The experience of hearing children as they cope with having a sibling with deafness

by

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submitted in partial fulfillment of the

requirements for the degree

MA in Counselling Psychology

in the

Department of Psychology,

University of Pretoria,

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Promoter: Doctor L M Eskell-Blokland

January 2006

Pretoria

Acknowledgements

The author wishes to acknowledge the following people, who assisted and/or contributed in some way to this work:

Linda Eskell-Blokland for her supervision

The research participants for their willingness to share

Dr Badenhorst and Jan Viljoen for giving research space when I needed it

My parents and family for their support and understanding

Pieter du Toit and Annemarie Maritz for their guidance and support throughout the journey

Declaration

I declare that: *The experience of hearing children as they cope with having a sibling with deafness,* is my own work, that all the sources used or quoted have been indicated and acknowledged by means of complete references, in accordance with departmental requirements.

I have not used another student's past work to hand in as my own.

I have not allowed and will not allow, anyone to copy my work with the intention of passing it off as his/her own work.

Signature_____

Notes about the text:

1. All participants in this research granted permission to present their conversations here.
2. Names of participants have not been used to protect their identities.

SUMMARY

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Abstract

The objective of this study was to describe the experiences of hearing children as they cope with having a sibling with deafness. From a constructivist point of view, this research process is seen as socially constructing a reality or realities, with the researcher included in, rather than outside the borders of his or her own research. Semi-structured and unstructured interviews were conducted with the subjects. These interviews were aimed at obtaining information regarding the subject's experience of the stressor of having a sibling with deafness.

The participants reported limited family interaction. Although most siblings say that they have good relationships with their siblings with deafness, their

primary feelings indicate that there are aspects of having a sibling with deafness that can be challenging. The participants described experiencing a variety of feelings which include the following: frustration, loneliness, anger, affection, resentment and pity.

The results of this study have shown that the siblings of children with deafness, need more professional support in terms of coping with the disability and its consequences. Siblings need guidance on active coping responses in coping with the stressor of having a sibling with deafness.

Key words:*constructivist approach, sibling relationships, coping responses, disability, deafness and stressor.*

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CHAPTER 1

INTRODUCTION TO THE STUDY

This research project explores and focuses on the experiences of hearing children as they cope with having a sibling with deafness.

In South Africa, very little research has been done on the experience, stress and coping resources of siblings of children with deafness. According to Motala (2000) the local study conducted by Brand and Coetzer (1994, cited in Motala, 2000) which primarily selected and focussed on the response of the parents towards deafness, is limited due to the exclusion of the experience of the hearing siblings. In line with Motala, Seligman (1983, cited in Isrealite, 1986) suggest that there is a limitation in research regarding how severe the emotional impact of having a sibling with deafness can be on the hearing sibling.

The researcher consulted several international resources and studies (e.g. Goode, 1994; Gregory, 1995 Spencer and Erting, 2000) which focussed on the deaf child and the family, but found the studies limited due to the exclusion of the experience and needs of the hearing

sibling. It appears that available research focuses mostly on the parents of the child with deafness and on the deaf child him/herself.

The researcher found several studies focusing on disability in general. These studies indicated that families with a child who is disabled, may experience greater stress than similar families without disabled children (Fischer and Roberts, 1983; Lobato, Meyer and Prizant, 1997). According to Crnic, Friedrich and Greenberg (1983), the presence of a disabled child, is a stressor that is ongoing and it precipitates numerous minor and major crises. Monat and Lazarus (1991), defined stress as "any event in which environmental demands, internal demands, or both, tax or exceed the adaptive resources of an individual, social system or tissue system" (p. 3). This research topic was chosen because of this identified need in the field.

Fisiloglu and Fisiloglu (1996) suggest, "according to the family systems perspective, the family is a system in which all components are interdependent …" (p. 231). Griffin (1993, cited in Fisiloglu and Fisiloglu, 1996) states that hearing loss in the family system threatens the

system's organization. However, little is known about the attitudes and relationships of the siblings of children with deafness.

This research project will primarily focus on the experiences of siblings who have brothers or sisters with deafness. A secondary focus will be directed towards siblings' experiences of disabilities in general. By studying the experiences of siblings of children who are deaf, their needs can be identified, as well as the family's needs with regard to coping with and adjusting to the stress induced by the presence of a child who is deaf.

A qualitative research design is chosen in order to focus on the socially constructed nature of the experiences of hearing children concerning the reality of having siblings with deafness. Data will be collected by means of semi-structured and unstructured interviews with participants.

For the purposes of this study the researcher will work from a constructivist paradigm. This paradigm is chosen because the focus of this study is directed towards the experiences (different constructions) of siblings with

brothers or sisters with deafness. According to Schwandt (1998), although people create different constructions of the same phenomena, these constructions still have the potential to be meaningful. Social constructivist thinking gives recognition to the idea that our hypotheses about the world can not be proven directly. As Kelly (in Efran, Lukens & Lukens, 1992) put it:

> None of today's constructions – which are, of course, our only means of portraying reality - [are] perfect and, as the history of human thought repeatedly suggests, none is final (p. 267).

Drawing on the constructivist tradition of research this researcher will try to understand the complex world of lived experience from the perceptions of the siblings that live and experience them. Constructivists believe that, in order to understand the world of *giving meaning*), it is necessary for the researcher to interpret it. Schwandt (1998) mentions that, "to prepare an interpretation is itself to construct a reading of these meanings; it is to offer the inquirer's construction of the constructions of the actors one studies" (p. 221). Knowledge is viewed as a process of construction and reconstruction of personal

meanings in the unique context of each individual. The relation between people and the environment is viewed as a dialectical one, in which both units are modified by their mutual and reciprocal action.

As already mentioned this study aims to explore the experience of children as they cope with having siblings with deafness. Objectives towards achieving the stated aims of this study include the following:

- To conduct semi-structured and unstructured interviews with siblings of children who are deaf to determine the following:
  - the participant's experience of the stressor of having a deaf sibling;
  - the coping resources utilized by the hearing sibling.
- To do a qualitative analysis of the emerging themes in the interviews with the subjects and to identify specific shared experiences among the subjects.

The primary objective of this study is to explore the experiences of children as they cope with having a sibling with deafness, in order to expand the theoretical knowledge

basis thereof in South Africa. This study may lead to the enhancement of the effectiveness of efforts to carry out programmes concerning families by generating new activities and strengthening existing ones.

Outline of chapters

Chapter 1 is the introduction to this study and serves to state the research problem, aims and motivation of the study.

Chapter 2 This chapter focuses on theory and the psychological frameworks which will serve as a model within which the research topic and results of the study can be explored and understood. The researcher attempts to explore the meaning and history of constructivism as well as the difference between constructivism and social constructionism. This will be done by drawing upon previous and recent critical literature within the field. Furthermore, two psychological theories which were used as frameworks through which the results of this study were understood and contextualised are discussed: Minuchin's Structural Family Theory and Lazarus's Theory of Stress and Coping.

Chapter 3 provides an overview of relevant literature and research which documents the impact which children with disabilities, including deafness, have on their families and, more specifically, on their siblings.

Chapter 4 describes the aims of the study, the research design, research method, data collection and analysis. Qualitative methods were used. The data was collected by means of semi-structured and unstructured interviews with the siblings of children with deafness.

Chapter 5 provides a discussion of the research results according to the themes that were found during the research process.

Chapter 6 provides concluding remarks and recommendations for further research are made.

CHAPTER 2

THEORY AND PSYCHOLOGICAL FRAMEWORKS

Introduction

This chapter focuses on the theory and the psychological frameworks which will serve as tools within which the research topic and results of the study can be explored and understood. Because the researcher works from a constructivist approach, it is necessary to explore the history of constructivism as well as the difference between constructivism and social constructionism. This will be done by drawing upon previous and recent critical literature within the field.

Secondly, although only one sub-system of the family system (the siblings) is the focus of this study, the results thereof require exploration within a family context. The siblings included in the study, are at an age where their primary milieu consists mainly of the family system. The first theory chosen to understand and in which to frame the results of this study is the theory of stress and coping by Lazarus (Lazarus & Folkman, 1984). This theory was chosen because it focuses on stress and coping

in families and is distinctively focused on families with a child with disability.

Thirdly, the second psychological theory which will be discussed is the structural family theory by Salvador Minuchin (1974). Minuchin divided the family into subsystems which therefore lends the theory to this study which looks at the family from the perspective of the sibling subsystem.

Each of these theories or perspectives and their implications will be discussed in turn below.

What is constructivism?

Constructivism is a philosophical perspective interested in the ways in which we construct social and psychological worlds in specific linguistic, historical and social contexts (Schwandt, 1997). It can be said that the most important underlying principle of constructivism, declares that there is no such thing as an objective reality. Constructivism postulates “there is no truth ‘out there’ about which any of us can be objective or scientific. However, von Foerster (in Watzlawick, 1984)

suggests that constructivism is not just an expansion of naïve solipsism, where reality is only found in the individual's mind.

"From a constructivist perspective, reality represents a human functional adaptation: humans, as experiencing subjects of the world, construct and interpret reality" (Anderson, 1997, p. 23). Constructivism does not deny the existence of a world outside the individual's mind, but it emphasises the existence of a co-created or co-constructed reality between individuals or among groups.

The history and development of constructivism

Constructivism is a philosophical theory of knowledge that can be traced back to Immanuel Kant and Giambatista Vico (Anderson, 1997; Efran et al., 1992; Watzlawick, 1984). Efran et al. point out that "at root, constructivism simply represents a preference for the Kantian model of knowledge over the Lockean" (p. 266). Kant saw knowledge as an *invention* arising when people interacted with their environment. In contrast, Locke viewed knowledge to be a *discovery* about the outside world. Efran et al. suggest that the disagreement between traditional thinking and

constructivist thinking as mirroring this basic difference between Kant and Locke.

Constructivist thinking in the field of mental health is often said to have originated from George Kelly. In this regard, Efran et al. (1992) suggest that:

> … Kelly, who introduced personal construct theory and is considered by many the first person to formally bring a constructivist perspective to the fields of personality theory and mental health, insists that we not confuse our inventions with discoveries. (p. 266)

What is the difference between constructivism and social constructionism?

There are two general threads of constructivist thought. The first thread, radical constructivism, focuses more on the individual knower and acts of cognition. The second thread of constructivism is called social constructionism and focuses more on social process and interaction (Schwandt, 1997, p. 19-20).

In line with Schwandt (1997), Gergen and Gergen (1991) suggest that the constructivist approach reflects a subject-object dichotomy, whereas for social constructionists “it is not the cognitive processing of the single observer that absorbs the object into itself, but it is language that does so” (p. 78). Social constructionists are of the opinion that it is within social interaction that language is generated, sustained and/or discarded. The focus is not on the individual mind, but on the meanings generated by us as we collectively generate descriptions and explanations in language. Knowledge is not placed in individual minds, but is part of the coordinated actions of individuals, which are used to achieve locally agreed upon purposes concerning what is real and good.

