

CHAPTER 1

CONTEXTUALISING DEAFNESS

1.1 Introduction

Hearing impairment is the most frequent sensory deficit in human populations, and nowhere is it more pronounced than in the developing world. The World Health Organisation's global estimates for disabling hearing impairment (>40dB) have more than doubled between the years 1995 and 2005, rising from 120 million to 278 million, of which 25% of these losses are estimated to have originated in childhood. The vast majority of infants with hearing loss reside in the developing countries of the world (WHO, 2006). On the whole, available data on the prevalence of hearing impairment is largely incomplete, with different studies utilising diverse criteria and therefore causing difficulties with comparisons and estimations of rates (Mathers, Smith & Concha, 2000). In addition to the developed world experiencing incomplete data there remains a scarcity of prevalence information on hearing loss and deafness for the majority of countries in sub-Saharan Africa (McPherson & Swart, 1997), and South Africa is no exception. In South Africa, accurate statistics on hearing impairment are extremely difficult to obtain. This is due to several reasons; firstly, there are many deaf people living in rural areas who remain unidentified. In addition, audiology clinics where people may be tested for hearing loss are scarce. It is clear that children in sub-Saharan Africa show higher rates of severe and profound bilateral hearing loss than typically observed in developed countries (McPherson & Swart, 1997; Picard, 2004). The Deaf Federation of South Africa (DEAFSA) make use of WHO statistics that state that approximately 1% of the population is deaf and 3% are hearing impaired. DEAFSA works on a figure of roughly 500 000 people as deaf in South Africa (DEAFSA, personal communication, 2008).

There are various types of hearing loss which are conventionally classified as conductive, sensorineural or mixed conductive-sensorineural. Conductive hearing impairments are caused by an abnormality or disease of the external ear, eardrum, or middle ear. Sensorineural hearing impairment is caused by an abnormality or disease

of the cochlea (inner ear) and a portion of the auditory nerve and mixed conductive-sensorineural refers to a combination of the above (Cone-Wesson, 2003).

Along with different types, hearing loss can also be classified by aetiology. Some hearing losses are caused by preventable diseases and others by genetics. The developing countries of the world are more affected by the preventable diseases that are often responsible for having a harmful effect on children's hearing (McPherson & Swart, 1997). The more developed countries are experiencing a decline in permanent hearing loss in newborns and infants. This is primarily attributed to widespread vaccination programmes that have done much to decrease common childhood infectious diseases that are capable of causing hearing loss, such as; mumps, measles and meningitis. Furthermore, such vaccination programmes have also dramatically reduced maternal rubella infection which is deleterious to the foetus's hearing. In the developing countries of the world these infectious diseases are still responsible for causing many of the cases of hearing loss (Picard, 2004). While meningitis appears to be the main cause of postnatal deafness in developed countries, measles, whooping cough and scarlet fever are the usual causes of deafness in developing countries. Other causes of deafness include: perinatal factors, prematurity, intra-uterine infection and syndromes (Pabla, McCormick & Gibbin, 1991). Interestingly, at least half of all cases of permanent hearing loss in children may have a genetic cause (Parker, Fortnum, Young, Davis, & Mueller, 2000, as cited in Picard, 2004). A mutation of a gene involved in cochlear functioning is the primary determinant of genetic causes of deafness (Cone-Wesson, 2003).

In addition to being classified by aetiology, hearing loss is also classified in terms of severity and by the degree to which the impairment affects a person's sound reception. Degree of hearing loss is measured by an audiogram where the measurement is recorded in decibels and hearing levels (dB HL) (Lim & Simser, 2005). There are five levels of hearing loss ranging from Mild to Profound and each with different effects. A Mild hearing loss which ranges from 26-dB HL to 40-dB HL has the effect of causing a person to struggle to hear faint or distant speech. Without the use of amplification devices a person with mild loss between 35-dB HL to 40-dB HL may miss 25% to 40% of speech signals depending on both the noise level in the room and the distance from the speaker. A 41-dB HL to 55-dB HL is considered

Moderate and will cause a person to miss 45% to 75% of speech signals, and without amplification a child with this loss is likely to have limited vocabulary and imperfect speech production. Moderately Severe refers to a range of 56dB HL to 70dB HL and for a child this will often result in marked difficulty in school, delayed language development and problems with social behaviours. A 90dB HL and above is considered Profound and without amplification, such a person is unable to hear any sounds (Lim & Simser, 2005).

Although early detection and intervention for infants with hearing loss is becoming the standard in many of the developed countries of the world; the same cannot be said of developing countries. Despite position statements being issued, South Africa has not yet implemented a systematic hearing screening programme for newborns. Due to this situation, hearing impairments are often only detected after 2 years of age or even later, when parents notice speech and language delays in their children. To add to the pressing issue of inadequate detection services, once diagnosed, South African children do not have access to early intervention. Furthermore, newborn hearing screening will be unable to achieve its goal unless an effective and comprehensive early intervention programme is in place (Storbeck & Calvert-Evers, 2008).

Early intervention services for children with hearing loss and their families must be designed to meet the specific educational and communication needs of this particular population (Prendergast, Lartz & Fielder, 2002). Prendergast et al., (2002) suggest that some quality indicators of early intervention services for deaf children and their families include involvement by professionals with specialised training in areas related to deafness, family involvement, as well as facilitation of both spoken language and sign language acquisition.

Until recently, South Africa did not have an early intervention service that provided home-based, unbiased and family centred support to families with a deaf or hard of hearing child. With strong documentation of the success of such early intervention services in the United States that yielded overwhelmingly positive results, the need for a similar programme in South Africa became apparent. Therefore, **HI-HOPES (Home Intervention- Hearing and Language Opportunities Parent Education Services)** was launched in August 2006 in response to the overwhelming need for

such a service. The Centre for Deaf Studies at the University of the Witwatersrand was responsible for its inception utilising seed funding from the Nelson Mandela's Children's Fund. Presently, the programme is limited to Gauteng with plans to expand nationally. This programme is based on the 35-year old SKI-HI model of early intervention which is a programme that is well accepted and utilised throughout the United States, Canada and Guam. Despite this international base, HI-HOPES is constantly being tailored to meet the unique needs of South African families enrolled in the programme (Storbeck & Calvert-Evers, 2008). The programme offers families of deaf children (ages 0-3 years) home-based, family-centred support and information. The aim of this programme is to partner with parents and provide information that is entirely unbiased in terms of technological or communicative intervention preferences. The programme will include anyone who is an important part of the deaf child's world- this may include, but is not limited to; parents, grandparents, caregivers and extended family. The programme provides the family with a Parent Advisor (trained early interventionist) who visits the family once weekly for one hour or more (Storbeck & Calvert-Evers, 2008). The Parent Advisor assists parents in managing the child's hearing aids, promoting early listening skills, establishing early communication with the child and providing information on various communication options as well as assistive technology devices available to parents (Watkins, Pittman & Walden, 1998).

In addition, should the family want, a Deaf Mentor will also form part of the team. The Deaf Mentor is a deaf adult who serves as a role model for both the child and the family. He/she will typically share personal experiences of being deaf with the family as well as share information regarding learning strategies of deaf people and information about deaf culture and sign language. Deaf Mentors and Parent Advisors are matched to families in terms of cultural, linguistic and geographic considerations. If a match is unable to be made, interventionists will receive training on the ethnographic and cultural factors characteristic of the family with whom they are matched (Storbeck & Calvert-Evers, 2008). Due to the HI-HOPES programme catering specifically for babies and infants up to 3 years of age, services to older children remains an area for development. Furthermore, Storbeck and Calvert-Evers (2008) highlight the need for more effective organisation and communication between

health care practices and intervention agencies to improve co-ordination and implementation of services.

HI-HOPES states that its goal is to serve every deaf or hard of hearing child and his or her family, regardless of race, class or language. Therefore efforts have been made through local community outreach to ensure that people in every community within Gauteng are aware of the services provided by HI-HOPES. This early intervention service is offered for three years to any family who has a deaf or hard of hearing child in the Gauteng region and is provided free of charge (Storbeck & Pittman, 2008).

1.2 The challenges facing hearing parents of deaf children

Ninety percent of deaf children are born to hearing parents (DEAFSA, 2003). In approximately ninety-four percent of deaf children, hearing loss occurs prior to their third birthday, or prior to the comprehensive acquisition of shared language (Eleweke & Rodda, 2000). The majority of hearing parents with deaf children have no prior experience with deafness and therefore face many challenging decisions concerning the development of their deaf child (Eleweke & Rodda, 2000). When hearing parents learn that their child is deaf, usually a range of emotions are experienced and a variety of challenges become apparent. Some of these challenges include: understanding the impact of a hearing loss, finding appropriate support and services, and developing strategies for communication with their child (Luckner & Velaski, 2004). Among the initial obstacles faced by hearing parents of deaf children, communication difficulties appear most prominent.

In general, parents of deaf children make a choice of communication modality that is usually categorised but not limited to, 3 approaches. Firstly, parents may choose the aural-oral method of communication (Li, Bain & Steinberg, 2007). Such an approach, perhaps most importantly, emphasises the use of amplification devices, such as hearing aids or cochlear implants to maximise the child's residual hearing (Eleweke & Rodda, 2000). Through this modern hearing technology the child can obtain maximum acoustic neurological advantages and through hearing all the features of speech can be assessed (Lim & Simser, 2005). Furthermore, this approach, through

amplification devices, will make use of auditory verbal training, oral training, lip-reading and cued speech, among other training methods (Li et al., 2007). However, many profoundly deaf children do not have sufficient residual hearing to be able to benefit from hearing aids (Morgan, 2001). Often when this is the case; cochlear implantation becomes the next option. However, even with a cochlear implant many children require extensive auditory and speech training and cochlear implantation is more effective on some than others (Eleweke & Rodda 2000). Alternatively, parents may choose manual communication. Such an approach will emphasise sign language as the first language of the child and the primary communication mode that will be utilised in all interactions between family members and the deaf child. Thirdly, parents may opt to use a combination of sign language and speech, this is known as Total Communication. In this instance one would sign and speak at the same time. Due to the structure of sign language being markedly different to that of the English language, sign language is not utilised in this instance in its fullest and most complete form (DEAFSA, 2006).

Making the decision of which communication method the child will learn is a critical choice for the family and one that is influenced by a variety of factors. This is much more than a simple choice of method as the method that is chosen often becomes the decisive factor in how well the child will manage in the future, within the boundaries of the family as well as outside of those boundaries (Magnuson, 2000). If a deaf child does not share the same communication mode with his/her family, feelings of frustration, isolation and loneliness may result (Foster, 1998). A lack of a common communication modality between a deaf child and his/her family can also have a profound effect on the development of a positive sense of self (Meadow 1969). It is evident that the choice of which communication mode to employ with a deaf child, is a decision that has far-reaching consequences for the child and is therefore an issue of considerable importance.

This research aimed to explore the experiences of hearing parents of deaf children and the process by which they come to choose a primary communication mode to use with their deaf children.

CHAPTER 2

COMMUNICATING WITH THE DEAF CHILD

2.1 Diagnosis of Deafness

When a hearing family is told that their child has some kind of hearing impairment, parents need to adjust both emotionally as well as practically. Parents react differently to this diagnosis and there exists wide-ranging variations with regard to both emotional intensity and the time that it takes to accept the diagnosis and the adjustments that needs to be made in order to live with the altered life situation. Many parents are in need of professional support in order to help them deal with their emotions regarding the news of a diagnosis of deafness (Backenroth, 1998). In this instance support groups and therapy can be of much assistance. In addition, the social networks that parents of deaf children have within their own families as well as with other families in the same situation bears an enormous significance on how parents deal with and learn to live with their deaf child (Backenroth, 1998).

