/her quest for answers to the above situation, the pastoral practitioner joins the conversation that these parents are in (maybe unwittingly so) with God, deafness, their child and also the greater society.

This research indicated that the greatest convictions maintained by parents of deaf children, which need to be addressed, are an exclusively pathological view of deafness and as a result of this conviction, also viewing their child in the light of having deafness as a disability.

Additional to identifying the false convictions, this specific context of deafness also calls for identifying ignorance in terms of deafness. Convictions about deafness are often formed by ignorance.

Their convictions about the Triune God and their relationship with Him determine their understanding of His sovereignty and to surrender to His plan and counsel.

⁴ Specifically in the African context where traditional beliefs including ancestral punishment might play a major role, cultural beliefs and convictions should be taken into consideration.

The convictions about their situation might cause parents to behave according to these convictions. They build their lives and conduct on these convictions and these convictions lead to certain emotions and conduct. The way parents assess their situation and view deafness (as disability or culture) and their deaf child (as disabled or as a culturally different gift from God), causes certain emotions which will influence parents' behaviour towards their deaf child, which in turn will influence the way the child will perceive himself. The child's behaviour, based on his/her own conviction, then again influences parents once again and confirms their convictions. Their view of deafness and their deaf child will ultimately play a determining role in the choices parents make in terms of hearing technology, education and communication. This conduct therefore leads to behavioural and cognitive habits to be established and this becomes a way of life and eventually leads to a destination.

The pastoral practitioner seeks to understand what leads to the convictions maintained by parents and what role lies and ignorance play in these assumptions.

Joining the conversation and discovering the convictions parent hold will then create the opportunity for the pastoral process to transition to the next phase of expanding perspectives in which Breed's Coram Deo phase can be applied as framework.

Providing hope from the start:

It is important to instil hope in the parents of the deaf child from the very beginning. The pastoral practitioner communicates that he/she really is attempting to comprehend what they are going through and where they are in their lives. Even if their situation seems hopeless and even though they cannot make sense of their situation at this moment in time and don't experience it yet, there is always hope.

5.6.2.2 Phase 2: Expanding perspectives

Once the pastoral practitioner has joined the conversation between the family and the loss they experienced and the basic assumptions of belief about the loss, deafness, God and their deaf child have been identified, the next step entails comparing these assumptions with the insights gained from recent research (chapter 3) and the Word of God (chapter 4) and replacing them with these discovered truths.

As explained in figure 5-5 this phase consists of two dimensions, being Coram Deo on the one hand and sensitization to Deaf Culture on the other. These two dimensions cannot be separated as two distinct successive phases. They are interrelated but for the purposes of

presentation will be discussed successively below as first and second dimensions of phase two.

Central convictions which need to be addressed are approached by firstly addressing parental grief as a result of experiencing intense loss due to deafness and in addressing the way parents view their deaf child, by Coram Deo (dimension 1). Secondly, by addressing the parental view of deafness by sensitizing parents to alternative views of deafness (dimension 2). However, it logically would make sense that Coram Deo (dimension 1) might result more naturally once parental sensitisation towards alternative views of deafness (dimension 2) is addressed and therefore the pastoral practitioner could opt to alter the sequence of the dimensions.

5.6.2.2.1 Phase 2-dimension 1: Coram Deo

(a) The Triune God as anchor

Before stepping into the Coram Deo part of this phase, the parents need to be anchored in the Triune God and understand the implication of God as the only One who can quench their thirst with His Living water and who can fill the gap left in man by the fall. Knowledge of the persons of the Trinity can form the frame for their lives as parents and also as family.

In the following pages then certain important aspects which might arise in the pastoral conversation will be discussed. However, it should be noted that the pastoral conversation is dynamic in nature. The pastoral conversation is dynamic since the Holy Spirit can guide the pastoral counsellor, parents and also the deaf children to come to discoveries of comfort and strength resulting from the knowledge of the Triune God's involvement with the family.

- **First anchor: the love of God the Father**

Psalm 23 as well can be utilized by the pastoral practitioner to bring the family (in particular the parents, later in ministry to the deaf child and also the child) to get to know the Lord's grace and love, in order to eventually be able to come to the sincere confession that the Lord is their Father and that they have all they need in Him (23:1).

Even in this time of turmoil, He is their Father and knows and understands them and their deaf child by name. He will also provide them with rest, in His time (23:2). They are guided to find renewed hope in the Lord, through His Word and Spirit and He leads them on a path with which He has a goal (23:3), even if they feel surrounded by darkness at the moment

(23:4). At this point parents can be asked whether they accept the guidance of the Lord and live for the sake of His name. If they live for the sake of their own name, they will feel that they need to fight for themselves.

Even in their deepest loss and pain, they can trust in the Lord and find comfort in His presence in their lives. He is not their enemy, but their Father. They are therefore guided to realise that God looks at them and their deaf child in love and to accept the promise of the Lord – that He is with them and that He will never forsake them (23:4). He loves them, has sent His Son to destroy their enemies and they have seats of honour at His table. As His children, they are forever embraced by goodness and mercy (23:5-6).

The pastoral practitioner guides the parents to do introspection in terms of how empty or full they perceive their cups to be and what they feel they need in order for their cup to overflow. Do they feel that they need their child to be fully hearing in order to have their cups filled? Do they expect the Lord to miraculously restore their child's hearing to attain this? The Lord never promises that this life will be without suffering and loss, but He does promise to be with believers. Parents can live for the sake of the name of the Lord and for His honour, even though they are going through the proverbial valley of death.

The most important matter is for parents to be guided to be able to say: "The Lord is my shepherd, He is with me, and I have everything I need, no matter what happens in this life. With His rod and staff He draws me closer and protects me." To experience that even though they are in this loss, the Lord cares and provides for them like a shepherd His sheep. They are honoured guests at His feast and children in the house of their Father and their cups overflow.

Here the pastoral practitioner can remind them that it is possible to be in this dark valley of experiencing severe loss at the moment, where the top of the mountain seems unreachable. Yes, loss causes severe pain, but it is possible, after falling and getting up many times, they can exit this valley, ascend to the top of the mountain and be able to confess that the Lord is their shepherd, He is all that they need, He is with them, and that they will trust in Him, regardless of the circumstances in their lives.

- **Second anchor: the encouragement of Christ: Philippians 2**

Parents of deaf children can have the same attitude as Christ, since they have the encouragement of Christ, meaning that they do not stand alone in this life and loss; but that they belong and that they do not have to fight for themselves. As believers, they have the

comfort of love, implying that they are encouraged by the fact that they have a Father in heaven who loves them and their deaf child and who takes care of them. They also have the participation in the Spirit and affection and compassion, since the Holy Spirit lives in them and reminds them of the promises of the Lord.

The parents need this encouragement of Christ to realise that they and their deaf child are acceptable to God and have a unique purpose in this life. The parents of the deaf child (and ultimately the deaf child) are therefore guided to find their strength in God's might.

- **Work of the Holy Spirit**

- **As helper/comforter:** The pastoral practitioner might not be able to understand the loss parents experience when learning about their child's deafness, and therefore cannot comfort them, but ultimately it is the Holy Spirit who comforts. He dwells in them and is with them in this situation. The pastoral practitioner might feel that he is only providing cliché-like guidance to parents but should trust that the Holy Spirit will also use that to work in the family. He is the Paraclete who can help them overcome their feelings of anger, depression and feelings of discouragement.
- **The Holy Spirit as Guide in truth and understanding (insight).** The Spirit therefore also knows every fear, desire, need and thought of each of the members of a family with a deaf child and can also prompt them to conform to the truth and to be sanctified in truth.
- **The Holy Spirit empowers to love (Romans 5:1-5).** God also uses the deafness of their child to strengthen parents' faith in Him. It is in these times that they are in conversation with their situation and may question their faith – did Christ really die for them; is the Spirit really in them; does God really provide and care for them like a father? The pastoral practitioner must guide the parents to view this affliction as something that the Lord utilises in their lives. They must cling to this truth knowing that endurance will produce character and finally hope. Having the love of God poured into their hearts means that parents can know and be sure of God's love for them and for their child and are also able to love others because of this knowledge of God's love.