Von Glasersfeld (1991) also stresses the significance of social interaction from a constructivist approach, when he suggests:

> The experiential world in which human knowers find themselves living is constructed, because it is a result of the cognitive agent’s own

> distinguishing and relating … The highest most reliable level of experiential reality then arises through interaction with those entities in the individual's experiential world that have been categorised by others. This social interaction yields on the one hand, the only objectivity feasible in the constructivist model and, on the other, an epistemological basis for the elaboration of ethics. (p. 26)

It seems that the differences between constructivism and social constructionism are not as substantial as we might think. Constructionists and constructivists both agree that observation does not create categories of understanding, and that it brings to the world forms of knowing by which the world is made meaningful. However, the social constructionists differ from the constructivists in that they believe that what is brought to the situation is not a state of mind but an array of linguistic capacities (Gergen & Gergen, 1991).

For both von Glasersfeld's radical constructivism and Gergen's social constructionism, it is the constructing and organising processes that are perceived to be important. It

seems that both views confront the traditional objectivist and rationalist views of inquiry, which keep the world at a distance and which hold knowledge as reflecting, or even corresponding to the world.

As mentioned in chapter one of this dissertation, the researcher will work from a constructivist paradigm with an openness to new themes emerging. Constructivists believe that, in order to understand the world of giving meaning, it is necessary for the researcher to interpret it. The researcher's interpretations will be explored in chapter four.

Lazarus's model of stress and coping

One of the models which the researcher chose in which to frame the research results, is Lazarus's model of stress and coping. Although the researcher did not intend to assess stress and coping in the family, she did hope to find more information on the experience of siblings in their living with the *stressor* of disability. Lazarus and Folkman (1984) and Monat and Lazarus (1991), stress the fact that Lazarus's model of family stress has been increasingly used by researchers who are primarily

interested in disability and allows for a variety of coping resources and responses. Lazarus's model of stress appraisal and coping resources is a theoretical approach to understanding stress and coping in the family. This theory can be applied to explore whether stress can be associated with the family situation for siblings of children with deafness. With this in mind, it seems essential that a model of stress and coping be included in this study.

This model focuses on a person's relationships with his or her environment. Monat and Lazarus (1991) view the area of stress to include any experience in which the environmental demands, internal demands, or both of them go beyond the adaptive resources of a person or social system. Lazarus and Folkman (1984) suggest that stress results when an individual appraises a situation as harmful, threatening or challenging. The degree of stress associated with this appraisal is dependent upon the strength of the commitment involved in the situation, with higher stress associated with more strongly-held commitments. Appraisal refers to the process that ascribes meaning to an experience or incident and is not based only on the attributes of the situation or stimulus, but also on the psychological makeup of the individual. When an individual has judged a

situation as harmful, his or her coping processes are set into motion (Monat & Lazarus, 1991).

Each family (and siblings) will likely have their own unique way of dealing with issues related to the child who is deaf, and this needs to be understood and respected by the researcher and professionals involved with the family.

Minuchin's structural family theory

Liddle, Breunlin and Schwarts (1988) suggest that structural family theory distinctively focuses on concepts which illustrate spatial relations eg. inclusion and exclusion, boundaries, closeness and distance etc. Family members relate consistently with certain arrangements in the family, which manages their transactions. The transactional patterns and the interactions between family members form the basis of the structural model (Goldenberg & Goldenberg, 2004).

The structure of the family embodies the rules which the family has created to determine the transactional patterns between its members and to manage how, when and to whom a family member relates (Becvar & Becvar, 2003). For

the purpose of this study, such rules would include the way in which the family interacts with the child with deafness.

Structural theory identifies three key subsystems which operate according to appropriate boundaries between generations (Becvar & Becvar, 2003; Godenberg & Goldenberg, 2004; Minuchin & Fishman, 1981). The subsystems are: the spouse subsystem, the parental system and the sibling subsystem. The sibling subsystem is the most important subsystem for this specific study as the study will explore the experiences of siblings -within their families- who have a brother or sister with deafness.

Conclusion

This chapter was included in this study in an effort to provide an overview of theories, research and psychological models which informed the research processes and which can be used to frame the results of the study. Constructivism was chosen because of how this approach can be used to understand the experiences of siblings with brothers and sisters with deafness. Lazarus's theory of stress and coping aids us to understand the results of this study because it specifically focuses on stress and coping

in families where there is a child with disability. Munichin's theory of family development lends itself to a study such as this one which looks at a family from the perspective of the sibling subsystem.

CHAPTER 3

THE IMPACT OF DISABILITY ON THE FAMILY SYSTEM

Introduction

This study focuses on the experience of siblings of brothers or sisters with deafness. However, because of the lack of research in this field, literature on the impact which children with disabilities (in general) have on their families (in general), and on siblings specifically, was consulted.

The impact of a child with a disability on the family system

This section has been divided into three sub-sections. In the first section the researcher will discuss significant literature and research which have documented the essence of the family system in general. The second section will explore influential research and literature which has documented the effect which a child with a disability has on the family system. Lastly, the focus will

be directed towards the impact of a child with deafness on the family.

The family system

All subsystems in the family affect one another (Becvar & Becvar, 2003; Godenberg & Goldenberg, 2004; Stafford & Dainton, 1995). The essence of a family system is that relationships are circular; that is, the interactive patterns and family processes are seen as influencing and being influenced by all member of the system. Besides relationships within the direct family, the family system theory also proposes an interactive relationship with the environment (Stafford & Dainton, 1995). Bowen (1988) explains these family relationships as a triangle: no member of the family is totally in control nor is unmoved by the actions of other family members. The individual life cycle takes shape and evolves within the family system (Carter & McGoldrick, 1999).

Theoretically, to comprehend the working of the system, the subsystems are arbitrarily divided from each other for closer internal analysis. However, in reality, it is impossible to detach the complex working of individual

subsystems within the family system as the subsystems mutually influence each other (Bowen, 1988).

The impact of a child with a disability on the family system

The birth of a child is an event often greeted with a myriad of emotions. It is a time for joy, anxiety and anticipation. The birth of a child with a disability is an unexpected event for which there is no socialization process that prepares the parent. Therefore, the birth of this child can have a tremendous effect on the whole family system (Turnbull, 1988; Yura, 1987). The presence of a child with a disability in the family may place excessive demands on the resources of the family, resulting in an unequal flow of energy into and out of the family (Bubolz & Whiren, 1984). However, Hartshorne (2002) suggests that, while the presence of a child with disability is a challenge for parents, many families are able to adjust. Hartshorne (2002) cites other researchers (e.g., Yau & Li-Tsang, 1999) who suggest that research has been too focussed on the negative influence of having a child with a disability and has disregarded the strengths of families who were able to adjust. Two authors who focus on the

positive influence of having a child with a disability are Powell and Ogle (1985), who suggest that “there is something unique, something special, about growing up in a family in which a brother or sister has a handicap” (p. 3).

Regardless of the lack of research exploring the positive accounts of families with children with a disability, some researchers have explored what factors assist some families to cope with such a child. Yau and Li-Tsange (1999) found that the availability of social support plays a big role in the promotion of healthy family adjustment to the stressor of having a child with disability. Also touching on the issue of social support, Mittler (1995) suggests that there has been a shift from parent-child centred services, towards family-centred services, which include the siblings of the children with disabilities. This step towards family-centred services for children with disabilities creates new challenges for professionals. This research will contribute to the advancement of the understanding of the needs of the siblings that need to be addressed within a family-centred service. Mittler (1995, p. 91) suggests that services offered by professionals and organizations to families in need should include the following: They should be

individually created to meet the unique needs of every family; support and provide a safe talking space for family members to express their feelings, perceptions and expectations; and ensure that the needs of each individual within the family are considered and facilitated as far as possible

The impact of having a child with deafness on the family

Although the focus of the study is on the experience of the hearing siblings as they cope with having a brother or sister with deafness, the following poem is included in this chapter to provide a talking space for the silenced children with deafness:

Thoughts of a Deaf Child

My family knew that I was deaf
When I was only three, and since then fifteen years ago
Have never signed to me.
I know when I'm around the house,
I try and use my voice,
It makes them feel more comfortable;
For me, I have no choice.
I try, communicate their way-

Uncomfortable for me.

My parents wouldn't learn sign

Ashamed or apathy?

I never cared about the sound of radios and bands;

What hurts me most is, I never heard

My parents' signing hands (Author unknown)

Gregory (1995) mentions that to have one's child diagnosed as deaf was, and still remains a major and stressful event in the life of most families. Whenever a family member is diagnosed with hearing loss, the parents are the only family members assumed to be experiencing major changes. The main concerns of parents are language development and ways of communication with other members of the family.

Little research concerns itself with characterising the nature of the interactions between deaf children and their hearing siblings. The lack of communication in the family will generate a high level of negative emotionality, such as jealousy or unconcern, in the hearing siblings toward the deaf siblings (Marschark, 1997). There are studies, however, that explored language preference of hearing and deaf twin pairs (Gaines and Halpern-Felsher,

1995). These two researchers found that twins, who were between three and five years old were at very different stages of language development, and the rate of communication between the twin with normal hearing and the twin with hearing loss was low, as both children directed conversation more to hearing members of the family.

The sibling subsystem and the impact of disability

This section has also been divided into three subsections. In the first section the researcher will discuss significant literature and research which have documented the essence of the sibling relationship (in the absence of disability). The second section will explore influential research and literature which have documented the effect which a child with a disability has on the sibling subsystem. Lastly, the focus will be directed towards the impact of a child with deafness on his or her hearing sibling.

"Normal" sibling relationships (without the presence of a disability)

Cicirelli (1995) defines the sibling relationship as the sum of the interactions of physical, verbal, and nonverbal contact of two or more individuals who share knowledge, perceptions, beliefs and emotions regarding each other. Relationships between siblings are among the most rich and enduring bonds that children and adults experience. Mchale and Crouter (1996) suggest that "sibling relationships are complex and multi-faceted" (p. 173). Siblings spend generally more time with each other than they do with any other member of the family (Lobato, 1990). Dunn (1985) notes that most children grow up with siblings and in some cultures are raised by siblings. Similarly Brody and Stoneman (1994) acknowledge that children's sibling relationships are important sources of influence in their lives. As Lobato (1990) suggested, there are several purposes and functions of sibling relationships of which a few can be seen in Figure 1 on page 28. In line with Lobato (1990), Dunn (1993) focussed on the functions of the sibling relationship and mentions that "a recent study reports children with siblings performing with much greater success on tests of understanding 'other minds' than do singletons" (p. 48).

The relationship between siblings, in general, was ignored for a long time (Connors & Stalker, 2003; Dunn, 1993; Siegel & Silverstein, 1994). Systematic studies of siblings began to surface during the 1980's. Dunn mentions that studies (e.g., Buhrmester, 1992; Furman and Buhrmester, 1985; Rafaelli, 1991) reflect an increased interest in describing the perceptions of siblings and their parents concerning the sibling relationship.

Sibling relationships in the presence of disability

The study of the impact of a disabled sibling on nondisabled siblings is emerging as a significant area of research and concern (Seligman and Darling, 1989). Powell and Gallagher (1993) cite several authors who have reviewed research on the relationship between a sibling and his or her brother or sister with a disability (eg. Cerreto & Miller, 1981; Senapti & Hayes, 1988; Simeonsson & McHale, 1981).