The vast majority of hearing parents have never come into contact with someone who is deaf or hard-of-hearing until the birth of their own child. Consequently, such parents have a limited knowledge and understanding of hearing loss and its implications (Luckner & Velaski, 2004). Hence their choice of which primary mode of communication to employ with their deaf child is a stressful and often confusing decision to make. Complicating this matter further, parents often report that members of the medical profession with whom they had contact lacked knowledge about deafness and communication options (Luckner & Velaski, 2004). Regardless of the communication modality that is eventually employed; an oral approach, a sign system, South African Sign Language (SASL); hearing parents will need to make significant adjustments in how they interact with their deaf child (Luckner & Velaski, 2004).

For parents, dealing with a diagnosis of deafness in their child can be very traumatic. What makes this time more difficult is that many parents do not know any deaf adults

or know very little about deaf people and are therefore unable to comprehend that there are scores of deaf children who grow up to be deaf adults who are fully engaged in the world and who succeed in all areas of life (Lane, Hoffmeister & Bahan, 1996).

Language development is both positively and significantly affected by the age of identification of the hearing loss and age of initiation into intervention services (Yoshinaga-Itano, 2003). Research has shown that the first 6 months of life represents a particularly sensitive period in early language development. In addition, this period can be seen as a window of opportunity for children with significant hearing loss to develop language skills that are within the normal developmental continuum (Apuzzo & Yoshinaga-Itano, 1995, Snyder & Yoshinaga-Itano, 1999 as cited in Yoshinaga-Itano, 2003). Undetected hearing loss can lead to language, speech and cognitive delays. In addition, the mere detection of a hearing loss is not sufficient as without subsequent early intervention, preferably before the age of 6 months, the child will be unable to develop and maintain age appropriate language development. Research has shown that children enrolled in early intervention services at younger ages receive greater benefits, such as reduced language delay (Carney & Moeller, 1998 as cited in Prendergast, et al., 2002). Despite the modality chosen what remains important is that detection and subsequent intervention occurs before the age of 6 months (Yoshinaga-Itano, 1998, as cited in Storbeck & Calvert-Evers, 2008).

2.2 Deafness, Sign Language and the Development of a Positive Sense of Self

Language is bound up in the development of self-image. The self is developed through interpreting interactions that occur with others with whom the child comes into contact. Often, the child is required to reconcile contradictory information that is received. These tasks require that the child shares a language with people with whom he/she is interacting. In addition, an elaborate system of language needs to be developed in order for successful reconciliation of information to take place (Meadow, 1969). Through the process of childhood socialisation, parents are able to aid in the reconciliation process by verbalising apparently contradictory appraisals. In the case of deaf children born into a hearing family, feelings of guilt, frustration and

grief on the part of the parents can have a negative effect on the socialisation process (Meadow, 1969).

Without a shared means of communication, the deaf child is frequently left out of casual conversations within the family as well as of more, formal conversations. Deaf children of hearing parents often miss out on information that is transferred in an indirect manner, such as the information that children pick up by overhearing their parent's communications. This communication barrier can have the very harmful effect of inhibiting the forming of close relationships with hearing people and particularly with the deaf child's own parents. Deaf children will often feel frustrated when attempting to communicate with family members as miscommunication is frequent and conversation is strained. In addition, deaf children that are unable to feel a sense of shared identity and acceptance traditionally associated with family will often feel feelings of enormous loneliness and isolation (Foster, 1998).

Many deaf individuals adapt satisfactorily to their deafness, however, many others experience socio-emotional difficulties. Problems that the deaf children with hearing parents are likely to experience include difficulties with self-esteem and social cognition (Jung & Short, 2002). Effective communication between parent and child is essential for positive adjustment. The communication barriers that are often present when deaf babies are born to hearing parents can affect the child's personality development in a negative way and can result in alienation from the family as well as from society at large. Lack of communication obstructs reciprocal feedback. Therefore, some deaf individuals experience a sense of social isolation as well as a decrease in feedback about the effects of their own behaviour on others. Anger and aggression are frequently identified as characteristics of deaf children and many parents report that their deaf child appears socially withdrawn. Indeed, deaf adolescents and adults are often described as socially aloof and isolated from those around them. They also often suffer from low-self esteem and a feeling of incompetence (Jung & Short, 2002).

2.3 Medical and Cultural Models of Deafness

For many years a conflict has existed regarding the best way to communicate with and therefore educate deaf children. The conflict existed, and to a certain extent today still exists, between proponents of the oral English approach and proponents of the manual signed language approach. This conflict is not simply a disagreement over which language is best to use in educating and communicating with deaf children, but rather it represents differences in philosophy or metatheory. The conflict in deaf communication and education, at a metatheory level, is between the medical model and the cultural model of deafness (Drasgow, 1998).

From the medical perspective, deafness is viewed as a disability and the failure of the hearing mechanism remains the focus of attention. Therefore, deafness is defined as a medical condition that requires treatment either through correction or compensation (Munoz-Baell & Ruiz, 2000). This is done through the fitting of hearing aids, cochlear implant surgeries and the initiation of intensive speech therapy (Lane et al., 1996). This model is based on the assumption that competency in spoken language is the only means for cognitive development in the child and therefore speech and lip reading are encouraged. Furthermore, a direct consequence of this model is the rejection of the use of sign language in schools (Munoz-Baell & Ruiz, 2000).

Professionals approached by hearing parents often speak much about the ‘disability’ of hearing loss and about how spoken language will be a struggle for the deaf child to attain. However, very little, if anything at all, is said about the acquisition of sign language and its benefits for effective communication and the development of confidence and a positive sense of self in the deaf child. In addition, very little is known, and hence very little is conveyed about the existence of a thriving deaf community with its shared history and rich culture (Lane et al., 1996).

On the other hand, active members of the Deaf community do not see themselves as having a disability. These members define deafness in cultural rather than audiological terms (Munoz-Baell & Ruiz, 2000). They view themselves as being members of a minority linguistic group that share a language, values, norms and a

unique culture (Lane, 1999). In fact, according to the cultural model, it is precisely deafness itself that is viewed as the defining characteristic of these individuals. Furthermore, sign language is what binds deaf people together and it lies at the very centre of deaf culture (Lane et al., 1996). In South Africa, there is evidence of a flourishing and diverse deaf community; with the presence of “Deaf clubs, Deaf churches, Deaf associations and Deaf women’s groups” (DEAFSA, 2003, p.15). Membership in the deaf community must be earned, and being deaf or having a certain degree of hearing loss is not the only criterion for inclusion. Other recognised criteria include: a common language (sign language), shared experiences, social participation and a sense of cultural identity and pride (Munoz-Baell & Ruiz, 2000).

These two opposing models are implicit in the writing of the word ‘Deaf/deaf’ in academic literature. The word ‘deaf’ (written in lower case) is representative of the medical model of deafness. Deaf people who consider themselves disabled would perhaps write ‘deaf’ in lower case. Such deaf people are often those who have been raised and educated using the oral approach, or those who became deaf later in life; they would not consider themselves as members of the deaf community. ‘Deaf’ (written with a capital letter) is linked to the cultural model of deafness. Those falling within this category would most often have a strong Deaf identity; close ties with the Deaf community and would use SASL as their primary mode of communication (DEAFSA, 2006). For the purpose of neutrality as well as convenience, in this paper, ‘deaf’ will be written in lower case.

Similarly, the definitions of deaf, hearing impaired and hard-of-hearing are largely dependent on whether one adheres to a medical or psychological perspective. The medical definition of deafness is based on measurement of audiological functioning and those with a Severe to Profound hearing loss are generally considered deaf because even with amplification they are unable to hear and understand speech. The term hard-of-hearing is often used interchangeably with the term deaf by medical professionals (Calderon & Greenberg, 1997).

2.4 Mode of Communication

While there is no one communication methodology designed to meet all of the individual needs of a deaf child and his or her family, there are three main approaches to teaching children who are deaf or hard of hearing (Lim & Simser, 2005). The first approach includes all visual methods, such as SASL and Pidgin sign languages are also utilised. Pidgin sign languages evolved over time, they have a simplistic structure and both natural sign languages and spoken language have been drawn upon. Manual sign (such as Signed Exact English and Signed Essential English) also form part of the visual method. These codes are artificially constructed systems that attempt to represent spoken language in a signed mode (DEAFSA, 2006). Auditory-based methods such as the Aural-Oral approach, forms another communication methodology. This approach emphasizes listening as a primary modality for the development of spoken language. This approach involves the use of amplification devices, group instruction sessions as well as individual speech and language therapy sessions. However, some profoundly deaf children do not have sufficient residual hearing to be able to benefit from amplification devices, such children are never able to function fully through speech; and are often termed “oral failures” (Morgan, 2001, p.3). Those with a lesser degree of hearing impairment and/or later onset of deafness exhibit greater proficiency in lip-reading and spoken language (Morgan, 2001) Lastly, Total Communication combines approaches that emphasize speech, lip-reading, natural gestures and a manually coded English system (Lim & Simser, 2005).

The oral approach to communicating with and educating deaf children aligns with the medical framework of deafness. The main aim is to make the deaf person fit into hearing society. This approach therefore demands that deaf individuals speak intelligibly and lip-read. However, this approach has several limitations. One of which is that profoundly deaf individuals do not have sufficient residual hearing to be able to benefit from hearing aids and therefore are never able to function fully through speech (Morgan, 2001). Furthermore, there is no evidence to suggest that deaf children are more skilled at lip-reading than hearing children. Also, even the ‘best’ lip-readers can only absorb 40% of what a speaker is saying, the rest is filled in by knowledge of English and prior experience (Charrow & Wilbur, 1975). Therefore, effective

communication through spoken English proves to be an almost insurmountable task for profoundly deaf children. Those with a lesser degree of hearing loss and/or later onset of deafness exhibit greater proficiency in lip-reading and spoken language (Morgan, 2001).

Diller, Graser & Schmalbrock (2001) espouse that by supporting the development of hearing through amplification devices and therapy, even children with profound hearing impairments can develop natural auditory-verbal skills, which are then comparable to those of children with normal hearing. Other studies have also suggested successful language and educational outcomes through the use of the aural-oral method (see e.g., Goldberg & Flexer, 1993; Robertson & Flexer, 1993; Roberts & Rickards, 1994 as cited in Eleweke & Rodda, 2000). However, it must be noted that a child's development will be impeded by factors such as late initial diagnosis, delayed supply of amplification devices, poorly adjusted hearing aids, short periods of wearing them as well as late commencement of early education (Diller et al., 2001).

Despite the many debates surrounding the issue of communication, studies have shown that through the use modern hearing technology children with hearing loss are able to develop intelligible speech and spoken language and are able to grow up in a regular learning and living environment which enables them to become independent and contributing citizens in mainstream society (Lim & Simser, 2005). Through the use of digital hearing aids and cochlear implants children who are deaf or hard of hearing are able to obtain maximum acoustic neurological benefits. These children are able to use sound to access auditory brain centres which enables the stimulation of neural growth (Lim & Simser, 2005).