The decision that believers are confronted with in terms of the work of the Holy Spirit as summarised by (Breed, 2015) applies aptly to the decision families with deaf children must make to believe that there is hope in suffering, knowing that suffering produces endurance and endurance produces character and character hope and that hope does

not put them to shame because God's love has been poured into their hearts through the person of the Holy Spirit who has been given to them. They are filled with the Holy Spirit and submit their will to the will of the Holy Spirit as He guides and comforts and reminds them of the love and the promises of God.

The Trinity's acts of salvation are the various parts of the armour provided by God, which enables man to stand firm in this battle (Eph. 6):

- **The belt of truth** (Eph. 6:14). If any false convictions exist in the minds of parents of deaf children, they need to be addressed in pastoral counselling, since these convictions can hinder them from living a fulfilled life. The truth in Christ changes them in their deepest being and these truths must be applied in each situation under the guidance of the Holy Spirit.
- **The chest plate of righteousness** is Christ's work of redemption by standing in our place and paying for our sin. For the parents of deaf children, this means that they can be liberated from feelings of guilt (in terms of the cause of deafness for instance or the way they dealt with deafness thus far), by accepting the absolution in Christ. The pastoral practitioner's role here is to direct the parents to this liberation from feelings of guilt by confirming to them that irrespective of how great their guilt is, when God looks at them, He sees them as if clean and without blemish.
- **Protective shoes (readiness given by the gospel of peace)** (Eph. 6:15). Parents should be guided to also be prepared to proclaim the Gospel to others, wherever God sends them (Breed, 2015). Readiness, not only to be the vehicle of the covenant and proclaim the Gospel to their child, but also readiness to share their newfound perspective on deafness with others. Actively recalling and sharing these perspectives with others therefore additionally results in making parents mobile in their faith.
- **Shield of faith** (Eph. 6:16). Making this conscious decision is an important pastoral principle since counselees can return to this decision in times of doubt or when their faith starts to waver. Having this decision to return the believer from having to go through the whole process of wrestling with the specific issue again. As soon as they start to doubt or feel that they are slipping back into old patterns of thinking or that they are starting to wrestle with the specific issue again, they need to deliberately stop and intentionally cling to the decision they've made about the issue. These choices that parents make are therefore choices made repeatedly in faith, which confirms that they

believe that these are indeed the truths which will free them and that the former convictions really were based on untruths.

- **The helmet of salvation symbolises the victory of Christ.** Parents of deaf children can be guided to hang on to this victory in Christ and be encouraged to truly believe that they are conquerors in Christ and as a result will be able to be victorious in overcoming the intense loss that they are experiencing specifically in the initial stages of the process of grief. This struggle might be hard, but it is important to make the reality of victory part of their life.
- **Sword of the Spirit, which is the Word of God.** Parents should be taught how to use the Word of God in driving Satan away. By memorising, quoting and repeating words from Scripture, believers internalise the Word of God, integrate it into their lives. Although it might feel unfamiliar to use a sword initially, continuous use will lead to being more comfortable and skilled in the use thereof.

In conclusion: Families with deaf children can prayerfully expect God to work through them with the same power with which He resurrected Christ from the dead. So even from this apparently hopeless situation, where parents feel like they have lost so much, God is able to do far more abundantly than all that they ask or think, according to the power at work within them (Eph. 3:20)

In parents' struggle to come to acceptance of deafness and the continued struggle with the challenges deafness brings, understanding the implication of the comfort in Christ plays an important role.

(b) Truths from Scripture

The family is guided to have the conversation on a Biblical foundation, to stand in the presence of God, lift their hearts to God and to converse with God about everything they are going through; all the questions they have and the questions and pain they are wrestling with, conversing with God and wrestling through this with God in order to attain a sense of clarity or calmness.

The pastoral practitioner brings the family to the Word of God and guides them to compare their convictions about their child's deafness and also the trauma they are facing, with the Word of God.

There are many assumptions and perceptions about deafness that need to be addressed, yet the scope of this study does not permit elaborate discussion on all. But the following are

assumptions and questions which the pastoral practitioner needs to address and bring in line with or elucidate from the Word of God. The pastoral practitioner must keep in mind that although he/she is now mainly focusing on the pastoral care and counselling of the parents, he/she is in effect also ensuring that the child is pastorally cared for, since ministry to children starts by ministry to their parents.

(i) Addressing parental grief

The pastoral practitioner addresses and validates parental grief by utilizing the perspectives gained from Lamentations. Parents are encouraged by the poet of Lamentations who did not avoid God during affliction but who turned to God in earnest prayer as he wrestled through his affliction.

By working through Lamentations with the parents of the deaf child, the parents' grief is articulated when words might fail them. The family is encouraged to embrace their grief, to bring it before God and to wrestle through these phases of grief with God. The book of Lamentations could be used to elicit conversation during pastoral counselling. Parents are invited to read passages from Lamentations and to attempt to phrase in their own words what they think the poet was experiencing after which they can reflect on how their own emotions differ or correspond with that of the poet. Parents can also be encouraged to put their emotions and feelings and deepest affliction down in writing and to bring these memoirs before God in prayer.

The function of recollection and remembrance is highlighted here and parents encouraged to not dwell on the things they don't understand such as the reason their child is deaf. In their process of working through their grief, parents need to realize at some point that man will never fully understand everything and be guided to intentionally decide to focus and reflect on the known attributes of the covenantal God (4.5.1.3).

Lamentations 3: 20-23: *"My soul continually remembers it and is bowed down within me. But this I call to mind, and therefore I have hope: The steadfast love of the Lord never ceases; his mercies never come to an end; they are new every morning; great is your faithfulness."*

(ii) Addressing ethical questions

It is impossible for the pastoral practitioner to answer all the 'why' questions parents might have since the sovereignty of God cannot be completely understood. The pastoral practitioner therefore can only answer the ethical questions as well as he is able to, but does

not pretend to be in any position to satisfactorily answer all their questions. Rather, he thus brings them back to *Coram Deo*, to stand before the Lord with their supplication: “O Lord, we do not understand,” and to subsequently be reminded of the anchor points and choosing each time to believe in them and the involvement of the Triune God in their lives. John 9:3, where Jesus replies to his disciples’ question about the cause of a blind man’s blindness: *“It was not that this man sinned, or his parents, but that the works of God might be displayed in him’.*” can be applied here. Lamentations 5 can specifically be utilized here to provide guidance in terms of accepting God’s sovereignty based on the covenant. Submission to God’s sovereignty ultimately leads to a longing for intimacy with God.

(iii) Addressing parental view of their deaf child

The pastoral practitioner emphasises the importance of parental acceptance to the overall wellbeing of their deaf child. The parents are therefore guided to see their child as a unique gift from God, a gift which He has placed in their particular family with a function to fulfil. In order to assist parents to make this shift in their minds and hearts, insights gained from 1 Corinthians 12 (4.5.2) are used to cultivate hope and to assist parents to view their child as having been fearfully and wonderfully made (Ps. 139), as a unique child with unique challenges and needs, but also a unique function to fulfil in the body of Christ and society.

The pastoral practitioner guides the family to make decisions on Biblical grounds and to eventually replace their previous convictions about their deaf child with truths from Scripture, to not only accept their child’s deafness but in fact to celebrate the uniqueness of their child.

Ideally they can be guided to say: “God gave us a unique child, and as a consequence we as a family have unique challenges. Our child is a gift from God and deafness is part of His grace (John 9:3).” This is a central conviction for parents of the deaf child to come to: That they see their child’s deafness as a unique opportunity and not an embarrassment or disability. This is the greatest mind shift parents must make. Reaching a point of submitting to God’s sovereignty and finding comfort and hope in His covenantal faithfulness can bring a sense of acceptance (4.5.1). It is a process of submission to God: that they surrender to God’s decision and plan, and that parents choose to believe that everything that happens flows out of His love.

This is a core conviction, a conviction to which the pastoral practitioner guides the parents into accepting the deafness and celebrating their deaf child - and all of this in relationship with the covenantal God.

(c) Process of change

The process of replacing previous convictions about their situation, deafness and their deaf child, consists of two elements. Firstly, parents discover what the anchor points and additional truths from Scripture (chapter 4) mean to them and ask of them in their situation. By reminding them of what the Triune God (God the Father who provides for them, the Son who saves them and the Holy Spirit who dwells in them) means to them, God is continually brought into their conversation with their situation.

These discovered truths might well stand in contrast to what they used to believe or didn't understand. They are guided to make decisions to choose these truths to confirm that they believe these new truths, and that the Word contains the words that truly give life.