There is a major lack of information about the consequences of disability. The lack of information may confuse non-disabled siblings in regard to several factors

Figure 1: Functions of the sibling relationship

(Adapted from Lobato, 1990, p. 3)

according to Wasserman (1985, in Darling and Selligman, 1989). The lack of information includes the following:

1. being held responsible for a particular condition;
2. whether it is transmittable;
3. if and how one should communicate to family and friends about the disability;
4. what implications the disabled child has for the siblings' future;
5. how one should respond to discomforting feelings such as anger, hurt, and guilt;
6. how to relate effectively to one's disabled brother/sister and to others in one's environment. (p. 113)

Lobato (1990) suggests that siblings are important in developing self-identity. It is a common phenomenon to hear siblings define themselves in relation to some characteristic of their sibling. In a sibling relationship where a disability is present, the reflecting of self-identity is often the result of a third party (eg. Siblings are often teased in relation to some characteristic of their sibling's disability).

Exploring the positive effects which brothers or sisters with disabilities have on their siblings.

Grossman (1972, in Powell & Gallagher, 2003) interviewed college students, whose siblings were mentally disabled. Her data revealed that one-half of college students interviewed described the presence of their sibling with a disability as a "positive, integrative experience in their family" (p. 43). Powell and Gallagher (2003) cite several authors who have also concluded that there are positive aspects associated with the presence of a child with a disability (Graliker, Fishler, & Koch, 1962; McHale, Soan, & Simeonson, 1986; Schipper, 1959; Schreiber & Feeley, 1965).

Some siblings show satisfaction in learning to cope and live with the strain induced by the child with a disability. These siblings report feelings of joy and pleasure with each accomplishment of the disabled child and show compassion for all people's unique needs and abilities (Powell & Gallagher, 2003).

Exploring the negative effects which brothers or sisters with disabilities have on their siblings.

The presence of a brother or sister with a disability creates a situation for mixed emotions, and siblings also report negative aspects of living with such a child. The researcher will briefly discuss relevant literature and research that document negative effects which brothers or sisters with disabilities have on their siblings.

Burbach and Peterson (1986, in Powell & Gallagher, 2003) suggest that siblings may be scared that the disability of their brother or sister might be contagious and thus be infected by it themselves. Similarly, Klein (1972, in Powell and Gallagher, 2003) suggest that siblings may fear that their own children too, will be born with disabilities.

Siblings of children with disabilities experience higher levels of anger than other siblings do (Seligman, 1983, in Powell & Gallagher, 2003). The anger may be the outcome of feeling ignored and unappreciated, because parents may spend excessive amounts of time with the disabled sibling. Because of these feelings of anger,

siblings may feel guilty about it (San Martino & Newman, 1974, in Powell & Gallagher, 2003).

Powell and Gallagher (2003) further suggest other intense feelings that may be experienced by siblings of children with a disability: e.g. loneliness, resentment, embarrassment, confusion, jealousy, pressure, and frustration. The development of negative feelings may be the result of various factors. Simeonsson and Bailey (1986, in Powell & Gallagher, 2003) note the following factors:

> Severity of the disability … Age of the child who has the disability … Age-spacing between the child with the disability and the other siblings … Birth order … Size of the family … Pressures exerted by the parents and professionals who are dealing with the child with the disability … Extent to which the child with the disability manipulates or mistreats the other siblings … The actual interactions among siblings… (p. 114-115)

Sibling relationships in the presence of deafness

At the First Africa Workshop on Mental Health and Deafness (AWMHD), 100 delegates from 10 African countries agreed to the following excerpt from the "Africa declaration on Mental Health and Deafness" (2004):

> Of the 70 million Deaf people in the world, 80% live in developing countries, 21,8 million in Africa. It is estimated that 700 000 suffer from mental health problems which means that there are approximately 560 000 Deaf people in developing countries, 218 000 in Africa, who need appropriate and accessible mental health services… (p. 1)

The statistics mentioned above indicate that 70 million people in the world are deaf and this precisely shows the magnitude of the prevalence of deafness in Africa and elsewhere. Many of these deaf individuals are children who have brothers and sisters. These siblings will share many of the same concerns that the parent of deaf children experience. They will also experience things that are uniquely theirs as siblings.

One of the primary focus areas in the present study include the relationship between the hearing sibling and the deaf sibling. However, little is known about the attitudes and relationships of the siblings of children with deafness. While busy with the ongoing literature study, the researcher could not find substantial literature that not only focuses on supporting the parents of the child who is deaf but also supports the unique needs of the siblings of such a child. However, Powell and Gallagher (1993) have identified a number of special concerns of siblings about their brother or sister with a disability in general:

> … the cause of the disability, the child's feelings and thoughts, prognosis for a cure or improvement, the services the child needs, how they can help the child, where the child lives, and what the future holds for the child … (p. 72)

Unfortunately, there appears to be a lack of research on the unique experiences and perceptions of siblings living in families with a child who is deaf. Seligman (1983, cited in Isrealite, 1986) suggest that there is a limitation in research regarding how severe the emotional

impact of having a sibling with deafness can be on the hearing sibling.

The reason why the focus on such siblings may be of utmost importance is that siblings will likely spend more time with the deaf child than any other person, with the exception of the mother of such a child. The sibling relationship is generally the longest lasting relationship in the family system and the brothers and sisters are likely to experience these concerns for a long period of time (Powell & Gallagher, 2003).

We live in a hearing world and sign language is not an easily acquired language without formal training. Because communication is evidently an obstacle between a hearing person and a deaf person, the sharing of feelings between hearing siblings and their siblings with deafness may also be problematic. The researcher suspects that limitations in a child's communication skills and social understanding, stemming from physical or cognitive disabilities may contribute to more frequent sibling conflict.

Human communication is largely language-based and the family is the prime socializing agency. If the deaf sibling

is to be habilitated successfully, he or she must first master communication skills whilst interacting with the family. The researcher is of the opinion that it is therefore imperative that both the child with deafness and his or her family (including the hearing siblings) receive intensive professional assistance immediately after the hearing loss is diagnosed. Featherstone (1980, in Powell & Gallagher, 2003) suggest that in attempting to establish a normal sibling bond with a disabled brother or sister (including effective communication), may lead to great levels of sibling frustration. However, early intervention programmes involving the hearing siblings and parents have not always been as successful as expected. Parents often fail to follow home programmes as prescribed by professionals depending on the specific needs and experiences of the family (Dunst, Trivette & Deal, 1988).

Particular issues in family dynamics have come to the fore regarding emotional stressors in families with a deaf child and hearing siblings. Calderon and Greenberg (1999) warn that parents of children with deafness may become overprotective resulting in the hearing sibling's perceptions that the brother or sister with deafness is not equally and appropriately disciplined. This may evoke

feelings of unfair treatment, negative self-esteem, anger towards the parents or sibling with deafness etc. Calderon and Greenberg (1999) further suggest that because parents may tend to spend more time and attention in meeting the needs of the child with a disability, the siblings may feel excluded from the family involvement. This also applies to families with children with deafness.

Furthermore, the effect of constant enquiries made to the hearing sibling with regard to the deaf sibling's condition and uniqueness, is an ongoing process that the hearing sibling needs to deal with on a daily basis. Powell and Gallagher (2003) suggest that siblings may express embarrassment when introducing the disabled child to peers and so forth.

Conclusion

Although there are several studies focusing on the impact of disability on the family, there seems to be a lack of research regarding the unique concerns and special needs of siblings and resources required by them due to the impact of living with a brother or sister with deafness. It is these obvious gaps in current research, which form the

heart of this research study and the formulation of its aims.

CHAPTER 4

RESEARCH DESIGN AND METHODOLOGY

Introduction

The previous chapters provide insight into the reasoning behind this study. In this chapter, the researcher will describe the aims of the research, the design, research method, data collection and analysis. Ethical considerations which were taken into account are also discussed.

Research design

Part of the philosophy behind this proposed study can be seen in the vision of Efran et al. (1992): “The leverage inherent in constructivism – the hopefulness of the approach – lies in the possibilities generated by the exploration of fresh terrain” (p. 274).

In order to reach the aims of this study, the researcher chose to adopt a qualitative research method. Snape and Spencer (2003) suggest that there is no specific acceptable way of performing qualitative research. They

suggest that it is the researcher's views on the nature of the social world and how knowledge is gained, that influence the way in which qualitative research is applied. Snape and Spencer (2003) claim that there are three different belief systems on whether there is a confined social reality and how this reality is constructed. The first position is called *materialism.* According to this there is a real world, but it only consists of material features. The second position is that of *realism* that suggests there is an external reality which exists independent of our beliefs about it. The final position is called *idealism* which claims that reality is only knowable by means of the mind and through socially constructed meanings (Snape & Spencer, 2003).

"From a constructivist perspective, reality represents a human functional adaptation: humans, as experiencing subjects of the world, construct and interpret reality" (Anderson, 1997, p. 23). Unfortunately Snape & Spencer (2003) did not mention the social constructivist approach, which does not deny the existence of a world outside the individual's mind, but it emphasises the existence of a co-created or co-constructed reality. According to this view, reality is constructed through language, learning,

expectations, and other psychological and interpersonal processes (Efran et al., 1992, p. 272). Keeping this in mind, a qualitative research design was chosen in order to focus on the socially constructed nature of the experiences of hearing children concerning the reality of having siblings with deafness.

Qualitative research contributes to the depth and openness of the research without constraining the researcher with predetermined categories of analysis (Patton, 1990). The researcher chose this research design hoping that the aforementioned advantage of qualitative research would contribute to an effective and meaningful process of the interpretation of the research data.

The researcher found several definitions of what qualitative research actually is. Garbers (1996) defined a qualitative research design to be a complex undertaking, because it covers a wide range of other methods within different research disciplines. Similarly, Denzin and Lincoln (2000) mention that qualitative research includes the views, methods, and also techniques of "ethnomethodology, phenomenology, hermeneutics, feminism, rhizomathics, deconstructionism, ethnography, interviews,

psychoanalysis, cultural studies, survey research and participant observation, among others" (p. 6). Strauss and Corbin (1990) also suggest that there are different types of qualitative research. According to Denzin and Lincoln (2000):

> Qualitative research is a situated activity that locates the observer in the world. It consists of a set of interpretive material practices that make the world visible. (p. 3)

A social constructivist grounded theory was utilized as the qualitative research design. The research method, data collection, data analysis and ethical considerations are discussed in the following sections of this chapter.

Research Sampling

Subject selection

During this study individual, semi-structured and open-question interviews were conducted with 5 children who have siblings with deafness. Because the researcher

considers age to be a significant factor in this study, the parameter was middle childhood. The motivation for choosing participants in this developmental stage will be discussed later in the chapter.

A non-random sampling procedure was used, due to the fact that subjects were selected according to convenience and accessibility, rather than according to statistical randomness. The particular non-random sampling method is known as purposive sampling. This sampling method allowed the researcher to select the subjects that were felt to represent a typical sample of the particular population under investigation. This type of sampling has a weak basis of generalization, because there is no guarantee that the sample obtained is a good representation of the population in question, and therefore any generalizations made can be queried with regard to their reliability (Chadwick, Bahr & Albrecht, 1984). This method was still significant for this specific study. Although generalizations made can be queried, this research will contribute to the advancement of the understanding of the needs of the siblings that need to be addressed within a family-centred service.