Although reading appears to be a visual skill many children with hearing loss have difficulty with reading, even though their vision is fine. Recent research has shown that the primary reading centres in the brain are located in the auditory cortex. Therefore the earlier and the more efficiently the child is provided with access to meaningful sound, with direction of the child's attention to sound, the greater the chance that the child will have to develop age-appropriate literacy, spoken language and academic skills (Lim & Simser, 2005). This approach supports the concept of placing deaf and hard of hearing children into mainstream schools. If children are

detected at a young age and are entered into oral habilitation early, mainstreaming can result in much success. This approach sees mainstreaming as being beneficial for both the deaf or hard of hearing children as well as for the surrounding hearing classmates (Lim & Simser, 2005).

In opposition to the above argument, the manual approach to communication is supported by the cultural model of deafness. Irrespective of what communication mode is employed in the classroom, most deaf children will learn to sign at school. Deaf children of deaf parents learn sign language as their first language from their parents at home and teach it to their peers born to hearing parents; the majority of whom do not learn sign language from their parents before coming to school (Morgan, 2001).

Several works have shown that sign language is a true language in its own right, governed by its own set of rules and possessing complex codes for information (Stokoe, 1969, 1972; Armstrong & Wilcox, 1995 as cited in Eleweke & Rodda, 2000). In addition, sign language is considered to be the 'natural' language of pre-lingually deaf individuals (deafened before the acquisition of language). Evidence supporting the notion that sign language is the 'natural' language of deaf individuals and should therefore be their first language comes from studies of young deaf children who were brought up in a purely sign language environment (Meadow, 2005).

The structure of sign language is markedly different from that of spoken English (Klima & Bellugi, 1979). Contrary to popular myth, sign language is in no way a manual representation of English, with individual signs corresponding to English words. Rather, it is a complete language, with all the properties of other languages of the world. In addition, it has evolved over time to meet the linguistic needs of its users (Drasgow, 1998).

If deaf children have complete access to language, they will proceed along a similar path of linguistic development as hearing children do (Meadow, 2005). Deaf children acquiring sign language from their deaf parents pass through a manual babbling stage and progress to the one-sign stage in a manner similar to their hearing counterparts. For hearing children, the one-word stage usually begins around one year of age but in

early exposed deaf children the first sign may emerge somewhat earlier. This is because motor skills used for signing develop earlier than motor skills used for speaking (Drasgow, 1998). Native signers then move onto two-sign utterances around the middle of their second year, which is at about the same time as hearing children produce two-word sentences. Sign language is morphologically complex and includes a process by which verb signs are altered to indicate grammatical categories such as agreement for number and person. Deaf children acquire this system in a predictable order, at age 2, in the two- and three-sign stage children do not inflect their verbs and then at ages 3 to 3 years, 6 months, signing children master the verb agreement system (Kilma & Bellugi, 1979).

Deaf children will naturally acquire sign language through rich exposure to it in natural contexts and through seeing others use it in different situations (Drasgow, 1998). From the above, it is evident that deaf children will acquire sign language in an effortless manner when they have full access to this natural language. However, there is one proviso; in order for the deaf child to acquire sign language effortlessly he/she needs to be exposed to it in the early years of childhood and the earlier the exposure the better. Early exposure to sign language allows the deaf child to acquire the conversational form of a language so that when he/she enters school, the learning can continue, rather than begin (Drasgow, 1998).

There is a large body of research that supports the early usage of sign language and views this as heavily supporting the subsequent development of English. These studies have tended to focus on comparisons between deaf children with hearing parents and deaf children with deaf parents. A consistent finding throughout such studies is that deaf children of deaf parents perform significantly better on measures of academic achievement, vocabulary, speech-reading, signing, fingerspelling, written language as well as reading than deaf children of hearing parents (Balow & Brill, 1975; Brasel & Quigley, 1977; Meadow, 1968; Quigley & Frisina, 1961; Stuckless & Bircg, 1966, as cited in Watkins et al., 1998). Some researchers have attributed the academic advantages of children of deaf parents to the development of an internal language base resulting from early exposure to a natural language, such as sign language. This early language development appears to also be responsible for producing faster processing skills, such as problem-solving skills. Furthermore, deaf

children who have acquired a natural language early on have a mode through which they can access information as well as a means to express and organise this information. On the other hand, deaf children of hearing parents may not have the same internal language base, because speech training and lip-reading does not always result in regular English language acquisition and also hearing parents may not possess adequate signing skills to communicate effectively with their children (Drasgow, 1998).

Academic advantages of deaf children of deaf parents have also been attributed to greater parental acceptance of deafness, which in turn increases successful parent-child interactions which then raises the child's self-esteem which has the effect of increasing achievement levels. However, it is also possible to find high levels of parental acceptance for children of hearing parents (Meadow, 2005).

Successful language acquisition does not occur in the absence of adequate environmental linguistic input. Deaf children have normal, intact, language learning abilities and these children can achieve successful language acquisition on condition that: they have full access to all aspects of language (phonology, morphology and syntax) and if the language to which they have full access is a natural one (Drasgow, 1998). Furthermore, access to the chosen modality, whichever it may be, must take place as early as possible in order to prevent significant developmental delays (Diller et al., 2001).

2.5 Stigma and Attitudes to Deafness

The deaf community has a long history of oppression and exclusion. In addition, the broader hearing community has long rejected the natural and preferred means of communication of deaf people, sign language. Furthermore, the dominant hearing culture often relegates deaf people to labels such as “disabled”, “handicapped” and “outsider”. However, deaf people are far more handicapped by their transaction with the hearing world than they are by their hearing loss (Munoz-Baell & Ruiz, 1999).

Even today, the social image of deafness is marked by a deeply rooted pathological stigma, negative stereotypes and prejudicial attitudes. Such negative evaluations of deafness are largely attributable to a lack of knowledge about deaf people and their unique language and culture (Munoz-Baell & Ruiz, 1999).

The sociologist Erving Goffman (1986, as cited in Lane, 1999) distinguishes between three different types of stigma all of which affect deaf people. These three categories of stigma include: physical, characterological and tribal. Physically, deaf people are judged as being 'broken' in some way by having ears that 'do not work'. Deaf people are seen as in need of treatment in order to fix their problem of deafness. Many remedies such as speech therapy, hearing aids and cochlear implants are sought out in an attempt to alleviate the impairment (Lane, 1999).

In a characterological sense, deaf people are viewed by the hearing world as social deviants, as they differ from the mould of a 'normal' person. Deaf people are perceived as having undesirable character traits such as concreteness of thought, impulsive behaviour and laziness. Furthermore, despite not having empirical backing, spoken language and intellect are viewed as being inextricably linked. Following this, deaf people are seen as having a defect of intellect (Lane, 1999).

In terms of tribal stigma, despite deaf people belonging to a community with a rich and unique heritage and being a linguistic and cultural minority, they are still subject as a community, to stigma (Lane, 1999).

When considering cultural attitudes towards deafness, one must bear in mind the diversity of Sub-Saharan Africa and therefore remember that there are exceptions to any generalisations (Kiyaga & Moores, 2003). "Beliefs about deafness in African societies range from acceptance and protection to rejection, including considerations of infanticide" (Kiyaga & Moores, 2003, p.21). Some beliefs in the region have the effect of isolating and marginalising those who are deaf. Some pity deaf children and some see them as burdens who are dependent on their families and lack the ability to be independent. This belief in the lack of capability of a deaf child may act to impede access to education. In other cases, cultural attitudes may result in the deaf child being hidden away from public view; the child is seen as bringing shame and misfortune

onto the family. Such beliefs can result in abuse, neglect and abandonment (Kiyaga & Moores, 2003). In addition, in many cultures throughout the world, Deafness as with other disabilities is often seen as a curse from G-d (Meadow, 1969).

In a more positive light, concepts such as 'Deaf pride', 'Deaf culture' and the 'Deaf way' have experienced a re-emergence in recent years. Although, still far off, the hearing world is growing more aware of the unique needs of deaf people as well as showing an interest in sign languages and deaf culture. Dictionaries of sign language have been developed and sign languages have been included in school and university curricula with departments of deaf studies as well as sign language studies being set up in universities (Branson & Miller, 2002).

CHAPTER 3

CONCEPTUAL FRAMEWORK

3.1 Conceptual Framework

The objective of this research is to understand how hearing parents decide on which mode of communication to use with their deaf child. Attitude models act as a valuable tool for achieving an in-depth understanding of the basic underlying factors inherent such a decision. One theory that is frequently used to understand volitional behaviour is the Theory of Planned Behaviour (Ajzen, 1985).

The Theory of Planned Behaviour proposes that intentional human behaviour can be predicted by three constructs, these include; attitude towards the behaviour in question, subjective norms and perceived behavioural control (Ajzen, 1985, 2002).

The theory argues that there are various beliefs that underlie its main constructs. Beliefs that underlie a person's attitude toward a particular behaviour are termed 'behavioural beliefs'. Each salient behavioural belief links the behaviour with a specific outcome. Therefore, the attitude toward the behaviour is determined by the person's evaluation of each salient outcome as well as by the strength of these evaluations (Ajzen, 1985).

'Normative beliefs' are the beliefs that underlie the subjective norms component of the theory. This involves a person's belief that important people in his/her life (important referents) believe that he/she should or should not perform the behaviour in question. Therefore, a perceived social pressure is formed, which is moderated by the degree to which the person wants to comply with these various important referents. However, it must be noted that several authors have argued that the normative component of this model is the weakest component (Van den Putte, 1991, Godin & Kok, 1996, as cited in Armitage & Connor, 2001). This was supported by the previous research carried out by the author in which subjective norms did not significantly contribute to the predication of the intention in question (Klein, 2007). As a result of this criticism of the model, several authors have removed subjective

norms from their analyses (Armitage & Connor, 2001). In a meta-analysis of the Theory of Planned Behaviour carried out by Armitage and Connor (2001) it was found that the subjective norm-intention correlation is significantly weaker than the other relationships with intention. Armitage and Connor (2001) suggest that this result does not provide sufficient evidence to warrant discarding the subjective norm construct all together, but it does indicate that it is a part of the Theory of Planned Behaviour that requires further study.

The perceived behavioural control element in the theory is determined by the total set of control beliefs, which are, beliefs that are seen to either facilitate or impede performance of the behaviour in question (Ajzen, 2002). At first, this theory was termed the Theory of Reasoned Action (Fishbein & Ajzen, 1975) and it was assumed that the majority of human behaviour was under volitional control and could therefore be predicted from intention alone. The construct of perceived behavioural control was then added to the theory so that the theory could incorporate behaviours in which people may lack complete volitional control. Hence, with this construct added, the theory became known as the Theory of Planned Behaviour.

The concept of perceived behavioural control is by no means new and is largely based on Bandura's concept of 'self-efficacy' (Bandura, 1991, as cited in Ajzen, 2002). Bandura (1991, p. 257, as cited in Ajzen, 2002) defined self-efficacy as "people's beliefs about their capability to exercise control over their own level of functioning and over events that affect their lives". There has been considerable evidence to suggest that a refinement of the perceived behavioural control component into self-efficacy and perceived behavioural control is needed. In a meta-analytic review of the Theory of Planned Behaviour, Armitage and Connor (2001) found that self-efficacy and perceived behavioural control are useful predictors of intention and behaviour. However, while self-efficacy and perceived behavioural control account for equivalent proportions of the variance in behaviour, self-efficacy explains somewhat more of the variance in intention than perceived behavioural control. It has therefore been argued that self-efficacy should be the preferred measure of 'perceived control' within the Theory of Planned Behaviour. However, further research is required that more fully evaluates the impact of different operationalisations of perceived control on intention and behaviour (Armitage & Connor, 2001).