Secondly, they need to do this repetitively in order to replace their old pattern of thinking by acquiring a new way of thinking, based on new convictions (truth). Each time the parents start thinking about their situation in the way they used to, or about the child in the pathological way or as a burden in any sense, they have to go through this process of recommitting. They recommit and proclaim that those convictions are not valid and that they don't want to think of their situation or their deaf child in this way any longer. They confirm what the Triune God means to them, they pray to Him and ask Him to comfort them and assist them in viewing their situation and their deaf child differently.

Not only is the family equipped and guided to work with the Word of God in this way, but additionally to stand in relationship with God and to grow in their relationship with Him.

(d) Place of prayer in the guidance to conversation with God.

In this whole process, the pastoral practitioners do not only pray for the family but also assist the family to pray to God themselves. The family might not yet have fully discovered what the true gift of prayer is and therefore the pastoral practitioner ought to show and lead them to discovering it. They can be brought to a place where they can talk to God about everything: What the conversation was that deafness initiated, how they've now heard and seen what His word says to them and their child; what the decisions are that they have now made based on these new insights; confess that they commit to these newfound truths and express their desire to live according to these new insights from now on; they can ask God to assist them in this new decision and in staying committed to it. If, however, they do give in to previous ways of thinking and feeling, they can also confess this to God and experience

forgiveness and be comforted anew with the conviction (4.5.1.3) that God is on their side in their struggle against the enemy (negative thoughts and Satan).

The family is guided to wrestle before God about their child's deafness and draw close to God, despite the fact that God has allowed this challenge in their lives. To express to God how they do not understand why He has created their child as deaf, but that they know that He has a plan with it and that he is busy with something in them, their child and also other people. They are guided to give themselves to the Lord and to search for the will of the Lord.

5.6.2.2.2 Phase 2-dimension 2: Sensitization to alternative views of deafness

Hearing parents of newly-diagnosed deaf children are often not fully informed of all aspects of deafness. The pastoral practitioner takes time to create awareness of all aspects of deafness (3.3) and to provide alternative views of deafness (3:3:4; 3.4).

It is important that the pastoral practitioner should provide unbiased and reliable information and guide parents through the overwhelming amount of information. Apart from the general information on deafness, the pastoral practitioner informs parents of Deaf Culture (3.4), and sign language (3.4.2). Options in terms of education (3.6.1.3.3), language and communication (3.6.1.3.2) and amplification are discussed and parents are sensitized to the issue of cochlear implants (3.6.1.3.1). By not only counselling from a mere pathological approach to deafness parents are given comprehensive information and guidance from which they can construct their own views of deafness and upon which they can make crucial decisions. Elements to pay special attention to in the counselling process include: emphasis on the indispensability of parental acceptance; the importance of early access to a comfortable language and the participation of the whole family in the process of establishing the optimal well-being and development of the deaf child. Additionally the pastoral practitioner abandons the myths about deafness and promotes the extensive cognitive and social benefits of a bilingual-bicultural (or multilingual-multicultural) approach to communication and education.

5.6.2.2.3 Conclusion of phase 2

Parental acceptance of their deaf child is a crucial goal of the pastoral counselling process. Accepting deafness and accepting their deaf child as he/she is, has a tremendous effect on the overall well-being of the child. If parents do not come to acceptance and are continually searching for ways to minimize ("fix") their child's deafness, valuable time for language acquisition is lost. The Deaf community pleads to be heard and for a bicultural approach to

be considered. If parents, after being guided through both dimensions 1 and 2 above, they are brought to a place where they adopt the attitude of Christ and are willing to reconsider their previous perspective and to also consider the alternative views to deafness and how members of the Deaf community view themselves and their deafness not in terms of its being a disability but rather a minority culture. By becoming convinced of this, parents' own perspectives on deafness, their deaf child, their deaf child's needs and also the choices they will subsequently make in terms of options related to hearing technology, communication and education, will be influenced.

5.6.2.3 Phase 3: Adaptation through perseverance and support

In the previous phase parents were guided to Biblical truths and sensitized to deafness and Deaf Culture. However, replacing previous convictions with these new truths and truly integrating them into one's life takes perseverance. As with the previous phase, this phase also consists of two dimensions, perseverance and informal support on the one hand and broadening support and exposure to Deaf Culture on the other.

5.6.2.3.1 Phase 3-dimension 1: Perseverance and congregational support

(a) Perseverance

Parents are guided to identify the triggers that might cause them to fall back into previous patterns of thinking. As they struggle to integrate the new convictions into their lives, they are reminded of the truths. In the case of parents with deaf children these triggers might come in times of transition, like when their child goes to school; when they are confronted with the ignorance of and the insensitivity of members of the hearing society or be brought to face communicational challenges in their family. These triggers may cause parents to once again experience periods of great loss and might feel discouraged and focus once again on the 'whys' and the things they don't understand. Parents are encouraged to make contact with other families with deaf children and/or the Deaf community in their area for support (dimension 2). Parents are encouraged to remind each other about the things they do know about God and continuously return to these anchor points - that the Lord says that He is their Lord, that He provides for them, that the Lord has given them this unique child with unique needs and gifts. They have to repeatedly make these truths their own again and persevere (Rom. 5).

The goal is not only for parents to passively tolerate their situation. By gaining this new perspective, parents are in an exceptional position to advocate for their deaf child. When

confronted by ignorance and insensitivity by others, they can use it as an opportunity to actively share their struggle with this situation and newly-found perspectives with others.

A possibility to keep in mind might even be organizing camps for families with deaf children or informal support groups where this proposed model can be applied by the pastoral practitioner to provide guidance and where families mutually encourage each other.

(b) Congregational support

The pastoral practitioner leads the congregation in support of the family of the deaf child. He is in the ideal position to facilitate a dialogue between the opposing worlds of the hearing and the deaf (3.6.1.3.3). Especially in the initial stages of loss, Lamentations can be used, with great sensitivity, in the liturgy of communal worship since it enables the family with the deaf child to work through their loss in public worship and in the space of the liturgy of the community of believers (4.5.2.1; 4.6).

The congregation is further led to awareness related to deafness and 1 Corinthians 12 (4.5.2.2) used to promote a compassionate and accepting attitude towards the family with the deaf child and deaf people in the greater society. They play an important role in supporting, encouraging and drawing them closer when the family faces challenges and discouragement. They ought to be guided to a place where they are willing to reconsider their own perspectives and look at deafness from the perspective of deaf themselves as well – deafness as a minority culture. If the community of believers truly accept the deaf child as a significant member of the community of believers, the implication would be that the needs of the deaf child will be recognized. Overall, emphasis is here on cultivating an appreciation of each other's 'otherness' and subsequently to narrow the separation between hearing and deaf people by growing toward each other which ultimately would reflect God in their relationship.

5.6.2.3.2 Phase 3-dimension 2: Broadening support and exposure to Deaf Culture

Parents indicated a need for both formal and informal support. The pastoral practitioner can incorporate other role-players, thereby broadening the support system of families with deaf children (for example the HI-HOPES programme, SLED, the THRIVE programme, DeafSA and congregations for the Deaf).

Exposure to people involved in working with the Deaf/deaf and their families facilitates awareness. Additional exposure to the Deaf community implies access to an additional culture and language. This acquaintance will lead to greater awareness and understanding

and assist parents in broadening their understanding and appreciation of their deaf child's uniqueness and unique needs. By exposing their child to Deaf role models they are contributing to their child's very crucial cultural and social nurturing.

5.6.2.4 Phase 4: Finalé: future continued support

As the practical practitioner cannot indefinitely provide intensive pastoral counselling, the pastoral process moves into a direction the family with the deaf child is equipped sufficiently to continue independently their conversation with God and their situation.

The pastoral practitioner might exit the conversation of especially the parents but must stay involved in the families' lives as they are confronted with new challenges and as the needs of the family change and the specific needs of the deaf child surface. The pastoral practitioner therefore exits the conversation but follows up continuously to provide support as the child grows older and as ministry to the deaf child in particular becomes a priority (3.6.2). But until then, the pastor practitioner can gradually exit the conversation between the family and their situation, God and each other. The pastoral counselling appointments could be spaced out farther and farther apart to attain gradual termination of formal pastoral counselling but with the reassurance that the pastoral practitioner will remain accessible should they be in need of formal support in the future.