The researcher decided to use this method because it is difficult to access the hearing siblings who have brothers or sisters at Transoranje School for the deaf. Most deaf learners come from provinces outside Gauteng due to the scarcity of deaf education. The five hearing siblings that were selected for this study: have brothers or sisters at Transoranje School for the deaf; and are learners from surrounding schools in the Pretoria Area. The Transoranje School for the Deaf is situated in Pretoria West, Gauteng and it is also one of the researcher's placements during her internship.

The subjects that were selected have siblings who are deaf. The subject's sibling who is deaf had to be a day scholar and live with his/her family (siblings need to be in contact with the child who is deaf on a regular basis, in order to be able to identify siblings' experiences).

According to Terre Blanche and Kelly (2000), "the subjects' willingness to share their experiences is important as the interview "is a process of getting to know one another better and of a relationship of mutual trust" (p. 130). The researcher agrees with Janesick (1998) that by establishing trust as early as the beginning of the

study, it will ensure that participants will be more willing to share their experience with a researcher. The subject's first language had to be Afrikaans or English (the data collected during the semi-structured interview had to be transcribed; and the researcher is in command of both languages). An information letter was given to each parent (see sample annexure B). Parents of the subjects signed a written consent form, giving their consent that their child may participate in the study (see sample annexure C).

Data collection strategies/procedures

Semi-structured and unstructured interviews

In this study data collection took place by means of semi-structured and unstructured individual interviews (Annexure D) with five children in middle childhood (between the ages of 7 and 11 years), who have siblings with deafness. Children in this phase of childhood are likely to have the cognitive and affective capabilities to share their experience of having a sibling with deafness (Powell and Gallagher, 2003). A semi-structured interview format was used because the researcher anticipated that

this procedure would provide her with some direction and structure, while the unstructured interviews would provide additional information and elaborate on certain areas.

Although some researchers suggest that ethnography or participant observation be used when studying children, Eder and Fingerson (2001) seem to differ. Eder and Fingerson (2001) suggest that interviewing can be successful when working with children from pre-school age up to the end of high school age. One of the reasons that makes the interviewing of children for research purposes meaningful, is that it gives them the opportunity to "give voice to their own interpretations and thoughts rather than rely solely on our adult interpretations of their lives" (Eder and Fingerson, 2001, p. 181). The researcher chose interviewing as data gathering method because she hoped to explore the subjects own interpretations (constructions) of dealing with having a sibling with deafness.

According to Terre Blanche and Durrheim (2002) the interview gives the researcher the opportunity to get to know the participants quite intimately "so that we can really understand how they think and feel" (p. 128). From a constructivist viewpoint, the researcher agrees with Terre

Blanche and Durrheim (2002) in that the interview *assists* in the understanding of a person, but disagrees with their statement "… really understand how they think and feel" (p. 128). The researcher is of the opinion that we can only have an *understanding* of those we study, because our interpretations are our own constructions itself and not an objective fact that leads to a definite explanation of our research findings.

The conducting of interviews is a modern instrument for the use of storytelling or narratives especially in qualitative research. Interviews give people, as a response to the questions posed by the researcher, a space for sharing either a specific part of his or her life or his or her life in totality. Kvale (1996) defines an interview as a means "to obtain descriptions of the life world of the interviewee with respect to interpreting the memory of the described phenomena" (pp. 5-6).

In this study each participant's semi-structured interview was conducted by means of eleven questions and took approximately 60 minutes to complete. For the sake of reliability, these questions were asked in the same order to each participant. For the sake of validity open

questions were asked in order to give each participant the opportunity to describe his or her personal experience of having a sibling with deafness, with as little as possible influence by the researcher. Open questions give each participant the opportunity to construct their personal narratives and share them with the researcher. The participants were fluent in Afrikaans which was also their home language. The interviews were all conducted in Afrikaans.

Educational authenticity is a principle concept introduced by Schwandt (1997). In this study, the principle is used in the process whereby the qualitative researcher attempts to strengthen the research participant's understanding and appreciation of the social environment and the constructions of others of having a sibling with deafness (Schwandt, 1997). By conducting individual interviews with the children who have siblings with deafness, the children were given the opportunity to become more aware of their situation, and of the possible support available to them from the community or elsewhere. The researcher identified some of the unique needs of the research participants, hoping that this would be meaningful information for the enhancement of the effectiveness of

family programmes. The subjects in this study all supported the idea of attending a "sibshop". The nature and aims of a "sibshop" will be discussed in the final chapter as part of suggestions for future research.

Transcription of the interviews

Transcription implies the translation from oral language, with a specific set of rules, to the written language, with a different set of rules. In this study the researcher performed the transcription herself. Kvale (1996) mentions that, "transcripts are decontextualized conversations … The flow of conversations, with its open horizon of directions and meanings to be followed up, is replaced by the fixated, stable written text" (p. 167).

Because the researcher worked from a socially constructed approach where both context and the interviewer make significant contributions to the realities that are constructed, the researcher attempted to address Kvale's observations above by including her experience after each identified theme in the research report. The themes and interpretations will be explored in the following chapter.

Transcripts and transcription have an ethical component that the researcher kept in mind. Interviews may address sensitive issues wherein it is important that the confidentiality of the participant is protected (Kvale, 1996). These ethical considerations will be discussed in a later section of this chapter.

Data analyses: A Grounded theory strategy

In this study the data analyses of the interviews were done by means of grounded theory strategies (Charmaz, 2000; Dey, 1997). Charmaz, 2000, (p. 514) writes of "a simplified constructivist version of grounded theory" as opposed to the more widely used objectivist grounded theory with a clear positivist bent. She suggests that "researchers may use grounded theory in conjunction with other approaches" and that "grounded theory methods may specify analytic strategies". Research conducted in this way suggested by Charmaz tends to use limited data gained through interviews and recognises the "relativism of multiple social realities … the mutual creation of knowledge by the viewer and the viewed, and aims toward interpretive understanding of subjects' meanings." Thus she distinguishes between earlier positivistic approaches of grounded theory and this

constructivist approach which furthers interpretive methodological aims (Charmaz, 2000).

As mentioned above the researcher worked from a constructivist paradigm with an openness to new themes emerging. Constructivists believe that, in order to understand the world of given meaning, it is necessary for the researcher to interpret it. Kelly (2002) suggests that:

> In forms of study that are orientated towards developing theory out of contextual research, most notably grounded theory, one would ideally find a medium between using established themes in the form of emerging theoretical forestructures which the researcher is becoming committed to and an openness to new themes emerging. (p. 414)

In order to analyse the data in a way which would meet the goals of this research project, Charmaz's model of content analysis was used (Charmaz, 2001). According to Charmaz, "… coding entails the researcher's capturing what he or she sees in the data in categories that simultaneously describe and dissect the data" (p. 684). Stated differently, coding entails the researcher's

construction of what he or she sees being constructed by the research participants.

In this study, intensive analyses of the semi-structured interviews resulted in the development of a theory regarding children's experience and perceptions of having a sibling with deafness. The process of identifying themes assisted the researcher to form an interpretive understanding of subjects' meanings of the social reality of having a sibling with deafness. The researcher focused on the hearing siblings' experience of having a brother or sister with deafness as a subjective experience. Thus the researcher was interested in what was essential to the phenomenon as defined by the siblings who experience it. According to Charmaz (2000), "as a result, a constructivist grounded theory may remain at a more intuitive, impressionistic level than an objectivist approach…" (p. 526). This allows the researcher to remain intuitively open to new themes emerging, and at the same time, demands that she be aware of her own role and subjectivity in the research process.

Constructivism's implications for this study and research process

From a constructivist point of view, this research process is seen as socially constructing a reality or realities, with the researcher included in, rather than outside the borders of his or her own research. Constructivism implies the use of reflexivity in research, where the concept of reflexivity means bending back on itself. The self to which this bending back refers should be understood as socially constructed (Steier, 1991).

Steier (1991) suggests that the researcher should always recognize his or her role in the research process by acknowledging his or her bias in the reality which the research initiates. The researcher should further acknowledge the reflexivity of this process. There have, however, been criticisms as to whether it is possible to do research while following a constructivist path. Steier (1991) responds to these criticisms in the following manner:

> Why do research if you cannot say anything about what is out there, and all research is self-reflexive? My

reply is: why do research for which you must deny responsibility for what you have found? (p. 10)

Ethical Considerations

For the purpose of this study the researcher considered the following ethical implications namely informed consent, harm to participants, confidentiality, reporting of research results, behaviour and skills of the researcher.

A stamp and signature of approval was given by the District Director of the Department of Education (Gauteng) in order to commence research (approval was acknowledged on the application letter of the researcher – Annexure A). The researcher submitted the research proposal to the research ethics committee of the University of Pretoria which was approved. The researcher made this study known to parents who have hearing children and children with deafness by means of a letter. Parents who wanted their hearing children to participate were asked to give written consent after reading an information brochure (Annexure B) and completing a consent form (Annexure C).

The researcher considered the above mentioned ethical implications that might arise from this research project. During the first contact session with the family, the participants' parents or guardians received an information brochure with an attached informed consent form. The brochure focused on the following aspects of the research:

- The researcher's contact particulars
- The title of the study
- The aim and purpose of the study
- The duration of the study
- Which procedures and methods would be followed during the study
- Whether the study had been approved on ethical grounds by the university's ethics committee
- The financial arrangements regarding the study
- What the child's rights would be as participant in this study
- How confidentiality would be dealt with

After the researcher explained the content of the brochure to the parents, further ethical considerations were explained and discussed. An informed consent form was

given to the parents to be completed and signed. The researcher compiled the information brochure and informed consent form by adjusting those used by Barnard (2004) in her study of the experiences of domestic workers who are HIV-positive. Barnard's (2004) information brochure and informed consent form were chosen by the researcher due the adherence of the prescribed ethical standards. The researcher found Barnard's (2004) strong ethical focus appropriate and informative to this study.

The researcher asked the parents to discuss the research project with the participants before the actual interviews commenced. The researcher made it clear that the parents should not sign the consent form if the participants did not agree to be part of this study. At the beginning of each interview, the researcher explained the following to the participants:

- The aim and purpose of the study
- The duration of the study
- Which procedures and methods would be followed during the study
- What the child's rights would be as participant in this study

After the researcher explained the above mentioned issues with the participants, she again asked them whether they were still willing to participate. All participants indicated that they were willing to partake in the study. To ensure maximum confidentiality no names were recorded on the audio cassettes made of the interviews. The data on the audio tapes were transcribed by the researcher herself so that a hard copy was available to complete the data analysis. After all the interviews were transcribed, the interviews on the cassettes were erased. Feedback will be given to the parents as soon as the research report is received from the research committee.

Establishing trustworthiness

Because the researcher worked from a constructivist paradigm, internal and external validity is replaced by trustworthiness and authenticity (Schwandt, 1997). According to Schwandt (1997), the authenticity of qualitative research is evaluated according to specific criteria. The criteria will be discussed in the following paragraphs.