The Theory of Planned Behaviour suggests that intention is the immediate precursor to behaviour. The theory goes on to suggest that a combination of attitude, subjective norms and perceived behavioural control will be useful in explaining an individual's intention to perform a specific behaviour (Ajzen, 1985). Despite several concerns about various constructs of the theory, specifically, the normative component, and the perceived behavioural control construct, the Theory of Planned Behaviour has emerged as one of the most influential and popular conceptual frameworks for the study of human action (Ajzen, 2002). Furthermore, this framework provides a logical and coherent structure and can be applied to a wide range of subjects.

The majority of studies employing the Theory of Planned Behaviour do so in a quantitative manner. Ajzen (2002) does not advocate using the theory qualitatively. He states that the theory was developed to predict and explain human social behaviour and can serve as a framework for behaviour change interventions. However, the theory can act as a heuristic framework that guides questions to be raised in qualitative research. Furthermore, the standard methods developed over the years for use with this theory are largely qualitative in nature (Ajzen, 2002).

Despite the theory being mainly carried out in a quantitative manner, there have been several researchers who have used it qualitatively. Sable and Libbus (1998) used the theory qualitatively to explore 'Beliefs concerning contraceptive acquisition and use among low-income women'. The researchers collected data by using an interview guide that was developed based on a framework suggested by Ajzen and Fishbein (1980). Questions were used to elicit participants' salient beliefs that affected women's decision making about contraception acquisition and use (Sable & Libbus, 1998). Panday, Reddy and Bergström (2003) looked at the determinants of smoking behaviour among the adolescent population of South Africa using the Theory of Planned Behaviour in a qualitative manner. Once again, a discussion guide was developed using the theoretical constructs of the Theory of Planned Behaviour. Themes explored in the discussions included: attitudes and social influence towards smoking behaviour, quit attempts, self-efficacy to stop smoking and knowledge of methods used to stop smoking. This study aimed to explore adolescent's opinions in this area as a precursor towards intervention development (Panday et. al, 2003).

The researcher (Klein, 2007), previously conducted a quantitative study utilizing Ajzen's Theory of Planned Behaviour in which the theory's predictive ability was tested. A measure of stigma was also added to the model. The model assessed whether hearing parents' intention to communicate with their Deaf child in sign language was influenced by the main constructs of the Theory of Planned Behaviour (attitudes, subjective norms and perceived behavioural control). Results of the study indicated that attitudes, perceived behavioural control and stigma, all contributed to the prediction of hearing parents' intentions. Contrary to the theory, subjective norms did not provide a significant contribution to the prediction of intention. Attitude emerged as the strongest significant predictor of intention, followed by perceived behavioural control and then stigma. Additional analyses revealed that contrary to the theory, attitudes and perceived behavioural control were not significantly predicted by their respective belief-based measures (Klein, 2007).

3.2 The Present Study

In the previous study carried out by Klein (2007), the Theory of Planned behaviour provided a useful framework for understanding parents' choice of communication modality and pointed to the importance of attitudinal considerations, efficacy beliefs and stigma in predicting hearing parents' intentions to utilise predominantly sign language with their deaf children. However, this study lacked a textured understanding of the processes and influences that hearing parents experience when faced with a choice of communication modality. The researcher wished to explore and further understand how these significant influences come to life for hearing parents. By utilising open-ended interviews the researcher was able to gain a contextual understanding of how these factors that emerged as important in the previous study play out in the participants' actual lived experience. Data received through face-to-face interviews is richer and more meaningful than that received from the closed-ended questionnaires utilized in the previous study by Klein (2007).

3.3 Research Question

This research aimed to explore the experiences of hearing parents of deaf children and the process by which they come to choose a primary communication mode to use with their deaf children.

CHAPTER 4

METHODS

The present research aimed to privilege participants' subjective knowledge by listening to them talk about their experience of communicating with their deaf child and in this way achieve an in-depth and textured understanding of the factors that influence hearing parents' decision-making processes regarding communication modality (Terre Blanche, Kelly & Durrheim, 2006). Furthermore, thematic content analysis was chosen as the method of data analysis. Burman (1996, p. 57) defines thematic analysis as "a coherent way of organising or reading some interview material in relation to specific research questions. These readings are organised under thematic headings in ways that attempt to do justice both to the elements of the research question and to the preoccupations of the interviewees". This chapter attempts to provide the reader with a detailed description of how the present study was operationalised. In so doing, methodological considerations are outlined as they pertain to the method of data collection, the instruments used as well as the form of data analysis chosen are examined. In addition, emphasis is placed on the reflexivity of the researcher and on ethical considerations.

4.1 Sample and Procedure

As the researcher had access to St. Vincent School for the Deaf in Melrose, Johannesburg, this was chosen as the site for the research to be carried out. In addition, this site provided a pool of potential appropriate participants from which to draw, namely; hearing parents of deaf and hard of hearing children. St. Vincent School for the Deaf is comprised of a pre-school, primary and high school. Bilingualism is the educational policy at the school. This means that children are encouraged to develop a proficiency in SASL, as this is the deaf child's first language, as well as learning a second language, English. Teachers at the school are responsible to ensure that they do their utmost to achieve a high level of proficiency in SASL. In addition, all members of staff are encouraged to use SASL or Signed English when

talking in front of learners or deaf members of staff so that incidental communication is accessible to all. Furthermore, the school is committed to assisting hearing parents of deaf learners to improve their SASL skills by providing free sign language classes once a week (St. Vincent Language and Communication Policy Document, 2008).

The deputy headmistress of the school identified parents who were proficient in English and a participant information sheet was sent out to these parents. English proficiency was important for this study as the researcher was English speaking and if participants were not proficient in English interpreters would have to be utilised. The researcher wanted to avoid this as this situation would greatly affect rapport and may affect the quality of the interview as self-disclosure may be kept to a minimum due to the nature of the topic and the rapport being compromised. In addition, the use of interpreters would remove the element of first-person accounts. Further to this criterion, it was also required that parents were hearing.

Several weeks after the study's participant information sheet was given to potential participants the identified parents were contacted telephonically and were invited to participate in the study. If they agreed, a meeting was set up either at the participants' workplace or at St. Vincent School for the Deaf. It was ensured that all interviews were carried out in a private room where noise was not a problem and privacy was ensured. Interviews ranged in duration from 20 to 40 minutes. In addition, interviews were audio-recorded and then transcribed.

4.2 Participant Characteristics

Seven interviews were carried out by the researcher of which one interview was conducted with a spousal couple. The sample was comprised of seven females and one male who were contacted by the researcher and agreed to participate in the study. Of the 8 participants, 2 were Indian, 2 were Black, 3 were White and 1 was Coloured. The ages of the participants' children varied between 2 years and 6 years of age, with the exception of one participant whose child is 18years old. Participants themselves ranged in age. The following section provides a brief description of each participant.

The first participants interviewed were a husband and wife pair. Their interview was analysed as one and in the analysis they are referred to as *Participant 1*. These participants are an Indian couple with three children. Their deaf son is their first born child and he was 4 years old at the time of the interview. Their son was diagnosed at the age of two years. They are first language English speakers. Both parents were very forthcoming with information and provided a very positive description of their deaf son. Their deaf son was presented as having very little difficulty communicating. It is possible that this very encouraging picture was conveyed in an attempt to positively present themselves and their son.

Participant 2 is a White mother of one who was interviewed alone. She is not married to her son's father, but they are engaged. Her son was 2 years at the time of the interview; this made him the youngest deaf child of all the participants'. She was proficient in English. Participant 2's son was one of the few children of interviewees that were diagnosed as being deaf fairly early. Hearing tests began when he was 6 months old and he was officially diagnosed at 10 months old. This participant utilises the services of HI- HOPES and she is currently undergoing their training programme to become a Parent Advisor herself for other families who have a deaf child. This participant seems to be very aware of the cultural model of deafness and spoke in her interview of concepts such as her son's 'cultural identity'.

Participant 3 is a Black, single mother of two children, an older girl and younger boy. Her deaf daughter was 6 years old at the time of the interview and she was diagnosed as being deaf at the age of 3 years. This participant spoke a lot about the difficulty that she experienced in communicating with her deaf daughter. She described that her and daughter often fight due to a difficulty in communication, she is unable to sign and her daughter often does not understand what she is saying. She explained that she feels she needs to learn sign language in order to improve communication with her daughter. However, her son communicates in sign language with his sister.

Participant 4 is a Black, single mother of one son. Her son was 3 years old at the time of the interview. Her son was diagnosed at approximately 1 year 6 months to 2 years of age; this was not entirely clear from the interview. This participant attends signing classes every Friday and also attended a programme at the University of the

Witwatersrand to learn more about the deaf. This participant utilises a Parent Advisor from the HI HOPES organisation. The participant's mother and sister also attend sign language classes.

In the case of Participant 5, it was the mother who was contacted to attend the interview. However, as she had just given birth to another child, she was unable to attend the interview and requested that her mother rather attend as she is very involved in her daughter's life. Therefore Participant 5 is the grandmother of a deaf girl who was 6 years old at the time of the interview. Participant 5 explained that her granddaughter spends many afternoons of the week with her as well as spending every weekend and school holiday with her and her husband. Participant 5 is a Coloured woman who was interviewed on her own. This participant's granddaughter was born with numerous health difficulties and had to be operated on at the age of 7 months. Also at approximately 7 months old, she was diagnosed as deaf and fitted with two hearing aids. However, Participant 5 reports that these did not help much. This participant spoke extensively about her granddaughter not staying deaf forever and she explained that she feels that at some point in her life she will be able to hear.

Participant 6 is a White, married mother of two deaf daughters, aged 9 years and 4 years at the time of the interview. She explained that both daughters have a syndrome that caused their deafness; however, she is unsure what the exact syndrome is. Her eldest daughter was diagnosed as deaf at 16 months of age and her younger daughter received her diagnosis at 9 months of age. Both daughters have received cochlear implants. Both daughters started at an oral-only school for deaf children, however, she explained that they were both not coping or progressing through this method of education and she therefore moved them to St. Vincent School for the Deaf, where she says they have greatly improved. Her, her husband and their two daughters have recently started to learn sign language.

Participant 7 is a married White mother of two sons, the elder son is deaf and the younger son is hearing. At the time of the interview the participant's son was 18 years old. This participant had the eldest deaf child in the sample. Her son was the earliest diagnosed child of all of the children in the sample, being diagnosed as deaf at 6 weeks of age. This participant spoke at length about her reaction to her son's

diagnosis and how traumatic this time period (diagnosis and following months) had been. She explained that through sign language, communication between her and her son greatly improved and she noticed that with this, his behavioural difficulties subsided.

4.3 Designing the Interview Schedule

The anthropologist Clifford Geertz (1973, as cited in Terre Blanche et al., 2006) said that the purpose of doing an interpretive analysis is to provide ‘thick description’ which means a thorough description of the characteristics, processes and contexts that constitute the phenomenon being studied.

The in-depth interview or as it has been described the “conversation with a purpose” (Webb & Webb, 1932, p.130 as cited in Legard, Keegan & Ward, 2003) is seen as being defined by its key features which were considered throughout the research process, from conceptualisation to instrument design to implementation. Structure combined with flexibility forms one of the key features of this type of interview with predetermined topics being covered but with room for probing and further exploration. In line with this feature, the present study utilised an unstructured interview schedule (Refer to Appendix A) that laid out specific questions that aimed to explore hearing parents’ decision-making process regarding communication modality. However, while ensuring that these areas were covered, the researcher remained flexible in her approach allowing room for unstructured questions, and free talk was encouraged by picking up on particular points in the participants’ responses which then gives rise to valuable and spontaneous information. (Legard et al., 2003).