During the last official pastoral counselling process the parents can be asked to share their emotions and thoughts on their journey thus far. The pastoral practitioner could in summary repeat important aspects touched upon in the counselling process. Finally the pastoral practitioner and the family end their final formal encounter by coming before God in prayer in preparation for the journey ahead and to ask for guidance, wisdom, perseverance and strength.

Since the community of believers form a more permanent form of support, the leaders in the church could equip fellow believers to assist and provide further support to the family.

5.7 SUMMARY AND CONCLUSION

The empirical study highlighted the experiences of families with deaf children after diagnosis and confirmed the process of grief they pass through as well as their needs and challenges during this time. The interpretative study confirmed the process of grief parents of deaf children go through, the difficult decisions they are faced with and provided insight into the more general (pathological) view of deafness held by hearing professionals and alternative views (cultural or linguistic) view of deafness maintained by many deaf people themselves. It also revealed the needs and challenges in terms of pastoral care and counselling provided to families with deaf children. This confirmed the necessity for the formulation of a practical theological model in order to equip pastoral practitioners to effectively provide pastoral care and counselling to families with deaf children.

In this chapter a transition from theory to practice was done by integrating the research results gained from the empirical, interpretative and normative tasks to propose a practical theological model for pastoral practitioners in the pastoral care and counselling of families with deaf children. Since the first letter of the various phases of the first dimension forms the acronym DEAF, this model can also be referred to as the DEAF model.

Man is a being in conversation with himself, his convictions and his environment in attempting to make sense of life and all its challenging life situations. Due to the fall, man's relationships with his fellow man, God and his environment were shattered and as a result man was left with an emptiness and pain that he tries to fill and cure by various means. This emptiness, however, is God-shaped, meaning that only God can fill it and provide permanent relief.

Man has the ability to form habits (based upon convictions) and by discovering the untruths man can create new habits (based upon new convictions in the light of Scripture).

Three anchor points form the theoretical framework for pastoral counselling: Knowledge of God the Father, the comfort of the work of the Son, Jesus Christ and the work of the Holy Spirit as Comforter.

Although each family with deaf children is different and have unique circumstances to take into account, the proposed model was constructed to include the most prominent elements of importance in the pastoral care and counselling of families with deaf children and consists of two dimensions, which occur simultaneously and in parallel:

The first dimension focuses on the pastoral counselling of the family of newly-diagnosed deaf children and consists of the following phases:

- Developing rapport and building relationship during which a trusting relationship between the pastoral practitioner and the family with the deaf child is established and families are encouraged to open up and share their emotions and experience of loss. In this phase the challenges and questions parents might be faced with are identified and the underlying convictions maintained by parents are determined.
- Expanding perspectives form the second phase of the pastoral process. This phase consists of two interrelated dimensions which address the parental view of deafness by sensitizing parents to alternative views of deafness (dimension 2) and address parental grief and the way parents view their deaf child by bringing them to *Coram Deo* (in dimension 1).
 - *Sensitization to alternative views of deafness* revolves around creating awareness of all aspects pertaining to deafness and alternative views of deafness. Equipped with unbiased and reliable information parents can construct their own views of deafness and subsequently make informed decisions about crucial choices regarding education, communication and treatment of deafness.
 - In *Coram Deo* the parents are brought before the Triune God as their anchor and guided to understand the implication of how the knowledge of the persons of the Trinity can form the framework for their lives and specifically anchor them in this challenging situation. The family is also guided to base their conversation with their situation, God, themselves and their deaf child on a Biblical foundation. Parental grief, ethical questions and the parents' view of their deaf child are addressed by facilitation of a process of change in which discovered normative truths replace previous untruths. The role of prayer and the Word of God play a fundamental role in this phase and thus in the guidance to conversation with God.
- Adaptation through perseverance and support forms the third phase of this proposed model. With emphasis on cultivating an appreciation of each other's 'otherness' the role of the congregation in support and encouragement of and involvement with the family with the deaf child is addressed.

Additionally the family with the deaf child is encouraged to effect exposure to Deaf culture to assist them in the broadening of their understanding and appreciation of their deaf child's 'otherness'. They are also brought into contact with existing formal support for families with deaf children.

- Finalé: further support forms the last phase of the proposed pastoral model. Once the family with the deaf child is sufficiently equipped to continue their conversation independently, the pastoral practitioner gradually exits the family's conversation and slowly concludes formal pastoral counselling. However, the pastoral practitioner informally remains involved in the lives of the family and remains available as the general and spiritual needs of the family and specifically the deaf child might change as the child grows older.

The second dimension, broader support and pastoral care of the family of a newly-diagnosed deaf child, as discussed above, entails:

- Sensitization to alternative views of deafness; and
- Exposure to Deaf Culture and bringing families in contact with support (and other families with deaf children, via, for example, the THRIVE programme).

CHAPTER 6

CONCLUDING INFERENCES AND RECOMMENDATIONS

6.1 INTRODUCTION TO AND PURPOSE OF THE STUDY

For most hearing parents having a deaf child is their first encounter with deafness and as a result they find themselves on an unfamiliar and often very challenging journey.

The focus of this study was on the formulation of a practical theological model for the pastoral care and counselling of families with deaf children. Therefore the overarching problem statement of this study was:

What practical theological model can be formulated for the pastoral care and counselling of families with deaf children?

The overall aim of this study was determined from the above problem statement, namely:

To indicate what the pastoral care and counselling of families with deaf children ought to entail by developing a practical theological counselling model to be utilized by pastoral practitioners.

6.2 STRUCTURE OF THE STUDY

The researcher used Osmer's model of practical theological interpretation for Practical Theology. Osmer's model comprises four questions that guide the researcher to concentrate on the four interrelated intellectual tasks of practical theological research. These elements of the model of Osmer were therefore used to title the various chapters of this study.

According to Osmer's model the current situation is described and examined to understand "*what is going on?*" after which an investigation into and interpretation of the causes that gave rise to the specific situation are undertaken to attempt to understand "*why this is going on?*". From here the desired situation, "*what ought to be going on?*" was described by using normative perspectives gained from Scripture. The insights gained from the investigations could then be used to formulate a strategy of "*how might we respond?*" to the problem formulated in the descriptive-empirical task.

The results yielded by the various chapters are discussed in the subsequent pages.

6.3 THE DESCRIPTIVE-EMPIRICAL TASK OF PRIESTLY LISTENING

This chapter was aimed at gaining a rich depiction of “*what is going on?*” in terms of the current situation of pastoral care and counselling of families with deaf children.

6.3.1 The research of the descriptive-empirical task indicated the following significant results

- The qualitative inquiry confirmed hearing parents’ lack of prior knowledge and/or exposure to deafness prior to their child being diagnosed as deaf and many parents’ response to the diagnosis of their child’s deafness is similar to the grieving process after great loss.
- The main challenges families with deaf children experienced and listed as specifically difficult during the family’s adaptation to deafness in the family included challenges related to communication, education, finances, spirituality and practical day-to-day issues.
- The medical professionals who assisted the families did so mostly from a medical perspective of deafness, the result being that the guidance received in terms of hearing technology and educational, communicational and intervention options was aimed at mitigating the deafness and little to no information in terms of Deaf culture and sign language was provided.
- The families interviewed indicated receiving sincere support from family and friends. Some families did not feel supported by their religious community at all, while other felt that their religious community did support them, at least in a similar way than family and friends – with sympathy and encouragement. None of the families reported receiving formal pastoral counselling or experienced pastoral care during the difficult time of adjusting to a life of deafness.
- The importance of the elucidation provided by the descriptive-empirical enquiry relates to the need for increased attentiveness and priestly listening to the particular needs and expectations families with deaf children (as it emanated from this study) as they serve as recommendations for the pastoral care and counselling of families with deaf children.

6.4 THE INTERPRETATIVE TASK OF SAGELY WISDOM

In order to set the interpretative perspective of “*why this is going on?*” the literature study was undertaken, thereby cultivating a better understanding of various aspects pertaining to the current situation of families with deaf children.