It seems that there exist two opposite views about the meaning of validity in qualitative work namely: (1) In qualitative research the findings are seen as valid if the viewpoints, perspectives and narratives of the research participants can be seen clearly and unambiguously in the texts, and (in opposition)(2) the view of no validity. According to Schwandt (1997):

> The most radical of postmodernists would argue that it is meaningless to talk of a *true* account of the world; there are only different linguistically mediated social constructions … validity is an empty issue because no single interpretation or account can be judged superior to any other. (p. 169)

The researcher's view in this regard is somewhere in the middle of the continuum of opposite views. She regards the data to be trustworthy if the experience and perspectives of the subjects are clearly reflected, and on the other hand, she believes that no single interpretation is greater than any other.

Tactical authenticity refers to the principle that the qualitative researcher should try to motivate and empower the participants to be actively involved in the research process or "are empowered to act" (Schwandt, 1997, p. 7). According to Gardner(1993) magic tricks "… facilitate attention and involvement of children…" in the therapeutic process (p. 99). The researcher shared a magic card trick with each participant at the beginning of each interview, taking her time until the participant seemed relaxed and comfortable. She found that this was useful in facilitating the child's active involvement with her.

Janesick (1998) suggests that the reliability of qualitative research can be increased by data confirmation. She introduces the following forms of confirmation used by qualitative researchers:

- *Data confirmation*: Janesick (1998, p. 46) defines data confirmation as "the use of a variety of data sources". The researcher of this study made use of different data sources. She performed an extensive literature study and conducted interviews with children who have siblings with deafness.

- *Researcher confirmation*: This type of confirmation implies "the use of several different researchers or evaluators" (Janesick, 1998, p. 46). A supervisor was involved in this study as an evaluator promoting researcher confirmation.

- *Methodological confirmation*: Janesick (1998) suggests that researchers should use different methods to study the same phenomena. In this study the researcher made use of a literature study, interviews, consultations with experts in the field (psychologists who are fluent in Afrikaans), and data analyses by means of a constructivist grounded theory strategy. The difference between methodological confirmation and data confirmation is that the first type of confirmation implies the use of different *methods* and the latter implies the use of different *resources*.

Conclusion

Because this research study explores siblings' experiences, it is unlikely that exactly the same results would come to the fore should the project be repeated. "The constructivist approach leans toward a story because it rests on an interpretive frame. Like a story, a constructivist grounded theory may contain characters and plots, although they reflect reality rather than dramatize it" (Charmaz, 2001, p. 691). However, the results of this study have been reflected in the light of similar research and related research findings. The results, represented by the themes which emerged from the data, are presented in chapter 5.

CHAPTER 5

RESULTS

Introduction

In this chapter the interview material will be presented and discussed in an attempt to meet the aims of the study. The researcher worked from a constructivist paradigm with an openness to new themes emerging. The process of identifying themes assisted the researcher to form an interpretive understanding of subjects' meanings of the social reality of having a sibling with deafness. A constructivist researcher takes "implicit meanings, experiential views, and grounded theory analyses as constructions of reality" (Charmaz, 2001, p. 678). In line with Charmaz (2001), Schwandt (1998) suggests "to prepare an interpretation is itself to construct a reading of these meanings; it is to offer the inquirer's construction of the constructions of the actors one studies" (p. 221).

A number of themes emerged from the interviews which will be presented in this chapter. Each theme will be outlined along with excerpts from the interviews of the

participants. As mentioned in chapter 4 the interviews were done in Afrikaans, but were translated into English by the researcher. To make it easier for the reader the translated English excerpt will be placed in a larger font size than the Afrikaans version which will follow immediately after the English quote. In addition, the themes will be discussed in the light of other research findings.

Four major themes emerged from the data of which some of these have sub-themes:

- Primary feelings about having a sibling with deafness
- Feelings about family interaction
    - Unequal treatment
    - Communication issues
- Pressures and stressors in the broader social system
- Knowledge about the disability

Primary feelings about having a sibling with deafness

During the interviews, all participants were asked how

they felt about having a sibling with deafness. The majority of the participants felt that it had a negative impact. One participant described her feelings about having a brother with deafness by saying:

> *Sometimes it's not nice … sometimes I have to look for him because you can't call him … then I must find him. Sometimes he makes noises, then I know where he is, but other times he is dead quiet … you can't hear or see him. / Partykeer is dit nie lekker nie … partykeer moet ek hom soek omdat 'n mens hom nie kan roep nie … dan moet ek hom soek. Partykeer maak hy geluide, dan weet ek waar hy is, maar ander kere is hy doodstil … jy kan hom nie hoor of sien nie.*

This same sibling seems to feel frustrated about her brother's disability. She says:

> *He sits in the bath and yells and then everyone must run after him to find out what he wants. Then I wish he can sit and talk in the bath / Hy sit in die bad en skree en dan moet almal agter hom aanhardloop om uit te vind wat hy wil hê. Dan wens ek hy kan in die bad sit en praat.*

She went on to say:

He cries about everything … sometimes he makes me angry then … then I just want to hit him, because he is very irritating sometimes. / Hy huil oor als … partykeer maak hy my kwaad dan … dan wil ek hom net slaan, omdat hy soms baie irriterend is.

Another participant seemed to be experiencing a sense of loss and shared her need to communicate with her sister. She explains:

It is not nice … sometimes I want to talk to her and I can't … she can't understand me. If I could understand her, we would be able to talk for hours and hours. / Dis nie lekker nie … soms wil ek met haar praat en ek kan nie … sy kan nie my verstaan nie... As ek haar kon verstaan, sal ons vir ure en ure kon praat.

One sibling said that it made her unhappy. She said:

When we sit and talk to our friends, they talk … then she doesn't understand it … then it makes me feel kind of sad… she cries a lot. / As ons sit en praat met ons vriende … hulle praat … dan verstaan sy dit nie … dan laat dit

my nogals hartseer voel … sy huil baie.

This same participant seemed to feel that her relationship with her sister would have been different without the deafness. She went on to say: *"If I could understand her more, we could have a closer bond if she could hear. / As ek haar meer kon verstaan, kon ons a 'closer bond' gehad het as sy kon hoor."* The youngest participant expressed feelings of loneliness. She says:

> *It is not nice to have a deaf sister … I wish my sister could talk, but she can't… It's not nice to go to school alone without my sister. / Dis nie lekker om 'n dowe sussie te hê nie … Ek wens my sussie kon praat, maar sy kan nie … Dis nie lekker om alleen skool toe te gaan sonder my sussie nie.*

Although the majority of participants were less positive about having a sibling with deafness, one participant felt that it has its advantages:

> *It's all right to have a deaf sister. When we listen to loud music, she doesn't have to worry us… because if a person is deaf then it is a bit better. / Dis 'alright' om 'n dowe sussie te hê. As ons na harde musiek*

luister, dan hoef sy ons nie te pla nie … want as 'n mens doof is dan is dit 'n bietjie beter.

Although this participant did not feel that it is such a bad thing to have a sister with deafness, she later said that she does feel sorry for her sister.

On the whole it seems that there are aspects of having a sibling with deafness that can be challenging. The researcher's interpretation (construction), of the constructions of the participants, is that it seems that these siblings experience a variety of feelings which include the following: frustration, loneliness, anger, affection, resentment and pity.

Feelings about family interaction

Another theme which emerged during the researcher's interpretation of the siblings' experience is that they have strong experiences regarding family interaction. There seems to be two main areas where the siblings talked about their family interaction. These included: unequal treatment and communication issues.

Unequal treatment

The participants seem to feel they are treated differently to their siblings with deafness. For example one sibling said:

> *We fight a lot … He cries about everything … he does anything he wants to do. Everyone must run after him. / Ons baklei baie … Hy huil oor als … hy doen net wat hy wil. Almal moet agter hom aanhardloop.*

Another participant feels that her sister gets spoiled too much. She explains:

> *I wish I was spoiled because she gets spoiled all the time … She gets a DVD player, a video machine and she got a cell phone from our grandfather. / Ek wens ek was bederf want sy word al die tyd bederf. Sy kry a 'DVD player', 'n video masjien en sy het 'n selfoon van ons oupa gekry.*

Although 2 out of the 5 participants expressed feelings that their sibling is treated differently to them, the remaining participants did not give any indications thereof.

Communication issues

On the whole, the participants seemed to feel that communication is a problematic aspect within their family interaction. It seems that there is a great need for effective communication with the sibling with deafness.

One sibling said that neither her parents nor anybody else helped her to learn the little bit of sign language she can talk. She also said that her parents can't really talk sign language. She says:

> *Nobody helped me. I had to learn sign language from my deaf brother. Every time when he comes home, he teaches me something new. I can only say a few words. / Niemand het my gehelp nie. Ek moes gebaretaal van my boetie leer. Elke keer as hy huistoe kom, dan leer hy my ietsie nuts. Ek kan net 'n paar woorde sê.*

This same sibling describes her brother's frustration when portions of the dialogue are missed or when he is excluded from a conversation. She says:

Sometimes when you struggle with what my brother is trying to say to you, he gets so angry, because you don't understand him. / Partykeer as jy sukkel met wat my boetie vir jou probeer sê, word hy so kwaad, want jy verstaan hom nie.

Another sibling said of her feelings about her communication with her sibling*:*

I don't want to use sign language, because I struggle a bit. We can only talk a little bit, not much. / Ek wil nie gebaretaal praat nie, want ek sukkel 'n bietjie. Ons kan net 'n bietjie praat, nie baie nie.

One of the participants who share the same difficulty with communication with her sibling says: *It is not nice … sometimes I want to talk to her and I can't … she can't understand me. / Dis nie lekker nie … partykeer wil ek met haar praat en ek kan nie … sy kan my nie verstaan nie."*

Although the majority of participants can't speak sign language well at all, one sibling showed extremely good communication skills. Of all the participants she is the only one who has direct contact with other children with deafness. She says:

It was me myself. I learned it from all the deaf children. / Dit was ek self. Ek het dit geleer van al die dowe kinders." She seems to have a positive experience of having a sister with deafness.

One sibling said of how she experiences communication between her parents and sibling with deafness:

My mother can, but not my dad. He says she must listen with her hearing aids. That's what he tells her. He says my sister must 'talk' to him, not 'sign'. / My ma kan, maar nie my pa nie. Hy sê sy moet luister met haar apparate. Dis wat hy vir haar sê. Hy sê my sussie moet met hom 'praat', nie 'wys' nie.

It seems that the sibling with deafness is shut from the social activities because of the disability. One participant shared her concern that her sister is not realy part of the family interaction: *"… but she is most of the time by herself … writing or drawing. / … maar sy is die meeste van die tyd op skryfwerk of teken."*

Pressures and stressors in the broader social system

All the participants had concerns when they talked about issues pertaining to introducing their sibling to their friends. They also had concerns about other's perception of their sibling with deafness.

Most siblings prefer not to tell their friends about their siblings' disability. One sibling in particular found explaining to others what is "wrong" with her sister the most difficult aspect of her brother's deafness. She says that she doesn't tell her friends about her brother's deafness at all. She shares her relief that not all *her friends know about her brother's deafness by saying:*

> *When my friends come to play, he usually plays on his own … Sometimes my friends don't even get to know he is deaf because we play on our own. / As my maatjies kom speel, speel hy gewoonlik om sy eie … Partykeer vind my maatjies nie eers uit dat hy doof is nie want ons speel op ons eie.*

A second sibling expressed difficulty to tell her friends about her sister's deafness. She explains:

When my friends ask me what is wrong with my sister, I don't tell them … I say nothing / As my vriende my vra wat is fout met my sussie, sê ek niks vir hulle nie … ek sê niks.