4.4 Conducting Thematic Content Analysis

The particular process of thematic content analysis carried out was based on guidelines set out by Terre Blanche et al., (2006). In addition, the researcher considered guidelines and cautions laid out by Braun and Clarke (2006).

In a qualitative study, there is no clear point at which data collection ends and analysis begins. Rather, what occurs is a gradual fading out of the one and a fading in of the other. So that, at first, the researcher is primarily concerned with data collection and by the end data analysis is his/her main concern (Terre Blanche et al., 2006). The following will provide a description of the steps followed:

1. Data Management

During the data analysis phase it is essential to immerse oneself in the data and gain an even deeper understanding of what emerges from the transcripts (Terre Blanche and Durrheim, 1999). In order for this to be achieved the researcher listened to recordings as well as read through transcripts several times each. Following the interviews, as well as during transcription, information pertaining to date, participant's identifying details and interview length was recorded. A designated book was allocated to data analysis in which all notes were kept. In addition transcripts were clearly numbered to avoid confusion. Through data collection one already gains a preliminary understanding of the meaning of one's data, even before data analysis begins (Braun & Clarke, 2006).

2. Inducing Themes and Further Data Familiarisation

This step involves further familiarisation with one's data exploring both its length and breadth (Braun & Clarke, 2006). During this phase potential patterns and points of interest were highlighted to mark attention for the subsequent analytic phase examining raw data and deciphering what themes are underlying this data (Terre Blanche and Durrheim, 1999). At this point, the

researcher began to identify various themes and patterns within the transcripts and highlighted data that fitted into different themes or patterns in different colours.

3. Coding

Coding data entails marking, in one way or another, different sections of the data as being relevant to one or more of the themes or sub-themes identified. Coding and the induction of themes will often blend into one another because during the coding process, as a deeper understanding of the material and themes is gained, themes may be subject to change (Terre Blanche and Durrheim, 1999). For the researcher, steps 2 and 3 were roughly blended into one, as further data familiarisation was carried out through a process of coding. At this point three main themes were identified, namely; diagnosis, mode of communication and stigma. Three different colours were used to highlight all quotes pertaining to each theme.

4. Elaboration/Themes Search

Themes were extracted by sifting through the data for the organising principles which underlie the texts. This involved identifying recurring ideas and patterns of beliefs and actions. Based on the list of codes generated, themes were generated (Terre Blanche and Durrheim, 1999). Various codes were grouped into potential themes and coded extracts were collated according to the identified theme (Braun & Clarke, 2006). Coding, elaborating and recoding occur until there are no further new insights that seem to be emerging (Braun & Clarke, 2006). It was during this stage in the data analysis that the researcher searched for more quotes that would fit into the identified themes.

5. Interpretation and checking

Once a set of initial themes were devised, the data extracts were reviewed once again to assess the degree of fit between themes, codes and their supporting quotations. Certain themes, at this point were broken down into sub-themes (Braun & Clarke, 2006). Specifically, the theme “Diagnosis” was divided into the sub-themes “Reaction of Parents to Diagnosis”, and “Information Provided by Professionals Consulted”. Another main theme “Mode of Communication” was sub-divided into smaller themes of; “Primary Mode of Communication Used”, “Important Referents Views on Preferred Mode of Communication” and “Lack of Communication”. Lastly, “Stigma” was divided into the sub-themes of “Treatment by Hearing Children” and “Perceptions of Deaf People”. This is a good opportunity to take a self-reflexive approach and examine the researcher’s role in the data collection and interpretation processes. It is acknowledged that it is not possible for the researcher to remain completely objective, however, it is expected that the researcher give some indication of how their personal involvement in the phenomenon being studied may have had an impact on the data collection process as well as on the analysis of data (Terre Blanche and Durrheim, 1999).

4.5 Reflexivity

By virtue of the specific roles assigned and adopted by researcher and participant, the in-depth interview is characterised by power differentials. The power differentials are not latent but rather are manifest, in that the interviewer not only has control over the interview itself, but over the entire research process, from devising the interview questions to setting up interviews and perhaps most importantly to the analysis and interpretation of the participants’ communications (Banister, Burman, Parker, Taylor & Tindall, 1994). Due to this dynamic, it is important for the researcher to employ a self-reflexive approach in an attempt to become transparent and to make visible the research process. Reflexivity is defined by Nightingale and Cromby (1999, p. 228) as requiring an “awareness of the researcher’s contribution to the construction of meanings throughout the research process, and an acknowledgment of the

impossibility of remaining outside of one's own subject matter while conducting research". Therefore, reflexivity advises "to explore the ways in which a researcher's involvement with a particular study influences, acts upon and informs such research" (Nightingale & Cromby, 1999, p. 228).

Personal Reflection

Despite having done research in this area before, my approach to the subject has somewhat changed throughout the process of conducting and reporting on the current research. Due to the very 'political' nature of the subject of deafness and communication options, I found myself getting caught up in one side of the political debate. However, after reflection, it became clear that both sides of the argument needed to be more fully explored and I then realised that each side of the argument makes very relevant contributions and it is restricting to only pay attention to one. My training in the area of South African Sign Language and Deaf culture was entirely located within the cultural perspective of deafness which advocates solely sign language and opposes oralism. Considering the nature of my training it became even more important for me to truly reflect on my interactions with participants as well as to reflect on the nature of reading I was undertaking as well as the way in which I was writing up my research. Through constant reflection and revision of this report the aim was to achieve a more balanced and considered perspective on the topic being researched.

4.6 Ethics

On arrival at the interview each participant was provided with a Participant Information Sheet as well as two consent forms (Refer to Appendices B and C). The first consent form confirmed that the participant agreed to be interviewed by the researcher and the second consent form was for the purpose of gaining consent to record the interview. The participant information sheet detailed the rationale, objectives and expectations. Participants were fully informed as to what their participation would require, namely a one-on-one interview to last approximately 30 minutes in which their experience with communication with their deaf or hard of hearing child would be discussed. This information sheet also outlined ethical

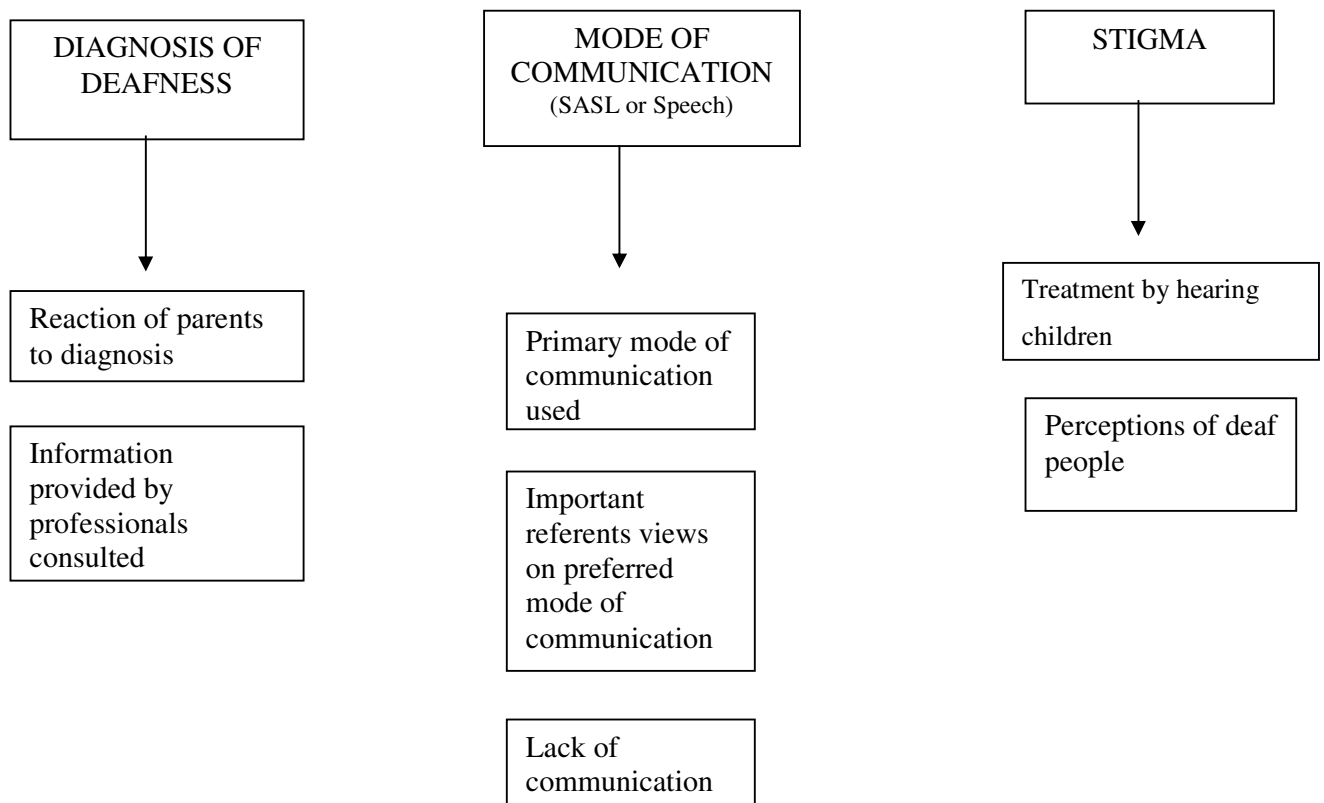
considerations such as confidentiality and anonymity. It was clearly laid out that participation in the study was entirely voluntary and that it would not advantage or disadvantage the participant in any way should he/she decide to participate or not. Furthermore, the participant was assured of absolute confidentiality as only the researcher and her supervisor had access to the raw data (recordings and transcripts). To further protect confidentiality, raw data was kept locked away by the researcher, in a safe and secure place at the University of the Witwatersrand. Participants were informed that recordings from the interview would be destroyed once transcription had taken place and interviews were transcribed without any identifying information, in order to protect the anonymity of participants. It was further reiterated that participation in the study was entirely voluntary and participants may withdraw from the study at any time should they wish to without any consequences. It is not possible for anonymity to be guaranteed using a qualitative interview method; however, the researcher ensured that the data was sanitised with all identifying information removed from direct quotations. Lastly, participants were advised that a copy of the research report would be made available to the school and participants wishing to access the findings from the study would be able to do so via the school.

CHAPTER 5

RESULTS AND DISCUSSION

5.1 Diagram of Study's Results

Data analysis yielded three main themes with various sub-themes falling under these. The diagram below provides a visual representation of the themes and sub-themes that emerged through analysis of the data. It must be noted that despite identifying three separate main themes, they are all interrelated and each one influences the next in important ways.



In a study carried out by Li et al., (2003) which looked specifically at parental decision-making and the choice of communication modality by parents who have a deaf child; it was found that parental decision-making was affected by several factors, such as recommendations made by professionals and family members, the parent's attitudes and beliefs about deafness and resource availability and services. Similarly, a study carried out by Eleweke and Rodda (2000) titled "Factors contributing to parents' selection of a communication mode to use with their deaf children" it was found that the influence of information provided to parents, parents' perceptions of assistive technology, attitudes of service professionals and educational authorities as well as quality and availability of support services were all found to influence parental choice regarding communication modality. In the present study, similar factors to the two studies described above that may affect parental decision-making were recognized. Furthermore, within the three main themes and sub-themes that were identified, the main components of the Theory of Planned Behaviour emerged. Within the sub-theme of *Primary Mode of Communication* both parents' attitudes towards sign language and oral methods emerged. In addition, within this sub-theme parent's efficacy beliefs became apparent. Under the main theme of *Mode of Communication*, falls a sub-theme titled *Important Referents views on Preferred Mode of Communication* which is reflective of the social norms component of the Theory of Planned Behaviour.