6.4.1 Research from the literature inquiry indicated the following perspectives

- An understanding of all facets of deafness is a crucial prerequisite to the guidance and care of families with deaf children. Not only is knowledge of terminology surrounding deafness and classification of deafness (knowledge of the levels, age of onset, aetiology and types of deafness) of importance, but also an understanding of the various models of deafness.
- Deafness is traditionally approached from either the dominant medical (pathological) view of deafness as a disability or the socio-cultural model of deafness where deafness is understood as a cultural and linguistic difference in which sign language plays a very important role in Deaf culture and binds Deaf communities together. The literature studied revealed a development additional to the two main opposing views of deafness to create space for a bicultural approach in which dialogue and negotiation between the views are possible. This approach proves to have many cognitive, social and overall developmental advantages.
- However, research into the nature of professional medical guidance usually provided to parents of deaf children, echoed the results from the empirical study, which showed that the information and the guidance provided by them are highly determined by their own personal views of and attitudes towards deafness and tended to be from a one-sided pathological view of deafness. The effect of this must be recognised, since parents are usually initially overwhelmed and uninformed and they rely heavily on the guidance of the medical professional in their decisions about treatment, education and language.
- An informed professional providing care and counselling to families with deaf children understands the intricacies of both Deaf culture and the experiences of hearing families with deaf children. On the one hand he/she recognizes the cultural view of the Deaf community and subsequent important role of sign language and exposure to Deaf culture but also understands the challenges and emotions hearing parents of newly-diagnosed deaf children typically go through.
- The literature study further confirmed the emotional response of hearing parents of newly-diagnosed deaf (from the descriptive-empirical task) and as similar to the process

of grief after great loss. Although the emotions and process of dealing with loss (shock, being overwhelmed, frustrated, struggling with the diagnosis, sadness and fear) vary and are unique to every individual, the importance of parental acceptance as a process of ongoing adjustment is viewed as essential.

- Since parents and professionals can play a very significant role in the cultivation of the deaf child's social and emotional competency a bilingual-bicultural approach could be of great value in addressing the needs of the child directly and in making decisions that are evaluated to be best for the deaf child. Researchers agree that the indirect impact of deafness affects emotional adjustment and social development much more than deafness as such. As a result researchers place great emphasis on the importance of early identification of deafness, followed by early intervention and full access to a comfortable language as determining in the outcome of the communication abilities and overall development of the deaf child. Parental acceptance and the parent-child relationship were also indicated as being crucial to the well-being of the deaf child.
- Understanding gained from a closer look at spirituality and deafness and the challenges of Deaf pastoral ministry highlighted the choice of communication and education as largely influential to the spiritual development of the deaf child. Hence the language needs of the deaf child ought to feature high on the list of priorities of any professional's agenda.
- Yet, in the pastoral care and counselling of families with deaf children, pastoral practitioners are often ignorant of the existence of Deaf culture and as a result are not equipped to guide the family in understanding and believing that their child can really flourish as a Deaf person. Supplementary to providing general care to these families, pastoral practitioners need to develop cultural competency. This entails becoming aware of his/her own assumptions about deafness, to make an effort to gain knowledge and understanding of people who are culturally different from him/her and to subsequently apply strategies in pastoral counselling and care which are both culturally sensitive and relevant. Even though cultural competency is usually only emphasised when working with counselees who are culturally different from the counsellor, it remains applicable in the care and guidance of hearing families with deaf children since the pastoral practitioner plays a fundamental part in becoming acquainted with the hearing family with a family they've been unaware of for most of their lives.

A paradigm shift away from the pathological view of deafness to adopt a bilingual-bicultural approach in understanding deafness as a condition of acquiring a culture could empower the family to progress from grieving for the loss of their envisioned future for

their child to a hopeful future in which their child can flourish as a normal deaf individual and uniquely contribute to this world.

- The need for the development of a practical theological model for the pastoral care and counselling of families with deaf children became increasingly evident from the literature inquiry which indicated the challenges of Deaf pastoral ministry and the lack of readily available and adequate spiritual and religious resources on deafness and working pastorally with families with deaf children.

6.5 THE NORMATIVE TASK OF PROPHETIC DISCERNMENT

In an attempt to conclude “*what ought to be going on*”, an exegetical study was done of relevant passages to determine what the ethical and normative perspectives from Scripture are for pastoral care and counselling of families with deaf children.

6.5.1 The following normative and ethical perspectives from Scripture of importance for the rest of this study are consequently formulated conclusively

The normative perspectives gained from the exegesis compared to the interpretative perspectives in determining how worldly wisdom appropriately relates to and interacts with the Wisdom of God yielded normative and ethical perspectives from Scripture in terms of what pastoral care and counselling of families with deaf children ought to entail.

6.5.1.1 Normative principles pertaining to the process of grief

In order to find perspectives pertaining to the process of grief, exegesis of the book of Lamentations was done since it specifically has a continuous refrain of articulation of grief.

- When experiencing grief after great loss, believers are encouraged to go through the grieving process and to earnestly converse with God and in honesty and with sincerity pour their hearts out before the Lord. In reflecting on Lamentations and comparable passages from Scripture, believers’ isolation might be eased as they realize how others before them have also wrestled with God in their affliction and have waited on Him in hope.
- God is the only one who truly knows believers and who understands their innermost thoughts and afflictions and therefore, when going through the phase of anger (Lam. 2), believers can wrestle through their anger with God and refrain from projecting in onto their environment.

- Remembrance of and reflecting on the attributes of God as well as the covenantal relationship with God can play a great role in working through grief as believers are guided to come to a point of understanding that they will never comprehend everything. This shift of focus from the incomprehensible to the known things about God (Lam. 3; Pss. 42; 73 and Hab. 3) is a continuous process of returning to the presence of the Lord and finding hope amidst hopelessness and despair.
- The Holy Spirit can help believers in conquering emotions of disheartenment, depression, anger etc. in the same way that the poet of Lamentations experienced God being 'on his side and against the enemy'.
- Acceptance (Lam. 5) can finally be found in the comfort of knowing that everything that happens to God's children flows forth from His love and covenantal faithfulness. This acceptance is attained when believers submit to God's sovereignty, even though they do not understand everything, and when they find hope in His covenantal faithfulness.

6.5.1.2 Normative principles pertaining to the attitude of hearing people towards deafness

Exegesis of 1 Corinthians 12 and in additional consideration of Philippians 2:4 and John 15:12-13, revealed that the variety of spiritual gifts found in the community of believers are all sovereignty and freely allotted by the same Source – God, and that these gifts are indeed all equally important. Since the community of believers are unified as the body of Christ, each individual member, regardless of how apparently 'strong' or 'weak' they are, has a specific function in the effective functioning of the whole body. Consequently each member is designed to be interdependent and therefore has an obligation to care for, be concerned for and love the other members for the benefit of the whole body.

Christ's exemplary attitude toward the 'weaker' (marginalized) members of society was one of involvement, humility and sincere compassion and love. As the body of Christ, believers ought to follow suit and adopt the attitude of Christ, implying that they be prepared to place the interests of others above their own, and be prepared to renounce their own perspectives and ideas out of love for the other. The boundaries between members who are different from one another can be overcome, not by "mitigating or undoing" the "otherness" of one party, but by a love that has acquired a recognition and appreciation of the uniqueness and otherness of that party.

Apart from increasing compassion between the hearing and the deaf, adopting an attitude as described above would enrich all members. Reaching out to each other creates a space

created where dialogue can occur and strangers can move nearer to each other, be enriched by each other and confirm each other's unique place in the body of Christ. Spiritual growth and development towards each other is encouraged by discovering and appreciating each other's differences, and this in turn reflects God in their relationship.

6.5.1.3 Normative principles related to the ethical questions pertaining to deafness

The goal of this thesis was not to judge all the practical ethical choices (in terms of education, mode of communication and treatment of deafness) as fundamentally 'wrong' or 'right', yet the research did lead to the conclusion that an attitude of humility, love and other-centeredness could form a strong basis for continued conversation in which the interests of the deaf child is placed above all else and where deafness can be viewed as an opportunity for the whole family to acquire an additional culture and language.

6.5.1.4 Normative principles related to the question of the sovereignty of God

Lamentations reflects the emotional turmoil of the poet in attempting to come to terms with his afflictions. In this dispensation the ways of the Lord can never be fully understood and therefore many 'why' questions are left unanswered. Wrestling with God about His mysteries about the things believers don't understand brings them to a turning point where the focus shifts from being perplexed about the affliction to reflecting on the known attributes of God. Remembrance plays a large role in progressing through grief after great loss and a change in perspective can be a source of comfort.