A third participant's description of sharing her sibling's disability with others mirrored the previous particpants' experiences, but also indicated a feeling of social isolation. She said:

My friends don't know about my deaf sister. They haven't come to play at our house yet. / My maatjies weet nie van my dowe sussie nie. Hulle het nog nie by ons huis kom speel nie.

Siblings described different reactions from their friends when told about their siblings' deafness. Only one participant described her friends' reactions as feeling sorry for the sibling with deafness. She says:

When I tell people she is deaf they feel sorry for her. I feel sorry for her too. / As ek vir mense vertel dat sy doof is dan voel hulle jammer vir haar. Ek voel ook jammer vir haar.

Another participant expressed that when she tells people about her sibling's deafness *"… it's almost if they are shocked. / … dis amper of hulle geskok is."* One participant's description of how her friends feel about her brother and the fact that he is excluded from children's parties, seemed to make her feel guilty and sad. She explains:

> *Sometimes my friends like him, but other times some of them don't really like him … I don't know why … My brother doesn't really get invited to parties. / Partykeer hou my maatjies van hom, maar ander kere hou party nie regtig van hom nie … ek weet nie hoekom nie. My boetie word nie regtig na partytjies toe uitgenooi nie.*

One participant shared that her friends tease her sister as soon as they find out about her deafness. She says: *"Sometimes when I do tell them, they tease her … It makes me feel bad. … Soms as ek vir hulle vertel, dan spot hulle haar … Dit maak my sleg voel."* Another siblings' experience mirrors the previous participant's experiences. She expressed sadness at the fact that her sister is being teased and called names by her friends. She says:

My friends don't like my deaf sister, but I don't know why … She cries when my friends tell her that she looks ugly. I don't know why. They say that my sister is a pig … then I feel sad. / My maatjies hou nie van my dowe sussie nie, maar ek weet nie hoekom nie … Sy huil as my maatjies vir haar sê sy lyk lelik. Ek weet nie hoekom nie. Hulle sê my sussie is 'n vark … dan voel ek hartseer.

This same participant reported that she received positive reaction from her new friends and that they are interested in knowing how to communicate with her deaf sibling. She says of her friends*: "My new friends say I can just show them how to sign! / My nuwe maatjies sê ek kan hulle net wys hoe om te praat!"*

On the whole it seems that the siblings found it difficult to explain to other people what is wrong with their siblings with deafness, not because of a lack of knowledge but rather their fear of rejection and the need to protect their sibling. This seems to cause most of the participants a great deal of stress.

Knowledge about the disability

On the whole the participants demonstrated varied degrees of understanding the cause of the disability, but all of them knew what their sibling's disability is called.

One participant, when asked how she found out what was "wrong" with her sister and what was explained to her, she said:

> *My mother and father told me. She could hear a little bit, and then the doctor made her deafer. I don't know … that is all I can remember what my mother and father told me. / My ma en pa het vir my gesê. Sy kon 'n bietjie hoor, en toe maak die dokter haar nog 'doofer'. Ek weet nie … dis al wat ek kan onthou wat my ma en pa vir my gesê het.*

Another participant shared the uncertainty of the previous sibling regarding the cause of the sibling's deafness. She says: *"My mother told me once that when she was born, she became ill and then she became deaf. / My ma het my eenkeer gesê toe sy gebore was, het sy siek geraak en toe het sy doof geword."*

Two of the participants were vague in their explaining of the cause of their siblings' disability. These participants seem to demonstrate a limited knowledge and understanding of their sibling's deafness. However, one participant when asked to explain how her brother became deaf, gave a rich description by saying:

> *When I was small, I asked my mother why he never talks … Then she told me he is deaf. I still didn't understand it, but now I understand it better. My brother became deaf many times, and then he became totally deaf … He was in hospital, because the doctors gave him the wrong medicine. Then he got meningitis and then he became totally deaf. Then my parents had to teach him to sit and walk and everything. He was like a little baby. / Toe ek klein was, het ek my ma gevra hoekom hy nooit praat nie … Toe sê sy vir my dat hy doof is. Ek het dit toe steeds nie verstaan nie, maar nou verstaan ek dit beter. My boetie het baie keer doof geword, en toe het hy heeltemal doof geword … Hy was in die hospital, omdat die dokters die verkeerde medisyne vir hom gegee het. Toe kry hy breinvliesontsteking en toe word hy heeltemal doof. Toe het my ma-le hom geleer om te sit en te praat en alles. Hy was soos 'n klein babatjie.*

The most common source of information about their siblings' condition seems to be the mothers, closely followed by the fathers. The researcher asked the siblings if they would like to go to a "sibling workshop" which provides siblings with opportunities to meet other siblings who experience the special joys and challenges that they do, all of them felt that they could benefit from it. The need for sharing and meeting other children with the same experiences seems to be an important aspect which will be expanded upon in the final chapter.

Conclusion

The researcher constructed certain themes in her interpretation of the interview data. Primary feelings of siblings around the issue of having a brother or sister with deafness were explored and shared. In addition, the siblings shared their feelings and experience of having to disclose their sibling with deafness to others. They spoke about other difficulties, including limited family interaction due to a lack of communication. The themes and the issues that emerged within the interpretation will be discussed in the following chapter.

CHAPTER 6

DISCUSSION AND CONCLUSION

Introduction

This study aimed to explore the experiences of siblings living with a brother or sister with deafness. By identifying unique needs of such siblings, this study hopes to assist the enhancement of the effectiveness of efforts to carry out support programmes concerning siblings by generating new activities and strengthening existing ones.

In the previous chapter the themes which were identified in the data were briefly discussed and supported by excerpts from the interviews. In this discussion, the themes will be explored in more detail and discussed in light of previous research findings and as they relate to theory presented in chapter 3. In particular and where applicable, the theoretical frameworks presented by Minuchin's structural family theory and Lazarus's model of stress and coping will be included in the discussion.

Primary feelings of having a sibling with deafness

Although most siblings say that they have good relationships with their siblings with deafness, their primary feelings indicate that there are aspects of having a sibling with deafness that can be challenging. The participants described experiencing a variety of feelings which include the following: frustration, loneliness, anger, affection, resentment and pity. Similar to the participants of this study, who reported mixed feelings about their sibling with deafness, Conway (1986, in Powell and Gallagher, 1993) shares her thought provoking account of her constructions about having a sibling with a disability:

> Being the sibling of a person with a disability is a paradoxical experience. It can be stressful and difficult, but it can also impart a deep sense of meaning to life. It can provoke concern and compassion, which these days seem increasingly rare. It can also elicit feelings which are powerful and contradictory. (p. 6)

Lazarus and Folkman (1984) suggest that stress results when an individual appraises a situation as harmful, threatening or challenging. The degree of stress associated with this appraisal is dependent upon the strength of the commitment involved in the situation, with higher stress associated with more strongly-held commitments. This implies that the participants in this study, who are in strongly-held commitments with their brothers or sisters with deafness, are experiencing a high degree of stress.

According to Minuchin's Structural Family Theory (Minuchin, 1981) and Lobato (1990), a sibling subsystem serves a number of functions within the family. Lobato (1990) suggests that siblings learn emotional experience and expression within the sibling relationship (e.g. affection, love, closeness, companionship, jealousy etc.). Lobato (1990) suggests that social experience and skills are developed within the boundaries of the normal sibling relationship (e.g. negotiation, play, sharing etc.). It becomes clear why the defectiveness of a sibling subsystem in the case of having a sibling with deafness can have a negative effect on the hearing sibling's functioning and the family as a whole.

Family interaction

The siblings reported two aspects regarding family interaction which they were dissatisfied with. They feel that they are not treated the same as the sibling with deafness and that there is a lack of communication in the family.

Unequal treatment

The participants seem to feel they are treated differently to their siblings with deafness. Siblings of children with disabilities experience higher levels of anger than other siblings do (Seligman, 1983, in Powell & Gallagher, 2003). The anger may be the outcome of feeling ignored and unappreciated, because parents may spend excessive amounts of time with the disabled sibling.

When one works from the approach of Munuchin's theory of family structure, one assumes that there must be boundaries that control the type of interaction between family members and subsystems. These boundaries help family members to experience independence from the family system, but also to experience being part of the system. (Becvar &

Becvar, 2003). Some participants of this study reported that their parents give more attention to their sibling with deafness. Stated differently, the amount of interaction between the parents and the sibling subsystem are not equally divided.

Communication issues

The lack of communication in the family will generate a high level of negative emotionality, such as jealousy or unconcern, in the hearing siblings toward the deaf siblings (Marschark, 1997). The siblings in this study feel that communication is a problematic aspect within their family interaction. The participants in this study revealed that they are more likely to use sign language and nonsign gestures than their parents who often focus only on spoken communication.

A sibling relationship or subsystem where there is an extreme lack of communication due to deafness does not provide the needed opportunity to learn to interact with peers. The results of this study suggests that although a deaf and hearing sibling subsystem may be much the same as any other sibling subsystem, without a shared language

social cues will not be able to be as clear. The participants in the study reported that they would like to talk to their sibling with deafness, but that they don't understand each other.

Minuchin and Fisher (1981) emphasise that "siblings form a child's first peer group. Within this context, children support each other, enjoy, attack, scapegoat, and generally learn from each other." (p. 19). It seems that the limited interaction between the participants of this study and their siblings, affects effective experimentation with peer relationships. However, Powell and Gallagher (2003) suggest that having a sibling with a disability can have positive effects on the normally developed sibling's interpersonal skills. A sibling with a disabled brother or sister shows more compassion for all people's unique needs and abilities (Marschark, 1997).

Pressures and stressors in the broader social system

All siblings in this study report concerns when they shared their experience of having to introduce their sibling to their friends. They also have concerns about

other's perception of their sibling with deafness. It seems that the siblings found it difficult to explain to other people what is wrong with their siblings with deafness, not because of a lack of knowledge but rather because of the fear of rejection and the need to protect their sibling.

Most siblings prefer not to tell their friends about their siblings' disability. All of the siblings in this study reported being teased and shared how others' behaviour had a negative impact on them. Connors and Stalker (2003, p. 138) suggest that where siblings are teased, it is only about one aspect of their lives: having a sibling with a disability. But on the other hand, the harmful comments made could be aimed at their 'whole person'. Stated differently, Lobato (1990) suggests that siblings are important in developing self-identity. In a sibling relationship where a disability is present, the reflecting of self-identity is often the result of a third party (e.g. siblings are often teased in relation to some characteristic of their sibling's disability.) This seems to cause most of the participants a great deal of stress.

Knowledge about the disability

The participants demonstrated varied degrees of understanding the cause of the disability. On the whole, it seems that the participants need a system to gather honest and direct information about their sibling's disability and how to resolve their own problems encountered due to the presence of a disabled sibling. It seems that siblings who have brothers and sisters with a disability "need affirmation that other people understand their problems and that they are willing to help." (Gallagher, 1993, p. 79).