As previously discussed in this paper, early diagnosis and treatment of hearing loss is critical to the linguistic, educational and social development of children with hearing loss. Despite this knowledge, the age of diagnosis and treatment of childhood hearing loss remains extremely high (Prendergast et al, 2002) and this is particularly the case in South Africa where a systematic hearing screening program for newborns, although recommended, has not yet been implemented (Storbeck & Calvert-Evers, 2008). The optimal age at which babies should be diagnosed and early intervention to begin is before the age of 6 months (Storbeck & Calvert-Evers, 2008). Only one out of the seven participants reported that her child was both diagnosed before the age of 6 months with intervention beginning almost immediately after diagnosis. The remainder of the participants' deaf children were diagnosed and started intervention between the ages of 7 months and 3 years.

5.2 Theme 1: Diagnosis of Deafness

All of the participants interviewed spoke at length about various elements related to the time that their child was diagnosed as being deaf. Two general sub-themes emerged under this rubric. All participants described their emotional reactions at the point of finding out that their child was deaf and therefore a sub-theme titled 'Reaction to Diagnosis' was formed. In addition, four out of the seven participants spoke about the limited information that was provided from professionals regarding the implication of their child's diagnosis, and hence the sub-theme titled 'Lack of Information Provided by Professionals Consulted' was formed. Calderon and Greenberg (1999) report that many of the stresses and challenges of raising a child with a hearing loss are most often associated with, among others, the diagnosis of the hearing loss, increasing contact with professionals in a number of different disciplines, (for example, medicine, audiology, speech therapy), purchasing and using amplification devices, as well as with the everyday experiences associated with having a child who is different and has a different system through which he or she communicates.

5.2.1 Reaction to Diagnosis

Munoz-Baell and Ruiz (2000) state that some of the reactions of hearing parents that may occur when their child is diagnosed as deaf and that need to be effectively dealt with include: denial of the diagnosis, guilt, grief, feelings of impotence, affection detachment and the need to seek many other professional opinions when informing them of an irreversible hearing impairment in their child. Respondents in this study evidenced many of these reactions mentioned:

Participant 5, despite her granddaughter being diagnosed as deaf at age 7 months and she is now 7 years old, denial seemed to be present in her response:

"I don't believe that she is going to be deaf for the rest of her life, I know that somehow she will start talking and she will start hearing, I just cannot know when, but it will happen. And even now as I am talking to you, I still have that feeling"

Participants tended to seek many opinions at the time of diagnosis. Participant 2 reported:

“In the beginning I went through numerous tests, we went to different audiologists, different speech therapists, and it was just you know, the grieving process took so much time”

Participant 7 spoke of the grief that she experienced at the time of her eldest son's diagnosis:

“It took me a very long time, it took anti-depressants...it was like a grief process and that all of your dreams are shattered, every single one of them. I don't know what because I didn't really have big dreams but when you compared things like your friends' kids having problems with homework...if that was your biggest problem in life, wow!”

Affection detachment often seems to centre on the difficulty in communicating with the deaf child. In terms of this, Participant 2 said:

“There are times when I look at him and I don't even want to communicate with him, I just say go to your father. So it's a long process”

Also in terms of affection detachment, Participant 7 spoke about the period of notification of her child's diagnosis:

“I kind of thought, why should I talk to this child if he's not going to hear me, so I kind of stopped...It took therapy, it took a long time to realise that it was OK to love him, because I gave birth to him, but I didn't have to like him”

Parents react differently to the notification that their child has a hearing-impairment; there are variations with regard to the emotional intensity as well to the time it takes to reach a level of acceptance and learning to live with the altered life situation (Backenroth, 1998). Parents appear to find it difficult to truly accept that their child is

deaf. It seems more difficult to accept the diagnosis particularly when it is their first child.

Participant 3 reported about her first child:

“At first, I didn’t believe, I didn’t believe she was deaf, like I said before, there was this other crèche that she was going to and she was coming home singing. Even now, to be honest, I haven’t accepted that my daughter is deaf; it’s difficult for me to accept it”

Calderon and Greenberg (1999) state that parental expectations have the ability to positively influence the lives of deaf children. Participant 1 constantly spoke of wanting to provide her son with all the necessary opportunities that are available so that he can pursue any avenue that he chooses and be successful. She also spoke about the lack of opportunities for deaf people in South Africa and said that she will do what she can to enable her child, should he choose to later on, go to the United States where she said that opportunities for deaf people were much more available. Participant 1 spoke about the positive expectations that her and her husband have for their son:

“I mean it was hard, when we found out, we were devastated. He was our first born and it actually affected our lives. But then we said, you know what, we can’t actually allow this to stop us, there is more out there for him, and we can offer it to him. We are his parents and we have to make the right decisions for him or else he is going to suffer”.

Luckner and Velaski (2004) reflect on several factors that contribute to being a healthy family with a child who is deaf, one such factor is having high expectations for the child with a hearing loss. Other participants spoke more about losing their expectations for the deaf children when confronted with the diagnosis. Perhaps due to many of the participants not knowing any deaf people, they immediately assume that as their child has a disability they will be unable to succeed in life or fulfil any expectations. In addition, parents have hopes and dreams for their children before they are born that they find difficult to rework when they find out that their child is deaf.

Participant 2 and 7 said respectively:

“You have this baby and you expect all these miracles from them, and then all of a sudden all the hopes and dreams you had are shattered...”

“When they confirmed that he was deaf, I looked at his ears and I thought, he’s got such perfect ears, wouldn’t it be lovely if they were really ugly but actually worked instead of being perfect and not working...I felt very depressed a lot of the time...I woke up and it was raining and I thought, my G-d, this child will never hear the rain”

Reaching an emotional as well as an intellectual acceptance of the diagnosis of deafness is a continual process and one that takes time (Backenroth, 1998). This was supported by Participant 2’s statement:

“It’s a long process... the grieving process took so much time”

Participant 7 spoke about attending individual therapy and Participant 6 spoke about joining a support group for hearing parents with deaf children. Several participants received emotional support from HI-HOPES and other participants seemed to be lacking in emotional support.

Mothers with better social support are more positive in their interactions with their deaf children. Receiving support as soon as possible after the diagnosis has been shown to be particularly important (Magnuson, 2000). The social networks that parents have within their families and with other families in the same situation bear an enormous impact on how the parents deal with and can learn to live with their deaf child (Backenroth, 1998). In addition, in a study carried out by Calderon and Greenberg (1999), it was found that extra-familial social support was particularly important for maternal and family adjustment to the newly received diagnosis.

Participant 6 spoke about belonging to a parent support group:

“It helped you feel that you weren’t totally in it alone, because you do sometimes feel that way. Because your family is your family, they support you but they can’t help you through, it only helps if it’s someone who’s going through the same”

Participant 2 spoke about her initial feelings towards becoming involved with the HI HOPES organisation:

“I don’t know where I would be without them. In the beginning, I was like, I don’t need a support group, I can do without them but after the first couple of visits I realised that Oh, I do need them”

Many parents interviewed described wanting more contact with other parents of deaf children but finding it difficult to initiate this contact. Support groups were reported by some participants to be difficult to find.

It is evident from reports made by participants that each parents’ reaction to the diagnosis of deafness in his/her child is handled in a somewhat different manner. Participants’ responses ranged from denial to anger to sadness and grief. However, what remained consistent throughout the participant’s reports was that this time of diagnosis was experienced as particularly difficult and that participants described needing assistance and support, mostly from outside sources as opposed to from their families.

5.2.2 Information Provided by Professionals Consulted

A recurrent topic in the scientific literature over the past few years has been the growing concern over the need for doctors to be aware of and understand the issues related to communication, low self-concept and social functioning when dealing with deaf clients and their families. However, from the responses gleaned from participants, relevant professionals in South Africa seemed to be ill-equipped to provide parents with the necessary information and support when their child was first diagnosed with a hearing loss. Four out of the seven participants reported not receiving adequate information and support regarding their child’s diagnosis. In a similar study to the present one, Eleweke and Rodda’s (2000) study showed that parents felt that they were lacking in guidance and they felt that they would have been in a better position had they been given all the options and not only told about amplification devices. Respondents in the present study felt that much of the

information regarding communication modes and education options had to be sought themselves. Many felt that they were alone and were unsupported by the medical profession.

When asked what information was given at the time of diagnosis, Participant 6 responded:

“Very little at first, it’s like, here’s all this, your child is deaf and they just dump it on you. We tried to look for a support group, but people were like, what are you talking about? You don’t know where to turn or where to go to get support...You have to figure it out yourself; hubby had to do all the research himself”

Much like the present study, Eleweke and Rodda’s (2000) research revealed that parents often do not receive full information regarding hearing aids and other assistive listening devices such as cochlear implants, and therefore parents often have unrealistic expectations about these devices. Participant 6’s two daughters both received a cochlear implant and she reported that it was in this area where her and her husband felt that more information and unbiased information about this device would have been helpful. She reported:

“It doesn’t work on every child. And that’s where we felt we could have had more guidance, but we had to figure it out ourselves”

Participant 2 reported that doctors didn’t provide her with much information, however:

“They just told us that he was deaf and that they would refer us to a support group and they sent us to HI HOPES”

“I think more information would have been good. I forgot the doctor’s name but she sent me to HI HOPES, so over the weekend I’ve got someone who comes and they teach me how to play with him and how to clean his hearing aids”(Participant 4)

“They gave us the basic information, like that we need to be clear in the way we speak, not a lot of information and they gave us booklets that we needed to read, to understand things better. And after we signed up for HI HOPES, they gave us a lot of information...they are so good, they’re very dedicated people. I really admire them for what they do. I mean especially for a family like ours who have never been with a deaf child or person before; they just give such great insight...she [Parent Advisor] spent quite some time with us explaining about deaf children and how to teach them and how to communicate with them...she gave us information about implants, how it has its pros and its cons” (Participant 1)

According to Li et al. (2003) information that families receive is likely to be influenced by the availability of specialists and educational and habilitative resources. It appears that parents whose children have been diagnosed as deaf more recently, in the last two years, have been fortunate to have been referred to HI HOPES. However, still there are several of the participants whose children have been diagnosed in the time since HI HOPES has been running who are unaware of their existence.

The four participants in the study who reported a lack of information maintained that the information they received from the professionals involved in diagnosing deafness in their children did not provide them with adequate information about their child’s diagnosis and its implications. Despite, some of these participants being referred to HI-HOPES where they were able to get information about their child’s diagnosis, those who were the first point of call for the participants, namely; professionals appeared ill-equipped to effectively provide these participants with the information that they required.

5.3 Theme 2: Mode of Communication

The decision of which communication method to employ with a deaf child is a critical choice for both the family and for the deaf child, and is one that is influenced by a variety of factors (Reamy & Brackett, 1999). Such factors may include the attitude of the family with respect to the hearing impairment, the acceptance of the child and the expectations of the family with regard to the child’s role in the family (Luterman,

1999, as cited in Magnuson, 2000). In addition, parents may have significant others to whom they turn when faced with a difficult decision, and the communication preferences or opinions of these significant others can have an effect on the parent's choice of communication modality. Furthermore, it can occur that parents' choice of communication modality will result in a lack communication with their deaf child and the effects of this can be detrimental to the child's development.