6.5.2 Implication of normative principles for a pastoral model for guidance of families with deaf children

Lamentations validates the process of grief found in both the empirical and interpretative chapters and can additionally be particularly useful in encouraging families to embrace the process of grief and to wrestle through this spiritual pilgrimage with God. Lamentations can be used in private pastoral counselling and also in the liturgy of public worship as a means to encourage articulation of grief. In embracing their grief in the presence of God, families with deaf children embark on a spiritual pilgrimage which will take them on the many ups and downs of the process of grief to, finally, a form of acceptance in the sense of submitting to the sovereignty of God and hope in His covenantal faithfulness.

In the same way the poet of Lamentations associated with the suffering of the people, the pastoral practitioner ought to be able to truly listen in priestly fashion to the situation of not

only the loss the family with the deaf child might be experiencing, but also to have compassion for the culturally Deaf community, their view of deafness and their culture. This would imply providing to the family with the deaf child accurate and unbiased information and guidance in terms of deafness. A pastoral model should therefore emphasise the interests of the deaf child and this requires the pastoral practitioner to be fully informed to understand and convey the impact of decisions on the spiritual, emotional and over-all well-being of the deaf child.

The importance of the deaf child in the larger body of believers forms the focus of the pastoral guidance of the family of believers since God has placed this particular child in this particular family with a function to fulfil. This focus might cultivate hope in the hearts of the parents as they gain a new vision of their child as a unique gift from God, a child with potential and future, a child who has an important function in the body of Christ as well as in society.

In the light of the above, the pastoral practitioner working with families with deaf children ought to recognise and assess his personal attitude towards deafness since it will determine the pastoral care and guidance he/she will provide. Apart from compassionately joining the parents in their wrestling with God the pastoral practitioner should be well-equipped in terms of all aspects of deafness, which will enable him to pastorally care for the family with the deaf child, to provide accurate and reliable information about all views of deafness and provide normative advice in terms of ethical issues.

All believers in the community of believers ought to be urged to adopt an attitude of Christ, by immersing themselves in the lives and experiences of the deaf and by considering their interests. Adopting the above attitude would be in congruence with the bilingual-bicultural dialogue approach to deafness, which emanated from the interpretive task of this study.

6.6 Results of the pragmatic task and establishment of a practical theological model for the pastoral care and counselling of families with deaf children

The necessity for the development of a practical theological model in order to equip pastoral practitioners to effectively provide pastoral care and counselling to families with deaf children was indicated by the research results gained from the empirical, interpretative and normative tasks of this study.

The pragmatic task marked the formulation and implementation of a strategy to address the problem formulated in the empirical-descriptive task (*"How might we respond/ How should*

we act?") by integration the above research results to transition from theory to practice by proposing a practical theological model (DEAF model) to address the above need.

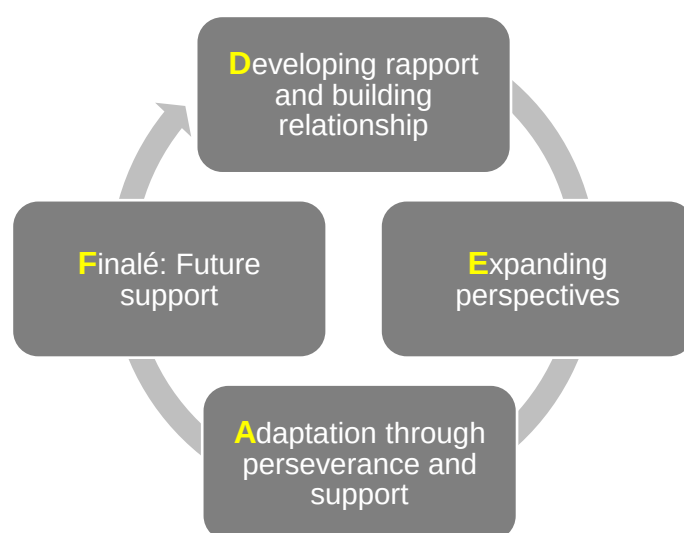


Figure 6-1: Phases of the pastoral counselling dimension of the DEAF model for the pastoral care and counselling of families with deaf children

The loss experienced by parents of newly-diagnosed deaf children can cause them to go through a process of intense grief. They may struggle to come to terms with the diagnosis, specifically if they're uninformed about alternative views of deafness and as a result view their child as disabled and with not too bright a future.

In the DEAF model parents are sensitized to alternative views of deafness, introduced to Deaf culture and encouraged to make use of existing forms of formal support for families with deaf children. This sensitization broadens the perspectives of families with deaf children in terms of deafness, which in turn facilitates parental acceptance.

Since parental acceptance has a remarkable effect on the overall well-being of their child, this model aims to work through the parental process of grief and to finally promote parental acceptance of deafness and acceptance of their deaf child even further by bringing them before the Triune God as their anchor in this situation and come to understand what the love of the Father, the comfort of Son and the work of the Holy Spirit means to them.

Through the pastoral counselling process convictions based on ignorance or untruths are addressed and replaced with truths discovered through the sensitization process and Coram Deo.

When parents adopt the attitude of Christ, it enables them to reconsider their previous perspectives and to consider the alternative views to deafness and how members of the Deaf community view themselves and their deafness not in terms of disability but as being a minority culture. By becoming convinced of this, parents' own perspectives on deafness, their deaf child, their deaf child's needs and also the choices they will subsequently make in terms of options related to hearing technology, communication and education, will be influenced. Not only that, but they themselves are empowered to use their own experience to advocate for their child when he cannot advocate for him/herself and to reach out to other families in similar circumstances.

Parents are guided to not only accept their child as deaf, but to celebrate his uniqueness and truly perceive their child as a unique gift from God, with unique challenges but also with his own unique gifts. These gifts ought to be discovered and cultivated in order for the child to eventually fulfil his/her indispensable function in the spiritual body of believers.

An appreciation for each other's 'otherness' is cultivated among the body of believers (faith community) to raise awareness among members to enable them to form part of the necessary informal support to the family with the deaf child.

Even when the formal pastoral counselling process comes to an end, the pastoral practitioner remains informally involved in the lives of the family. He/she remains informally involved in their lives to address the future challenges and altered needs brought about as the dynamics in the family changes and the child grows up. As the child grows up the focus of pastoral care will then shift to focus more on addressing the spiritual needs of the deaf child.

6.7 FINAL INFERENCES

The researcher's final inference after completion of this study is that – as the central theoretical argument of the (chapter 1) states clearly - families with deaf children could greatly benefit from a pastoral practical theological counselling model for much-needed pastoral care and counselling.

The researcher was able to compile valuable questions for both the questionnaires and the semi-structured interviews for the empirical study (chapter 2). Keen participants were found and provided the researcher with rich information related to families with deaf children's experiences. The researcher is of the opinion that her report on the empirical data was comprehensive and thorough and therefore makes a contribution to the current body of research on specifically the spiritual needs and expectations of families with deaf children.

The literature study (chapter 3) contributed significantly in terms of insight into specifically the classification of deafness, various models of deafness and Deaf culture. The literature study confirmed some of the findings of the empirical study and additionally highlighted aspects of importance for inclusion in a model for pastoral care and counselling of families with deaf children.

Scripture (chapter 4) elucidated perspectives pertaining to the process of grief and how knowledge in the Triune God as anchor is key in working through intense loss. Scripture does not provide pertinent information on deafness per se but attitudes towards deafness and ethical questions pertaining to deafness could be deduced.

By means of integrating the above results, as well as studying Breed's Biblical pastoral model for counselling the researcher could construct an own practical theological model for pastoral care and counselling of families with deaf children (chapter 5).

The researcher views this study as relevant, valid and significant. The outcomes of this study can form an indispensable part of the pastoral ministry to hearing families with deaf children.

In the light of the above the researcher evaluates this study as successful in contributing to the deficient amount of literature of the specific group addressed in this study and would maintain that all research objectives have been attained.

6.8 POSSIBLE LIMITATIONS OF THE STUDY

This study concentrated on hearing families with deaf children. It did not include pastoral care and counselling of adult deaf persons or deaf parents raising hearing children. Additionally this study would ideally have had a higher number of participants.

The focus in terms of the pastoral model eventually centred more on the pastoral counselling of specifically the parents of the deaf child, since parents go through a process of grief after the diagnosis of their deaf child, and not necessarily the child him/herself. Parents additionally play a crucial role in the overall optimal development of their deaf child. For this reason, the study was demarcated to focus less on the extended family and the deaf child him/herself.