Conclusion

The aim of this research project was to explore the experiences of siblings of children who are deaf, in their adjustment to the family stressor of having a sibling with a disability. In South Africa and elsewhere, very little research has been done on the experience, stress and coping resources of siblings of children with deafness. Much of the research which has been conducted with the aim to explore the impact of deafness on the family, only focussed on the response of the parents or children with deafness themselves towards deafness. This has meant that

there is a limitation in research regarding how intense the emotional impact of having a sibling with deafness can be on the hearing sibling.

The value of this study

The aims of this research project have been achieved. The researcher explored and tried to understand the complex world of lived experience from the perceptions of the siblings that live and experience them. The themes which the researcher interpreted (constructed) by analysing the participants' experiences (constructions), point to the definite need for support among siblings of children with deafness.

A critique of the study

Although this study achieved its aims certain aspects could have been dealt with differently. Four of the siblings who participated in the study were predominantly younger than their sibling with deafness. It is possible that younger siblings respond to a sibling with deafness in a different way than an older sibling will. In this study, the younger siblings became competitive with their older

sibling with deafness. In contrast, the one participant who was older than her sibling with deafness did not seem competitive. Children in middle childhood may lack the cognitive skills to evaluate long-term psychological sequelae.

Another factor which could impact research results is that of the gender of the hearing siblings. In this study, all of the participants were females. Consequently, it is advised that researchers who choose to explore this area further and who aim to assess the sibling population across its broad spectrum ensure that a random sample representative of the sibling population generally is used.

Suggestions for future research

In retrospect, it seems possible that siblings of disabled children (in general) are not at risk in terms of their overall ability to cope but that they may experience difficulties which relate to disability itself. Stated differently, siblings of children with deafness may have different experiences (constructions) and needs than those who have brothers or sisters with another type of disability. More specifically, other studies focussing on

siblings from children who are severely intellectually challenged, report that the siblings experience fear of getting married and having disabled children themselves or the need to succeed to reassure them that they are not deficient in any way. None of the mentioned concerns were reported by the participants in this study. Areas such as those mentioned above, then, are possibly where the researcher in the field of disability needs to focus on in the future.

Finally, there is a need for the development of an effective contextualised program that gives siblings of children with deafness an opportunity for peer support. Participants in this study experienced the impact of having a brother or sister in many different ways. The variety of constructions (experiences) has to be recognised in order to plan an effective intervention plan. It is suggested that future researchers develop, implement and evaluate such a program.

Meyer and Vadasy (1994) suggest the development of a program called a “sibshop” that provide siblings of children with special needs a chance to meet other siblings of children with special needs. Sibshops also provide the

parents and other professionals the opportunity to understand the concerns and needs of brothers and sisters of children with special needs. Because communication seems to be such a great stressor for siblings, it is suggested that the teaching of sign language forms part of such a programme.

Concluding remark

While we, the researchers, are busy constructing the "perfect" accounts of the reality experienced by those we care to study, we should keep in mind that we are included in, rather than outside the borders of our own study. I would like to conclude this study with a quote by Heinz von Foerster (in Poerksen, 2004) on the themes of the observer and constructivist philosophy of distinctions:

> Every human being is tied into a social network, no individual is an isolated wonder phenomenon but dependent on others and must – to say it metaphorically – dance with others and construct reality through communality. The embedding into a social network necessarily leads to a reduction of arbitrariness through communality; however, it does

not at all change the essentially given freedom. We make appointments, identify with others and invent common worlds – which one may give up again. The kinds of dance one chooses along this way may be infinitely variable. (pp. 19-20)

List of references

Anderson, H. (1997). *Conversation, language and possibilities: a postmodern approach to therapy.* New York: Basic Books.

Atkins, D. V. (1987). Siblings of the hearing-impaired: Perspectives for parents. *The Volta Review, 89(5)*, pp. 32-45.

Barnard, J. P. (2004). MIV-positiewe huiswerksters se konstruering van hul ervarings van MIV & VIGS binne die werkgewersgesin. Master's thesis, University of Pretoria, Pretoria.

Becvar, D. S. & Becvar, R. J. (2003). *Family therapy: a systemic integration* (5th ed.). Boston: Allyn and Bacon.

Bubolz, M. M. & Whiren, A. P. (1984). The family of the handicapped: an ecological model for policy and practice. *Family Relations, 33,* pp. 5-12.

Calderon, R. & Greenberg, M. T. (1999) Stress and coping

in hearing mothers of children with hearing loss: Factors affecting mother and child adjustment. *American Annals of the Deaf, 144 (1),* pp. 7-18.

Carter, B. & McGoldrick, M. (1999). Overview: The expanded family life cycle: individual, family and social perspectives. In Carter, B. & McGoldrick, M. (Eds.), *The expanded family life cycle: Individual, family and social perspectives* (pp. 1-25). Boston: Allyn and Bacon.

Chadwick, B. A., Bahr, H. M. & Albrecht, S. L. (1984). *Social science research methods.* New Jersey: Prentice Hall.

Charmaz, K. (2000). Grounded Theory: Objectivist and Constructivist Methods. In Denzin, N. K. & Lincoln, Y. Z. (Eds.), *Handbook of Qualitative Research*, (2nd ed., pp. 509-535). California: Sage Publications.

Cicirelli, V. G. (1995). *Sibling relationships across the life span.* New York: Plenum Press.

Coffey, A. & Atkinson, P. (1996). *Making sense of*

qualitative data: Complimentary research strategies. Thousand Oaks : Sage.

Crnic, K.A., Friedrich, W. N. & Greenberg, M. T. (1986). Adaptation of Families with Mentally Retarded Children: A Model of Stress, Coping, and Family Ecology. *American Journal of Mental Deficiency, 88(2)*, pp. 125-138.

Denzin, N. K. & Lincoln, Y. S. (2000). Introduction: The Discipline and Practice of Qualitative Research. In Denzin, N. K. & Lincoln, Y. Z. (Eds.), *Handbook of Qualitative Research,* (2nd ed., pp. 1-27*)*. Thousand Oaks, California: Sage Publications.

Dey, I. (1997). *Grounding grounded theory: Guidelines for qualitative enquiry* (pp. 16-17). Londen: Academic Press.

Dunn, J. (1993). *Young Children's Close Relationships: Beyond Attachment*. California: Sage Publications.

Dunn, J. & Kendrick, C. (1982). *Siblings*. London: Grant McIntyre Ltd.

Dunst, C., Trivette, C. & Deal, A. (1988). *Enabling and Empowering Families.* Cambridge: Brookline Books.

Eder, D. & Fingerson, L. (2001). Interviewing children and adolescents. In N. K. Denzin & Y. Z. Lincoln (Eds.), *Handbook of Qualitative Research*, (2nd ed., pp. 181-198). California: Sage Publications.

Efran, J. S., Lukens, R. J. & Lukens, M. D. (1992).Constructivism: what's in it for you? In R. Simon, C. Barrileaux, M. S Wylie, & L. M. Markowits (Eds.), *The evolving therapist. Ten years of the Family Therapy Networker* (pp. 265-277). New York: The Guildford Press.

Fischer, J. & Roberts, S.C. (1983). The Effect of the Mentally Retarded child on his siblings. *Education, 103*, pp. 399-401.

Fisiloglu, A. G. & Fisiloglu, H. (1996). Turkish families with deaf and hard of hearing children: A systems approach in assessing family functioning. *American Annals of the Deaf. 141(3)*, pp. 231-234.

Gaines, R. & Halpern-Felsher, B. L. (1995). Language preference and communication development of a hearing and deaf twin pair. *American Annals of the Deaf. 140,* pp. 47-55.

Garbers, J. G. (1996). *Effective research in the human sciences.* Pretoria: van Schaik.

Gardner, R. A. (1993) *Psychotherapy with children*. New York: The Guildford Press.

Gergen, K. & Gergen, M. (1991). Toward a cultural constructivist psychology. *Theory and Psychology. 7,* pp. 31-36.

Glaser, B. G. & Strauss, A. L. (1995). The Discovery of Grounded Theory: Strategies for Qualitative Research. New York: Aldine de Gruyter.

Goldenberg, I. & Goldenberg, J. (2004). *Family therapy: an overview (6th ed.).* Pacific Grove, CA: Brooks/Cole.

Goode, D. (1994). *A world without words: The social*

construction of children born deaf and blind. Philadelphia: Temple University Press.

Gregory, S. (1995). *Deaf children and their families.* Great Britain: Cambridge University Press.

Hartshorne, T. S. (2002). Mistaking courage for denial: family resilience after the birth of a child with severe disabilities. *The Journal of individual Psychology, 58(3),* pp. 263-277.

Institute for the Deaf. (2004*). Africa declaration on Mental Health and Deafness.* Retrieved on 25 May 2005 from http://www.deafnet. co.za/article/150.

Isrealite, N. K. (1986). Hearing impaired children and the psychological functioning of their normal hearing peers. *The Volta Review. 86 (1),* pp. 47-54.

Janesick, V. H. (1998). The dance of Qualitative Research Design. Metaphor, Methodolatry and meaning. In N. K. Denzin & Y. Z. Lincoln (Eds.), *Strategies of Qualitative Research* (pp. 35-55*)*. Thousand Oaks, California: Sage Publications.

Kelly, K. (2002). Hermeneutics in action: empathy and interpretation in qualitative research. In M. Terre Blanche & K. Durrheim (Eds.), *Research in practice: Applied methods for the social sciences* (2nd ed., pp. 398-420). Cape Town: University of Cape Town Press.

Kvale, S. (1996). *Interviews: An Introduction to Qualitative Research Interviewing.* Thousand Oaks, California: Sage Publications.

Lazarus, R. S. & Folkman, S. (1984). *Stress, appraisal and coping.* New York: Springer.

Liddle, H. A., Breunlin, D. C. & Schwartz, R. C. (1988). Introduction. In H. A. Liddle, D. C. Breunlin, & R. C. Schwartz (Eds.), *Handbook of family therapy, training and supervision* (pp. 13-16). New York: The Guilford Press.

Lobato, D. J. (1990). *Brothers, sisters and special needs.* Baltimore: Paul Brokes Publishing.

Lobato, D. J., Meyer, E. C. & Prizant, B. M. (1997).

Brothers and sisters of Young Children with Communication Disorders. *Seminars in Speech and Language, 18(3)*, pp. 263-279.

Marschark, M. (1997). *Raising and Educating a Deaf Child.* New York: Oxford University Press, Inc.

Mchale, S. M. & Crouter, A. C. (1996). The family contexts of children's sibling relationships. In G. H. Brody (Ed.), *Sibling relationships: their causes and consequences* (pp. 173-195). New Jersey: Ablex Publishing Corporation.

Meyer, D. J. & Vadasy, P. F. (1994). *Sibshops: workshops for siblings of children with special needs*. Londen: Paul H. Brooks Publishing Co., Inc.

Mittler, H. (1995). Families speak out: international perspectives on families' experiences of disability. Cambridge, MA: Brookline Books.

Motala, R. (2000). The impact of deafness on the family:

a case study of a child with a prelingual hearing impairment. Unpublished Master's thesis, University of Durban, Westville.

Monat, A., & Lazarus, R. S. (1991). Stress and coping: Some current issues and controversies. In A. Monat & R. S. Lazarus (Eds.), *Stress and Coping: An Anthology* (3rd ed., pp. 1-15). New York: Columbia University Press.