5.3.1 Primary Mode of Communication Used

It appears that the majority of participants in this study use speech and sign simultaneously, although there seemed to be somewhat of a focus on speech. Perhaps this focus is present because in order for a deaf child to be able to speak he/she needs to make a tremendous effort and much training is needed for the deaf child. Also, parents want ease of communication with their deaf child and as speech is their primary mode of communication it is one that they want to use with their child. People tend to avoid situations and activities that they believe exceed their coping abilities and rather select environments they judge themselves to be capable of handling (Bandura, 1989). This may also point to a reason for parents' focus on speech. Many participants reported their difficulty in learning sign language (this will be discussed further later on in this chapter). However, that being said, participants consistently recommended learning sign language as a way to facilitate communication with their deaf child. It appears that despite a desire for their children to speak, participants see that when some sign is utilised communication with their child becomes that much easier, this too will be further examined at a later point.

Participants reported the following in terms of a choice of primary communication modality employed:

"More speech than sign, if he doesn't understand then we sign to him... She [deaf mentor from HI HOPES] signs and talks which is what we wanted, someone who signs and talks" (Participant 1)

“So because we are all hearing in the family, we want him to experience sound and speech but at the same time don’t want to take his deaf identity away from him so we do the sign language as well... language is key, as long as he’s getting the language and he knows that there is language, whether its written or spoken or signed language...” (Participant 2)

“We are trying very hard to learn sign language...we speak and sign” (Participant 5)

Participant 3 reported not knowing sign language and therefore only using speech, however, she reported that this was affecting communication between herself and her deaf child and that she felt she needed to learn to sign:

“Most of the time we fight, like when we try to speak to each other...I am the one who is supposed to come to get real lessons so that we can communicate well...I am going to have a problem in the future, like when she goes to grade 1, 2, 3 and when she has homework and stuff, if I don’t know how to sign properly, it is going to be a problem for me to help her with her homework. So the best thing I can do is for me to come and attend sign language lessons, so that I can learn to sign and we can communicate properly”

Participant 6 saw sign language as a last resort and when an oral approach failed, sign language was employed. The participant’s deaf children progressed extremely slowly when a purely oral approach was used and communication with her child was exceptionally difficult as well as being ineffective. She therefore decided to employ some sign with her children and to move her children from an exclusively oral school to one that employs both sign and speech. This participant explains that her and her husband and their deaf children have only recently started to learn sign language after utilising an oral-only approach for some years:

“...Only after 9 years, if you listen carefully, you’ll hear the words, but just. But her actual conversations, she is now starting to converse in sign”

“Well, we also have the other two who have to learn as well to speak ,they are normal speaking so that’s an advantage for him because he will pick up more vocal and it’s good for the other two as well” (Participant 1)

Participant 1 seemed to contradict themselves in that despite making a considerable effort to learn sign language the husband stated:

“We don’t use much sign, we just talk normally and he understands what we are saying....he somehow understands what we are saying”

It appears that there is some incongruency present in that the couple would not need to make an effort to learn sign language if their son is easily able to communicate via spoken language. There seems to be an element of denial of the deaf child’s hearing loss and the implications that come with such a loss.

It appears that parents often emphasised speech in an attempt for their children to be considered ‘normal’. Participant 6 remarked:

“Our best intention was to give her as normal as possible, in life. Because a totally deaf child, there’s not much hope, people don’t even want to associate with them because they can’t talk...”

However, Participant 6 decided to remove her daughters from an oral-only school to a school that also employs sign language. This was done because her daughters were not progressing through utilising an oral method in isolation and Participant 6 and her husband realised that the way their daughters were being educated needed to change:

“We didn’t want to see the alternative [sign language] until it was the last resort...she’s three years behind because of it”

Participant 6 went on to say that an advantage of sign language is that:

“At least you know what your child wants via sign, because although she can’t talk to you verbally, she understands what you want from her and she’ll do it”.

In a similar study by Eleweke and Rodda (2000), a participant interviewed also reported that her child's language and communication skills greatly improved since she started using sign language and communication in the family showed marked enhancement.

All of the respondents in the sample reported making at least some effort to learn sign language as they realised that through using sign language, communication with their deaf children would improve. If learning sign was not already initiated by some participants, there was a plan in place to do so. It must also be taken into account that this effort and interest in sign language that emerged in the sample may not be representative of all hearing parents of deaf children. As St. Vincent School for the Deaf is not an oral-only school, on the whole, parents of children at this school will not be opposed to the use of sign language, which they may be were their children to attend an oral-only school.

"I bought this book and if I don't know a sign I look in the book and I attend sign language classes every Friday...sometimes I can't because of work, but I think I've only missed one class this year..." (Participant 4)

"We're getting to learn sign language...I picked up from the homework...I try go [to classes] on a Friday and he [husband] goes on a Saturday" (Participant 6)

An encouraging aspect that emerged from the data was that some of the respondents reported that other extended family members were interested in learning sign language so that communication with the deaf child can be improved. This is heartening as it has the implication of reducing isolation of the deaf child in his/her hearing family.

Participant 1 spoke about needing to find a sign language course that was more economical as so many family members wanted to attend, and this is how they became involved with HI HOPES:

"...there were so many of us, this aunt and that aunt..."

“My sister is attending [sign language classes] at WITS...I take him to my mom and then I take the book with him so if she has time she can do the things” (Participant 4)

“Her aunty is not staying far, and her and her husband are also keen to learn sign language and my husband and our friends, they are also learning” (Participant 5-grandmother)

“I mean my mom is 55 years old and she’s now learning sign language, my sister-in-law’s mother is also learning...” (Participant 2)

Many hearing parents, including the majority of respondents, have little formal training in sign language and find the use of sign language unnatural and difficult. They do not feel comfortable with sign language, especially in public, and tend to sign only when they are alone with their child (Vaccari & Marschark, 1997). Participants did not explicitly say that they tended to only sign with their children in private, however, as will become clear later on, many did report finding sign difficult to learn.

In a study carried out by Klein (2007), it was found that parent’s perceived control over their ability to sign contributes significantly to the prediction of their intention to use sign language. Many hearing parents have little formal training in sign language and they often find the use of signs impractical for most everyday needs (Magnuson, 2000). Many parents in this study seemed to doubt their ability to sign, pointing to poor perceived self-efficacy in this area.

“We are trying very hard to learn sign language, its not a very easy language, and I can tell you that.....it takes a long time, especially when you start at my age....” (Participant 5)

“I am not good in signing, I am not” (Participant 3)

“A disadvantage is that it’s taking us a long time to learn his language” (Participant 2)

Parent's communication is often limited to tangible things, which is a shortcoming that becomes more pronounced when the deaf child matures and then needs explanations of more complex social as well as emotional aspects (Vaccari & Marschark, 1997). (Magnuson, 2000). This does not seem to be the case with the participants interviewed. As these parents are only beginning to learn sign language recently, their communication is most likely restricted to tangible things as their signing skills are, at the moment, very basic. In addition, it is not the case with any of the participants interviewed that they are ahead of their children in terms of signing skills. In fact, many parents reported learning signs and their structure from their children. This will have an impact on the amount parents can assist in their child's linguistic, intellectual and social development.

Parents interviewed in a study by Eleweke and Rodda (2000), reported seeing behavioural difficulties when the oral method was being used in isolation. Similarly, in the present study participants spoke about the frustration felt by their deaf children and the temper tantrums that would often occur as a result of them not being able to effectively communicate with hearing family members. Participants also spoke about how their children showed a love for sign language:

"She was very frustrated, it was like do it my way and that's it, she couldn't express whether she was hungry, whether she was thirsty, whether she wanted to go to sleep, we just used to put her in bed and switch the light off...the advantage is at least you know what your child wants via sign" (Participant 6)

"He loves his sign language! He picked up on it very very quickly" (Participant 2)

"She can express herself much better, using the correct sign language and she is also helping us to use the correct sign..." (Participant 5)

"I mean if you look at him now and you look at him a year ago, you can see that he is loving sign language, at least we know what he is trying to say and he knows what he is trying to say..." (Participant 2)

Participant 7 explained:

“And what happened was, as I learnt sign language, his frustration levels got lower, because we could communicate. His frustration levels just went down...”

Despite, the majority of participants using mainly speech and only some sign with their children, many reported seeing improvements in their child’s development when their child started to attend school and started to communicate in sign language and hence the parents also started to utilise some sign language. It appears that participants would like their children to speak, although they are making a considerable effort to learn sign language so that they can improve communication with their children.

5.3.2 Important Referents Views on Preferred Mode of Communication

In a study carried out by Klein (2007) it was found that contrary to the Theory of Planned Behaviour, subjective norms did not provide a significant contribution to the prediction of intention to utilise sign language as the primary communication modality with one’s deaf child. Several respondents spoke about turning to their HI HOPES Parent Advisor or Deaf Mentor for support and guidance when faced with a difficult decision regarding their deaf child and communication. Others spoke about turning to family members for advice in this regard. However, in line with findings from the study carried out by Klein (2007), this did not appear strongly and participants’ did not speak in depth about referring to others in their life for help and only when asked did participants speak about turning to others for advice.

“At the moment if I am in trouble and I can’t make a decision [about communicating with my son], I ask for advice from my Parent Advisor or my Deaf Mentor...they are really helpful, I mean they don’t give us the biased decision, they say, OK here are your options so please make a decision based on what is best for you” (Participant 2)

Participant 5 (grandmother) reported that her daughter would turn to her when faced with a decision regarding her deaf child, although the family speaks as well as signs with their deaf child, Participant 5 reported:

“When she has a difficult decision she will ask me whether I think what they want to do will work...we would much like her to talk”

Participant 6 initially had placed her daughters in an oral-only school. Progress was exceptionally slow there and she therefore moved her daughter to St. Vincent School for the Deaf where she describes an improvement. She reported her family as important referents to whom her and her husband turn:

“They said we should have put her in the signing school from the beginning”

Participant 7 reported turning to the speech therapist for support, she said the following:

“She said give him everything, total communication, whatever he absorbs will be better...it’s not an issue of sign language or verbal, whatever the kid absorbs and uses is fine”

Hearing parents tended to turn to professionals in the field or to family members. For those who turned to professionals, it was more likely that these parents would follow through with the suggestions given regarding communication modality. This indicates the large degree of influence that professionals seem to have over hearing parents regarding considerations of their deaf children.

5.3.3 Lack of Communication

A lack of communication between deaf children and their hearing parents can lead to severely disabling consequences such as a low self-esteem in the deaf child as well as childhood isolation and feelings of inadequacy (Munoz-Baell & Ruiz, 2000).

Communication breaks down because of the failure of language, and language is the

essential tool of human socialisation (Munoz-Baell & Ruiz, 2000). Children's attitudes, values and ways of relating to both themselves and to their environment grow out of the interaction they have with their family and their society or culture. Furthermore, it is through interaction with their environment that children learn to deal with feelings of contentment, frustration and disappointment (Backenroth, 1998). The failure to develop an effective and sophisticated language at an early age has negative consequences for all aspects of psychological development, and therefore for children's mental health (Hindley & Parkes, 1999, as cited in Magnuson, 2000). The breakdown in communication between hearing parents and their deaf children seems to be rife and many respondents reported knowing parents whose communication with their deaf child is entirely absent. Most participants referred to *knowing* of such parents, only one participant reported a severe lack of communication between herself and her daughter and Participant 5 spoke about the challenges in communication that she experiences with her granddaughter.