Although the researcher believes all objectives to have been met, there are certain limitations which should be taken into consideration, since it may affect the generalisability of the results. The participants of this study consisted of a limited number of hearing families with deaf children from the North West Province only.

Other aspects that could potentially place a limitation on this study, is the fact that all the families comprised married couples and were Caucasian (white). If single parent families and/or other ethnic groups had been involved in this study, different perceptions and attitudes could possibly have surfaced. Although many approaches to deafness exist (each with their own advantages, disadvantages and successes) this study was done mainly from the bilingual-bicultural approach to deafness. The above ought to be taken into consideration were any future research related to this topic ever to be conducted.

The section of this study in which the proposed practical theological model for pastoral care and counselling of families with deaf children was discussed, did not elaborate on the practical accommodation of the deaf child and other deaf people in ministry due to the limited scope of this study.

6.9 RECOMMENDATIONS FOR FURTHER RESEARCH

- Pastoral guidelines regarding pastoral ministry to the Deaf community in the South African context.
- Decolonizing Deaf ministry in South Africa and exploring Deaf theology in South Africa.
- Broadening the scope to exploring practical ministry to facilitate spiritual development of deaf children and other deaf members in hearing congregations
- Exploring the practice of faith healing to mitigate deafness and the experiences of attending these faith healing worship services on deaf children, their hearing families and deaf adults.
- Addressing African cultural beliefs (including ancestral punishment) and convictions in pastoral ministry to families affected by deafness.
- Broadening the scope of research to include the role of the Deaf community in reaching out to the hearing community in order to narrow the distance between the hearing and the Deaf.
- Exploring the translation of Biblical metaphors and imagery in a way that would make their meaning more applicable to the Deaf.

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APPENDICES

APPENDIX 1

Letter to school/hospital/clinic/audiologist

Consent form: participation in a research project.

Research on the pastoral care and counselling of families with deaf children.

I am currently busy with a Doctoral degree in Practical Theology at the North-West University (NWU), Potchefstroom. My research is titled "Pastoral care and counselling of families with deaf children: a practical theological model". As part of my research I am interviewing hearing families with deaf children in order to generate data. This research is done under the supervision of Dr Rudy Denton of the Department Practical Theology and Ms Ruanna Reddy of the Language Department of the NWU.

Permission is hereby sought to interview clients from your practice/ parents of children at your school who are part of families with deaf children.

The personal information they disclose, will be treated anonymously and confidentially. The interviews will be audio-recorded with a digital recorder in order to ensure the accurate reproduction and processing of the data. Confidentiality will be achieved by storing the audio recordings in a safe place to which no-one but the researcher and her promotors will have access. Further, the anonymity of the clients/parents and their children will be ensured by the use of pseudonyms. The data will be treated with respect and integrity.

During the research process, I, as the researcher, undertake to adhere strictly to the prescribed ethical rules and undertake to treat the data discussed during interviews with respect and integrity.

The benefits of participation in this study are that they (the relevant parties) will have the opportunity to express and share their experiences and to contribute to the improvement of the pastoral care and counselling provided to families with deaf children.

Your consent to interview your clients/parents at your school, as well as assistance in contacting and scheduling interviews with the parents, would be greatly appreciated.

Rineé Pretorius

E-mail: rineepretorius@gmail.com

Consent form:

I,..... hereby give consent to Rineé Pretorius to interview my clients in order to conduct the above research (dealing with pastoral care and counselling of families with deaf children).

Signature

Date

APPENDIX 2

Research participation information

and consent form

(Participants: families with deaf children)

Consent form: participation in a research project.

Research on the pastoral care and counselling of families with deaf children.

I am currently busy with a Doctoral degree in Practical Theology at the North-West University (NWU), Potchefstroom Campus. My research topic is "Pastoral care and counselling of families with deaf children: a practical theological model". As part of my research I am interviewing hearing families with deaf children in order to generate data. This research is done under the supervision of Dr Rudy Denton of the Department Practical Theology and Ms Ruanna Reddy of the Language Department of the NWU. I received the recommended ethical approval from the Research Ethics Committee of Theology and the NWU Institutional Research Ethics Regulatory Committee (NWU-IRERC) for this empirical research. The ethics number awarded to my research is NWU-00122-15-A6.

You have been recruited to participate in the research because you are a parent of a deaf child (umbrella term used in the research to refer to both deaf and hard-of-hearing children). You will be expected to fill out a short questionnaire which will be followed by an in-depth interview. For your own convenience, I will conduct the interview in the comfort of your own home or any other appropriate private setting which you may prefer.

You will not be offered any form of incentive or financial remuneration for your participation in this research; however, you will personally benefit from participating in this study since you will have the opportunity to express and share your experiences and additionally contribute to improving the pastoral care and counselling provided to families with deaf children.

The research results of the current study will be made available online to all respondents upon the completion thereof. I will be available for any questions or discussion of the results.

The personal information you disclose, will be treated anonymously and confidentially. The interviews will be audio-recorded with a digital recorder in order to ensure the accurate reproduction and processing of the data. Confidentiality will be achieved by storing the audio recordings in a safe place to which no-one but the researcher and her promotors will have access. Furthermore, the anonymity of the parents and their children's will be ensured by the use of pseudonyms. The data will be treated with respect and integrity. During the research process, I, as the researcher, undertake to adhere strictly to the prescribed ethical rules and undertake to treat the data discussed during interviews with respect and integrity.

The benefits of partaking in this study are that you will have the opportunity to express and share your experiences as well as contribute to improving the pastoral care and counselling provided to families with deaf children.

For any concerns or questions about this study. please contact me.

Rineé Pretorius

E-mail: rineepretorius@gmail.com

Declaration by participant

By signing below, I agree to take part in the research study titled: **Pastoral care and counselling of families with deaf children: a Practical Theological model.**

I hereby declare that:

- I am willing to participate in the above research project of Rineé Pretorius dealing with pastoral care and counselling of families with deaf children, and that I will participate in the semi-structured interview that she will conduct with me. I have read this information in a language I am fluent and comfortable in.
- The research was clearly explained to me.
- I have had an opportunity to ask questions of the researcher and all my questions have been answered satisfactorily.
- I understand and confirm that my participation in this research study is voluntary..
- I am aware that I have the right to change my mind and that I may withdraw from the research process at any time without having to provide reasons for doing so

Signed at (place) on (date) 20....

.....

Signature of participant

Declaration by researcher

I (name) hereby declare that:

- I explained the information in this document to I did/did not use an interpreter
- I encouraged him/her to ask questions and to take adequate time to answer them
- I obtained informed consent for this research.
- I am satisfied that the participant understands all aspects of the research sufficiently , as described above.

Signed at (place) on (date) 20....

.....

Signature of researcher

APPENDIX 3

Qualitative questionnaire to participants of the study

(Participants: families with deaf children)

QUESTIONNAIRE: FAMILIES WITH DEAF CHILDREN

Dear participant

Thank you once again for your willingness to participate in this study. As explained previously, all information will be dealt with anonymously and confidentially.

Particulars of participant:

- a. Respondent number/Pseudonym: _____(To be completed by researcher)
- b. Gender:
- c. Age:
- d. Home language:
- e. Church denomination:
- f. Mode of communication
- g. Today's date:

Answer the following questions in writing. Please try to do so as thoroughly and elaborately as possible. You can return this questionnaire electronically via email (see address below) or contact me telephonically to collect it from you personally.

What is your experience of being part of a family with a deaf child? Questions that emanate from the above question:

- 1. How and when did you learn about your child's deafness?
- 2. What was, up to that point, your knowledge about and attitude towards deafness?
- 3. What was your response? What emotions did you have to deal with?
- 4. What was the response of your extended family and friends?
- 5. What was the response of your religious community?
- 6. What were your family's greatest challenges?
- 7. Did learning about your child's deafness have an impact on your spiritual life?
- 8. Did you and if so to whom, did you turn for guidance and advice in learning to live with deafness?
- 9. What were your needs and expectations in terms of your religious community?

Thank you

Rineé Pretorius:

Email: rineepretorius@gmail.com

APPENDIX 4

Research participation information and consent form

(Participants: pastoral practitioners)

Consent form: participation in a research project.

Research on the pastoral care and counselling of families with deaf children.