Minuchin, S. (1974). *Families and family therapy.* Cambridge : Harvard University Press.

Minuchin, S. & Fishman, H. C. (1981). *Family Therapy Techniques.* Cambridge, Mass: Harvard University Press.

Orford, J. (1987). Integration: A general account of families coping with disorder. In J. Orford (Ed.), *Coping with disorder in the family* (pp. 266-293). Great Britain, Worcester: Billing & Sons Limited.

Patton, M. Q. (1990). *Qualitative Evaluation Research Methods* (2nd ed.). Newbury Park: Sage Publications.

Poerksen, B. (2004). *The certainty of uncertainty: Dialogues introducing constructivism*. Charlottesville, USA: Imprint Academic.

Powell, T. & Gallagher, P. A. (1985). *Brothers and Sisters: A special part of exceptional families* (2nd ed.). London: Paul Brookes.

Ross, E. (1990). *Young adult deaf persons' transactions with ecological systems: Effects on self-esteem.* Unpublished Master's thesis. University of the Witwatersrand, Johannesburg.

Schwandt, T. A. (1997). *Qualitative Inquiry: A dictionary of terms*. Thousand Oaks, California: Sage Publications.

Seligman, M. & Darling, R. B. (1989). *Ordinary families, special children: A systems approach to childhood disability.* London: The Guilford Press.

Siegel, B. & Silverstein, S. (1994). *What about me? Growing up with a developmentally disabled sibling*. New York: Plenum Press.

Snape, D. & Spencer, L. (2003). The foundations of qualitative research. In J. Ritchie & J. Lewis (Eds.), *Qualitative research practice: A guide for social science students and researchers* (pp. 1-22). London: Sage.

Spencer, P. E. & Erting, C. J. (2000). *The deaf child in the family and at school: essays in honour of Kathryn P. Meadow-Orleans.* New York: Lawrence Erlbaum Associates, Inc., Publishers.

Stafford, L., & Dainton, M. (1995). Parent-child communication within the family system. In T. J. Socha & G. L. Stamp (Eds.), *Parents, children and communication: Frontiers of theory and research* (pp. 3-22). New Jersey: Lawrence Erlbaum Associates.

Steier, F. (1991). *Research and reflexivity.* London: Sage Publications.

Strauss, A. & Corbin, J. (1998). *Basics of qualitative*

research: Techniques and procedures for developing grounded theory. Thousand Oaks, California: Sage Publications.

Terre Blanche, M. & Kelly, K. (2002). Interpretive methods. In M. Terre Blanche & K. Durrheim (Eds.), *Research in practice: Applied methods for the social sciences* (2nd ed., pp. 123-146). Cape Town: University of Cape Town Press.

Turnbull, A. P. (1988). The challenge of providing comprehensive support to families. *Education and training in mental retardation, 23,* pp. 261-272.

Von Glasersfeld, E. (1991). *Radical constructivism in mathematical education.* Dordrecht, Netherlands: Kluwer Academy.

Watzlawick, P. (1984). *The invented reality: How do we know what we believe to know?* New York: Norton.

Yura, M. T. (1987). Family subsystem functions and disabled children: Some conceptual issues. *Marriage and Family Review, 11,* pp. 135-151.

ANNEXURE A

AUTHORIZATION LETTER FROM AUTHORITIES

Department of Education

ANNEXURE B

INFORMATION BROCHURE

(Afrikaans version used)

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INLIGTINGSBROSJURE EN TOESTEMMINGSDOKUMENT

(Moet deur die ouer/voog van die kind voltooi word.)

(Elke ouer/voog wie se seun/dogter in die studie betrek gaan word moet hierdie dokument ontvang, lees en begryp alvorens daar met die studie begin mag word.)

1. WAT IS DIE NAVORSER SE KONTAKBESONDERHEDE?

Indien u vooraf of tydens die verloop van hierdie studie graag met die navorser kontak wil maak kan u vir Liezl Schreuder by die volgende telefoon nommers skakel:

- Selfoon : 072 4142606
- Huis : 012 253 1565
- Werk : 012 386 6072

2. TITEL VAN DIE STUDIE

Die ervarings en persepsies van horende susters/broers rakende die impak van ‘n broer/suster met Doofheid op hom/haar binne die gesin en oor die algemeen.

3. INLEIDING

U horende kind word uitgenooi om vrywillig aan bogenoemde navorsingsprojek deel te neem. Die doel van hierdie dokument is om u te help besluit of u u kind aan die studie wil laat deelneem. Voordat u onderneem om u kind aan hierdie studie te laat deelneem, moet u eers verstaan wat die studie sal behels. Indien u nie heeltemal gemaklik voel met die studie en metodes wat gevolg gaan word nie, moet u asseblief nie onderneem om u kind aan die studie te laat deelneem nie. Indien u verdere vrae het moet u nie huiwer om die navorser te kontak nie.

4. WAT IS DIE DOEL VAN HIERDIE STUDIE?

U het ‘n kind met Doofheid asook ‘n ander kind/kinders wat wel horend is. Die navorser is ‘n geregistreerde intern voorligting sielkundige en vra u om te oorweeg dat u horende kind/ers aan ‘n navorsingsprogram deelneem om inligting te bekom oor watter ervarings en persepsies u horende kind het rakende die impak van ‘n broer/suster met Doofheid op hom/haar binne die gesin en oor die algemeen. Die navorser wil ook probeer vasstel of u horende kind/kinders moontlik bekommernisse of spesiale behoeftes het, waarvan u moontlik nie bewus is nie.

5. HOE LANK SAL HIERDIE STUDIE DUUR?

Daar sal twee kontaksessies tussen die navorser en u horende kind/kinders, op ‘n plek wat vir u kind gemaklik is, gereël word. Tydens die eerste sessie sal die navorser haarself aan u kind/ers bekend stel en verhouding met hom/haar stig. Tydens die tweede sessie sal die navorser met u kind/ers ‘n individuele onderhoud voer. Hierdie individuele onderhoud sal ongeveer 90 minute duur.

6. WATTER METODES EN PROSEDURES GAAN GEBRUIK WORD?

Tydens die individuele onderhoud, sal die navorser 12 vrae aan u kind vra en versoek dat hy/sy dit so eerlik moontlik beantwoord. Omdat dit moeilik is om ‘n hele onderhoudsgesprek akkuraat neer te skryf, versoek die navorser dat u toestemming gee dat die onderhoud op ‘n oudioband opgeneem mag word. Dit sal slegs as ‘n hulpmiddel dien om te verseker dat die navorser u kind se bydrae korrek kan integreer met die navorsingstudie. Hierdie oudiobandopname sal onder geen omstandighede aan ander persone gegee word nie. Indien u of u kind nie gemaklik voel met die gebruik van ‘n oudiobandopnemer nie, het u die reg om dit te weier. Indien dit wel die geval is, sal die navorser die onderhoud so akkuraat moontlik probeer neerskryf. U kind en gesin se identiteit sal onder geen omstandighede bekend gemaak word nie.

Op grond van die inligting wat u kind/kinders en ander soortgelyke kinders van ander gesinne aan die navorser gee, sal sy kan vasstel watter ervarings en persepsies horende kinders het rakende die impak van ‘n broer/suster met Doofheid op hom/haar binne die gesin en oor die algemeen. Die inligting sal deur die navorser gebruik word om ‘n navorsingsverslag op te stel.

7. IS HIERDIE STUDIE OP ETIESE GRONDE GOEDGEKEUR?

Die protokol van die genoemde studie sal aan die Navorsingsetiek Komitee van die Universitiet van Pretoria voorgelê word alvorens die studie mag begin.

8. FINANSIëLE REëLINGS TEN OPSIGTE VAN HIERDIE STUDIE

Deelname aan hierdie studie sal vir u of u kind geen finansiële vergoeding of onkostes meebring nie. Die navorser onderneem hierdie studie om te voldoen aan die vereistes vir die meestersgraad in Voorligting Sielkunde en sal dus geen finansiële vergoeding vir hierdie projek ontvang nie.

9. WAT IS U KIND/ERS SE REGTE AS DEELNEMER(S) AAN HIERDIE STUDIE?

U kind/kinders se deelname aan hierdie studie is vrywillig en hy/sy kan weier om deel te neem. U kind/ers se deelname aan hierdie studie kan enige tyd op u versoek gestaak word sonder dat u of u kind redes daarvoor aan die navorser hoef te verskaf. Die navorser het ook die reg om, indien u kind se deelname aan hierdie studie nie in haar/sy belang blyk te wees nie, u kind van die studie te onttrek.

10. HOE GAAN VERTROULIKHEID IN HIERDIE STUDIE HANTEER WORD?

Alle inligting wat die navorser tydens hierdie studie bekom is streng vertroulik. Die navorser mag ‘n navorsingsverslag en/of ‘n wetenskaplike artikel vir publikasie skryf om die bevindinge weer te gee, sonder om u kind of gesin se identiteit bekend te maak.

ANNEXURE C

CONSENT FORM

(Afrikaans version used)

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MAMELODI CAMPUS

TOESTEMMINGSVORM

Hiermee gee ek, …….……, ouer/voog van ……......, toestemming dat my kind/kinders vrywilliglik aan hierdie studie mag deelneem:

Ouer/voog se naam:_____(Drukskrif asseblief)

Ouer/voog se handtekening:_____

Datum:_____

Hiermee gee ek, …….……, ouer/voog van …….…..., toestemming / nie toestemming dat die navorser 'n oudiobandopname mag gebruik / nie mag gebruik nie:

Ouer/voog se naam :_____(Drukskrif asseblief)

Ouer/voog se handtekening :_____

Datum :_____

Navorser se naam :_____(Drukskrif asseblief)

Navorser se handtekening :_____

Datum :_____

Die getuie moet asseblief teenwoordig wees gedurende die voltooing van hierdie toestemmingsdokument:

Die getuie se naam :_____(Drukskrif asseblief)

Die getuie se handtekening :_____

Datum :_____

Dankie dat u die tyd geneem het om hierdie inligtingsbrosjure te lees en die toestemmingsdokument in te vul en te onderteken.

ANNEXURE D

SEMI-STRUCTURED QUESTIONNAIRE

(Afrikaans version used)

Onderhoud: Semi-gestuktureerde vrae

Vraag 1: Ek wil vandag met jou gesels oor jou broers en/of susters. Hoeveel broers en susters het jy?

Vraag 2: Vertel my ‘n bietjie meer van X (broer of suster met doofheid)?

Vraag 3: Het iemand jou al vertel hoekom X nie kan hoor nie?

Vraag 4: Hoe voel jy daaroor om ‘n boetie of sussie te hê wat doof is?

Vraag 5: Wat vertel jy jou maatjies van X? Wat weet hulle van X en sy/haar doofheid?

Vraag 6: Wat sê hulle dan?

Vraag 7: Van al jou boeties en sussies, met wie baklei jy die meeste?

Vraag 8: Wie in julle huis kan gebare taal praat?

Vraag 9: Hoe sou dit wees as X en jy kon gesels?

Vraag 10: Watter speletjies speel jy en X? Wat doen julle gesin op ‘n naweek?

Vraag 11: As jy drie wense kon wens, watter drie sou dit wees en hoekom?