Participant 5 is currently learning to sign. She both signs and talks to her granddaughter. She says of some of the challenges that come with the communication mode employed:

"The challenges are that there are so many things that you want to say to this child but you cannot say it, like she wants something and we do not understand what it is, exactly what it is that she wants. And then she'll point, if it's something in the house then it's fine, but if for instance she wants to go to the mall or to watch a movie and we don't know what she is saying, it's very hard and she gets frustrated and she starts banging things"

Participant 3 explains that she doesn't know how to sign and therefore communication with her daughter is difficult:

"We try to communicate but we don't much. If I must help her with her homework, we just fight, we fight, so I can't say we communicate...she knows that when she speaks to me with sign I just agree with everything that she is saying, because I don't know what she is saying"

Several participants spoke of other parents who do not communicate at all with their children:

“These kids go home to parents who don’t learn to sign, the parents don’t communicate with them....Deafness is the most exclusive disability, because this child will be in the family but they’re not even part of it...Parents do not speak to their children, and if you cant have a relationship with your own parents, how do you go out and have your own family? How do you function?” (Participant 7)

“I mean I’ve heard stories of parents who don’t communicate much at all because they don’t know how to respond to their child so they ignore them. And that’s not how we want it to be” (Participant 1)

“We’ve learnt from other people and from our deaf mentor’s experience, what happened to them and how they were treated in their community just because they were deaf. There wasn’t much communication, they were ignored and couldn’t just say to their mom or dad that they want to have a conversation, they were just ignored basically” (Participant 1)

There appears to be a link between accepting a diagnosis of deafness in a child and communication ability. Several participants spoke about a difficulty accepting deafness in their child and the implication may then be a refusal to learn sign language. Participant 7 spoke about a lack of communication between hearing parents and their deaf children that she has noticed. When asked what she thought the causes of this breakdown in communication may be, she replied:

“Well it’s the whole thing of not accepting...they don’t accept it. If you were to jump on the road and at least start accepting the fact, you would at least come to sign language”

Participant 2 spoke about her child’s father’s family not wanting to accept that her child is deaf and therefore not wanting to learn sign language:

“I think that they don’t want to learn sign language because they don’t want to admit that he is deaf”

It is evident from the above that lack of communication is rife among hearing parents and their deaf children. In addition, despite participants reporting knowing many parents who struggle with this lack of communication it is likely that many participants themselves find communicating with their deaf children difficult and for some perhaps it is even to the extent of a complete absence of communication. Furthermore, there appears to be a connection between not accepting the child’s deafness and a lack of communication. If parents are in denial about their child’s diagnosis it appears that are unlikely to attempt to use manual communication with their deaf child and if their child is profoundly deaf a complete absence of communication may be the result.

5.4 Theme 3: Stigma

Deaf people, the world over, are subject to pathological stigma, negative stereotypes and prejudicial attitudes (Munoz-Baell & Ruiz, 1999). Participants in the present study mostly referred to stigma in relation to the way their deaf children were treated by their hearing counterparts; hence the sub-theme ‘Treatment by Hearing Children’ was developed. In addition, participants spoke about the perceptions of others regarding their deaf child as well as their own perceptions of deafness, hence the sub-theme, ‘Perceptions of Deafness’ was formed.

5.4.1 Treatment by Hearing Children

“The hearing and the deaf communities share a linguistic challenge. Both encounter a communication barrier when having to deal with each other” (Munoz-Baell & Ruiz, 2000, p.41). Luckner & Velaski (2004) in their study on healthy families with a deaf child found that a challenge that many families had to overcome was finding friendships for their deaf child. Several respondents reported that their children get treated differently by hearing children and that this often has a profound effect on the parent as well.

“Even with other kids, sometimes they reject him and then I say, hey, there is nothing wrong with him, he can understand perfectly what you say and what you do. Sometimes you’ve got to teach the hearing kids that because their parents don’t teach them those things” (Participant 1)

“The kids are very funny to him, they will be playing outside and he will go to join them because he loves playing and they just pack up all their little toys and go inside, just because he’s wearing hearing aids and he’s different” (Participant 2)

“You watch her when she plays with hearing children, you can see she gets frustrated. It’s like if she plays outside with the neighbours children, we always have to have the window open or the door open so we can see what they are doing to her because she doesn’t know. Sometimes they are teasing her, and it frustrates us as well. Sometimes she wants to say something and they think it’s a joke, they start laughing and she doesn’t want them to laugh, she wants them to play...” (Participant 5)

“The one day we were at a friend’s house and they were playing by the Wendy House, all these kids shut her out and she didn’t like it” (Participant 6)

From the above quotes it is evident that often hearing children treat deaf children in an inappropriate manner, largely because the deaf child is different. It is also clear that parents of the deaf child are in many instances, just as affected by the actions of hearing children as their deaf child is.

5.4.2 Perceptions of Deafness

Many of the participants interviewed expressed having to face stigma regarding their child’s deafness. At times stigma was not only experienced externally but also internally. Many participants had not encountered a deaf person prior to having their own deaf baby. Therefore, in many instances, participants had to first confront their own stigma regarding deafness and disability and then still had to face stigma from the outside world.

“I don’t think it’s accepted, it’s out of the norm. Actually having one of your own deaf babies it becomes more acceptable, in the beginning, you worry what people are going to think, what people are going to say. But after a while when you are finished the grieving process, it becomes a lot easier...I’ve got the attitude that if they don’t accept it too bad then they don’t accept me either” (Participant 2)

“I just see on TV that there’s sign language but at the place where I’m from, the place where I grew up, there’s no such thing as sign language and its so hard to know that there are deaf people, because you don’t hear people talking about it” (Participant 4)

There are various superstitious notions that exist that view deafness as a punishment from G-d (Meadow, 1969). Participant 5 spoke of such notions:

“They think that because she’s not ugly, she shouldn’t be deaf, but it’s not only the ugly ones that are deaf...in my community, they think; that family, they must be cursed somehow. They feel that that family is not part of us; they want to know why we are having a deaf child? The community doesn’t just accept a deaf person”

Participant 6 initially only wanted her child to be oral and rejected sign language usage, only after the oral method failed did she turn to sign language which has improved communication in the family. Perhaps the denial of sign language and wish for her daughter to be ‘normal’ was driven by an internal stigma. She said the following:

“I used to not use the word deaf, I used to use the word hearing impaired, I didn’t like the word deaf”

It is evident that deaf children face stigma of various kinds. Many hearing parents have little experience with deafness prior to the birth of their deaf child and therefore have to face their own prejudices once their child is diagnosed. Also, stigma is present from the outside world in many forms, one of which is superstitious notions of deafness.

CHAPTER 6

CONCLUSIONS AND IMPLICATIONS OF THIS STUDY

6.1 Conclusions and Implications of this Study

When parents first receive the diagnosis that their child is deaf it marks the beginning of a long and often very difficult process. Parents are faced with various emotions of different intensities such as denial, grief, sadness and anger. It is recommended that due to parents often needing immediate psychological support because of the immense difficulty inherent in coping with such a diagnosis (Magnuson, 2000); doctors should refer parents to psychologists, counsellors or to support groups. Participants in the present study reported finding support groups most helpful.

Participants struggled with a lack of information provided by relevant professionals when their children were first diagnosed as deaf or hard of hearing. Welch (1996, as cited by Eleweke & Rodda, 2000) states that the process of making informed choices and decisions depends to a large extent on the availability of adequate information. Doctors need to be equipped with information regarding communication methods, education options and support services for deaf children and their families (Munoz-Baell & Ruiz, 2000).

There were some respondents who said that the doctors who provided them with the diagnosis referred them to HI-HOPES, which they found to be most useful. There are however several areas in which HI HOPES seem to be lacking. This programme provides services for deaf children only up until the age of 3 years, therefore an organisation that assists families with children older than this is a much needed service in South Africa. Given the fact that many parents, as in this study, only become aware that their child is deaf well after the optimal age for diagnosis, problems then already exist in terms of social and linguistic development. It therefore appears that these families are also very much in need of help in order to remedy, as best as possible, their situation and avoid even further developmental delays in their deaf children. An additional service for older children would be ideal, however, South Africa is faced with a severe shortage of financial as well as human resources in this

area and therefore HI-HOPES, at least for the moment, is likely to remain the only home-based intervention service of its kind available.

In addition, at present, HI-HOPES only operates within the Gauteng Province and as it is the only early-intervention home-based programme that is unbiased in its approach to communication modalities and education options and is free of charge, it is most likely that the remainder of provinces in South Africa are without such intervention services. Hopefully, with time and enough human and financial resources the HI-HOPES early intervention programme will be operative in many other South African provinces.

Participants in the present study seemed to place an emphasis on speech, yet at the same time, these parents stressed the importance of sign language for effective communication with a deaf child. This discrepancy may be able to be made sense of if one considers that parents emphasis on speech may stem from their wish for their child to be 'normal' and therefore able to speak, also speech is very difficult for a deaf child to acquire and therefore an emphasis is needed as it takes up much of the child's and parents' focus. Furthermore, many of the participants in this study reported finding sign language difficult to learn and they perceived their signing abilities as poor. What emerged as interesting from the findings was that parents reported that their children's' levels of frustration seemed to decrease when sign language was employed with them.

Due to profoundly deaf children severely struggling to communicate effectively using spoken language, sign language is often the only option and this study has shown that with manual communication children's frustration levels decrease and communication is improved. It is therefore recommended that sign language classes become more available and accessible to the hearing population.

Low self-esteem, childhood isolation and feelings of inadequacy may be the result of a lack of communication between deaf children and their hearing parents (Munoz-Baell & Ruiz, 2000). In the present study there appears to be a connection between lack of acceptance of deafness in a child and a lack of communication between child and parent. One participant reported a complete absence of communication between

herself and her daughter while many of the other participants reported knowing of families where communication between parent and child is entirely absent.

This study showed that deaf children are often subject to ill-treatment by their hearing counterparts. There is a general lack of acceptance of the deaf child, largely because he/she is different. In addition, people's perceptions of deaf people are often characterised by superstitious as well as inaccurate notions.

Perhaps Sign Language should be offered as an optional subject choice in mainstream schools. An advantage of having sign language and deaf culture as a school subject is the possibility of hearing children, who have not been exposed to anyone who is deaf, becoming more sensitized to deaf children and thus not treating them differently. However, until SASL is recognised as an official language in South Africa it is unlikely that it will be offered within mainstream schools (DEAFSA, 2006). The prevailing view of sign language within the country can contribute to parents' choice of communication mode (Magnuson, 2000).

6.2 Limitations of the Present Study

It is important to consider the various limitations that are inherent in this study and to examine how such limitations may affect the generalisability of the findings.

It must be noted that results from this study may only be generalised with extreme caution as this sample is by no means representative of the population under investigation, namely hearing parents of deaf children. This sample is not representative for several reasons. Firstly, the vast majority of the sample was comprised of mothers with input only from one father. Furthermore, St. Vincent School for the Deaf has a language and communication policy that is driven by SASL and supported by English, therefore the views of parents who prefer a strictly oral approach could not be gleaned.

Due to the 'political' nature of the different communication modalities that are employed with deaf children and due to the method of face-to-face individual

interviews being utilised, it is possible that participants felt somewhat restricted in providing the researcher with his/her true feelings on different methods of communication. In addition, due to the social construction of good mothers as exclusively caring and gentle, participants may have been reluctant to express negative feelings towards their deaf child for fear of judgement.

Due to limited time the researcher did not return to the participants of the study with the findings gained. Had this been done, it would have allowed participants' to provide their views on the analysis carried out and therefore an even deeper and more textured account of the subject matter could have been gained.

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