I am currently busy with a Doctoral degree in Practical Theology at the North- West University (NWU), Potchefstroom Campus.. My research is titled “Pastoral care and counselling of families with deaf children: a practical theological model”. As part of my research I am interviewing pastoral workers in order to generate data. This research is done under the supervision of Dr Rudy Denton of the Department Practical Theology and Ms Ruanna Reddy of the Language Department of the NWU.

The personal information you disclose, will be treated anonymously and confidentially. The interviews will be audio-recorded with a digital recorder in order to ensure the accurate reproduction and processing of the data. Confidentiality will be achieved by storing the audio recordings in a safe place to which no-one but the researcher and her promoters will have access. Further, the anonymity of you and your child will be ensured by the use of pseudonyms. The data will be treated with respect and integrity.

During the research process, I, as the researcher, undertake to adhere strictly to prescribed ethical rules and undertake to treat the data discussed during interviews with respect and integrity.

The benefits of participating in this study are that you will have the opportunity to express and share your experiences as well as to contribute to the improvement of the pastoral care and counselling provided to families with deaf children.

For any concerns or questions about this study, please contact me.

Rineé Pretorius

E-mail: rineepretorius@gmail.com

Consent form:

I,..... hereby declare my willingness to participate in the above research project of Rineé Pretorius dealing with pastoral care and counselling of families with deaf children, as well as in the semi-structured interview that she will conduct with me.

The purpose of these studies is to obtain information from the semi-structured interviews in order to design a practical theological model for the pastoral care and counselling of families with deaf children.

The research was explained to me and I am aware that I have the right to change my mind and that I may withdraw from the research process at any time without having to provide reasons for doing so. All information will be treated confidentially and anonymously.

I understand and agree that my participation in this research study is voluntary.

Signature

Date

APPENDIX 5

**Informal preliminary correspondence in the form of questionnaires
to participants of the study**

(Participants: pastoral practitioners)

QUESTIONNAIRE: PASTORAL PRACTITIONERS

Dear participant, thank you once again for your willingness to participate in this study. As explained previously, all information will be dealt with anonymously and confidentially.

Particulars of participant:

- a. Respondent number/Pseudonym: _____(To be completed by researcher)
- b. Gender:
- c. Age:
- d. Home language:
- e. Church denomination:
- f. Occupation/position in the church:.....
- g. Today's date:

Answer the following questions in writing. Please try to do so as thoroughly and elaborately as possible. You can return this questionnaire electronically via email (see address below) or contact me telephonically to collect it from you personally.

- 1. What is your experience in terms of working with families with deaf children?
- 2. What do you know about deafness and its causes, types and levels?
- 3. What do you know about Deaf culture and Sign Language?
- 4. During your training, did you receive any training in dealing with families with deaf children?
- 5. What do you think the needs and challenges of families with deaf children are?
- 6. If a family with a deaf child came to you for pastoral care and counselling, what would your plan of action be?
- 7. What do you think the responsibility is of the church, the pastoral worker and the other church members towards families with deaf children?

Thank you

Rineé Pretorius:

Email: rineepretorius@gmail.com

APPENDIX 6

**Summary of results of informal preliminary correspondence in the
form of questionnaires to pastoral practitioners**

The informal preliminary correspondence with practising pastoral practitioners indicated pastoral practitioners' lack of awareness related to deafness and the consequent lack of competence in terms of pastoral care and counselling of families with deaf children:

QUESTIONS POSED TO PASTORAL PRACTITIONERS	PARTICIPANT					THEMES
	A	B	C	D	E	
1. What is your experience in terms of working with families with deaf children?	None	None in my Pastoral work.	I don't have a lot of experience yet in terms of accompanying families with deaf children on their journey. One family in our congregation has a little child with hearing limitations, as a result of this he underperforms – I have more experience with older people whose hearing is deteriorating.	They are always concerned whether they've got the correct information.	Little to none. I have met maybe a handful of deaf people in my life. Cannot say that I have any experience "working" with families with deaf children.	Little to none
2. What do you know about deafness and its causes, types and levels?	Very little	Only what I have researched on the Internet on a very superficial level.	I don't have much knowledge of deafness or its causes.	To be honest, I know nothing.	I don't know anything more than what one would call "general knowledge". I know some babies are born deaf; other scenarios could be due to an accident or illness.	Very little General knowledge
3. What do you know about Deaf culture and Sign Language?	Nothing	Not much. Only through contact with a PhD student on the subject.	I have very little knowledge of deaf culture and all I know about sign language is what I've seen people use it – also on television.	I know nothing about deaf cultures but I know a little about sign language.	Very little. Only the few basic signs that I have come to know on those cards that deaf people sometimes "sell" or give away for donations.	Not much
4. During your training, did you receive any training in dealing with families with deaf children?	No	Only on a very limited scale – training was limited to general principles of counselling but no mention of dealing with this category.	No, none.	Not at all.	No, I unfortunately did not receive any training.	None limited

5. What do you think the needs and challenges of families with deaf children are?	<i>Unsure</i>	<i>From the Church point of view I would think that families need understanding of the total situation within which they find themselves. They would need more moral, emotional and spiritual support than anything else, and also for pastoral care to be made available when needed. A general challenge would mainly be to provide loving care for the child. Specific challenges would involve clinical matters such as speech therapy, sign language tuition and educational assistance.</i>	<i>Being behind in terms of in scholastic abilities as a result of limited reading and speaking skills. Loneliness and isolation from the community. Stigma that deaf children are also dumb. Possible financial expenses.</i>	<i>They wish to know sign language; they need their daughter to understand everything (which is not always possible). The challenge is even in the church – no one understands sign language.</i>	<i>One of the most obvious needs that comes to mind is finding schools that accommodate hearing “disabilities” (I know it’s a terrible word, sorry), and the need never stops, from pre-primary, primary-, high school and university.</i>	Families need understanding and moral, emotional and spiritual support Pastoral care and loving care for the child Clinical matters Stigma Challenge to the church
6. If a family with a deaf child came to you for pastoral care and counselling, what would your plan of action be?	<i>I would have to try and find someone to assist with communication</i>	<i>I would assist them as far as I possibly could from a general pastoral point of view. Ideally I would refer them to a person who is a professional in this field and provide as much general information and assistance as required to the professional, should the family be members of my Church.</i>	<i>I will find out about the specific child and family and then accompany them on their journey. The questions in terms of faith, related to people with limitations will have to be dealt with, with the child and with the parents. Provision will have to be made for the religious education of the child.</i>	<i>Understand their problem and try to study the culture and language of Deaf people.</i>	<i>Probably use the parents as interpreters, ask them for a few basic signs-words to communicate friendliness and acceptance, and to show I am willing to make an effort. And depending on the age of the child, I could use a writing board / pen and paper to communicate in writing.</i>	Find someone to assist with communication Pastoral assistance Refer to professional Religion Study culture and language of Deaf people

7. What do you think the responsibility is of the church, the pastoral practitioner and the other church members towards families with deaf children?	<i>I think it is vitally important for the church to be as accommodating as possible, be willing to learn how to accommodate these special needs families</i>	<i>Equally as much, if not more, as any other pastoral challenge that there may be in the Church.</i>	<i>Acceptance/creating space for such a person to be able to function in a religious community / emotional and financial support to the family as needed.</i>	<i>They must support them; if possible send someone who is interested to study the culture and sign language and to then come back to work in the same community.</i>	<i>I think the responsibility of the above- mentioned parties, is in essence the same as towards all other people: acceptance and respect, irrespective of who they may be; I do think that the occurrence of deaf children is very rare, and that is probably why it is not something that receives a lot of attention from churches in general. If and when somebody has a specific need, then I believe it should be handled with respect and love, to show willingness to accommodate the need. For instance; we have a few (about 4-5) elderly people who have difficulty hearing. To them, I give a printout of the sermon so that they can follow during the service. We also have a blind elderly lady, who is in a wheelchair. For her need, I communicate with her family a day or two before the Sunday service, in regards to the hymns and Scripture applicable for the coming service.</i> <i>I strongly believe that deaf children and families with deaf children should receive more attention during any formal training, or at least be supplied with the necessary tools and contacts to facilitate learning and growth with a positive</i>	Accommodating and support Willing to learn culture and sign language Formal training Faith community Humble servanthood
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					<i>attitude of confidence. Rather than shying away from a seemingly difficult situation, and never having the confidence and willingness to engage / approach deaf people, and in effect never grabbing the opportunity to grow through humble servanthood.</i>	
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