

Abstract

**THE COPING RESPONSES OF THE ADOLESCENT SIBLINGS OF  
CHILDREN WITH SEVERE DISABILITIES**

The objective of this study was to describe the coping responses of the adolescent siblings of children with severe disabilities in their adjustment to the family situation of having a sibling with a disability. Open-ended structured interviews were conducted with the children at their homes. These interviews were aimed at obtaining information regarding the subjects' perceptions of having a sibling with a severe disability, the available family resources, and their coping responses in adjusting to the situation.

by

**Sannette Beatrix Opperman**

**Submitted in partial fulfillment of the requirements for the degree**

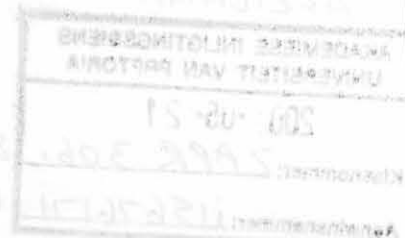
of

**MA in AAC**

in the

**Faculty of Humanities, University of Pretoria**

**October 2000**



## Abstract

The objective of this study was to describe the coping responses of the adolescent siblings of children with severe disabilities in their adjustment to the family stressor of having a sibling with a disability. Open-ended, structured interviews were conducted with the subjects at their homes. These interviews were aimed at obtaining information regarding the subjects' appraisal of the stressor of having a sibling with a severe disability; their available coping resources; and their coping responses in adjusting to the situation.

The subjects reported limited family interaction and it was found that they were not freely expressing their feelings about their sibling with a disability. The subjects and their parents have received limited professional support regarding their siblings' disabilities and its consequences. The young adolescents experienced feelings of guilt regarding their feelings about their siblings with disabilities. The results of this study have shown that the parents and siblings of children with severe disabilities, 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 a disability.

Further research is recommended to describe the sibling relationships of young adolescents with normal siblings, to provide comparative data for the present study.

# TABLE OF CONTENTS

## Acknowledgements

I thank God for His grace in helping me to finish this research project. I would also like to thank the following people:

- Professor Alant for her expert knowledge, patience, time and motivation
- The adolescent siblings of the children with severe disabilities for their willingness to participate in this study
- The parents of the adolescent siblings that participated in the project, for their permission to conduct the interviews and for the information they provided themselves
- Mrs Jean Greyling for the language check
- Mrs Cynthia Kleingeld for the editing of the study
- My friends for their support
- My family and Cobus for their support and love

2.4	Social support networks	19
2.5	Summary	20
<b>CHAPTER 3 : METHODOLOGY</b>		
3.1	Aims	21
3.1.1	Main aim	21
3.1.2	Sub-aims	21
3.2	Research design	22
3.3	Subject selection	22
3.3.1	Selection criteria	22
3.3.2	Method of selection	23
3.3.3	Descriptive criteria	24
3.3.3.1	Description of the children with severe disabilities	24
3.3.3.2	Description of the adolescent siblings of the children with severe disabilities	27
3.4	Pilot study	28
3.5	Main study	30
3.5.1	Data collection procedures	32
3.5.1.1	Data collection procedures regarding the children with severe disabilities	32
3.5.1.2	Data collection procedures regarding the parents of the subjects	32
3.5.1.3	Data collection procedures regarding the subjects	33

# TABLE OF CONTENTS

## ABSTRACT

## CHAPTER 1 : INTRODUCTION

Outline of chapters .....	3
Abbreviations .....	3
Definitions of terminology .....	4

## CHAPTER 2 : LITERATURE REVIEW

2.1 Introduction .....	6
2.2 Factors impacting on the siblings' experience of having a brother/sister with severe disability.....	7
2.2.1 The sibling system as part of the family system .....	8
2.3 Models of familial stress & adaptation.....	11
2.3.1 Lazarus' model of family stress .....	11
2.3.2 The Double ABCX Model of Adjustment & Adaptation .....	13
2.3.3 An Adaptation Model .....	14
2.3.3.1 Defense Mechanisms .....	15
2.3.3.2 Coping .....	16
2.4 Social support networks .....	18
2.5 Summary .....	20

## CHAPTER 3 : METHODOLOGY

3.1 Aims .....	21
3.1.1 Main aim .....	21
3.1.2 Sub-aims .....	21
3.2 Research design .....	22
3.3 Subject selection .....	22
3.3.1 Selection criteria .....	22
3.3.2 Method of selection .....	23
3.3.3 Descriptive criteria .....	24
3.3.3.1 Description of the children with severe disabilities.....	24
3.3.3.2 Description of the adolescent siblings of the children with severe disabilities.....	27
3.4 Pilot study .....	28
3.5 Main study .....	32
3.5.1 Data collection procedures .....	32
3.5.1.1 Data collection procedures regarding the children with severe disabilities.....	32
3.5.1.2 Data collection procedures regarding the parents of the subjects .....	32
3.5.1.3 Data collection procedures regarding the subjects.....	33

3.5.2	Material for data collection .....	34
3.5.2.1	Questionnaire for parents .....	34
3.5.2.2	Material for the interviews .....	34
3.6	Data analysis and interpretation .....	38
3.6.1	Reliability and validity of category ratings .....	45
3.7	Summary .....	46

## CHAPTER 4 : RESULTS AND INTERPRETATION

4.1	Results as obtained from the questionnaire for parents .....	47
4.2	Results as obtained during the interviews with subjects .....	49
4.2.1	The subjects' primary feeling about having a sibling with a disability .....	50
4.2.2	The subjects' feeling about family interaction, regarding the influence of the sibling with a disability .....	51
4.2.3	The available social support networks .....	53
4.2.4	The subjects' knowledge of the disability .....	56
4.2.5	The subjects' expression of his/her feelings about the sibling with a disability .....	57
4.2.6	The subjects' future expectations regarding their sibling with disabilities .....	60
4.2.7	The subjects' perceptions of how others view their siblings with disabilities .....	62
4.2.8	The subjects' perceptions of how they are viewed by their peers .....	64
4.2.9	Conflict situations within the family and conflict resolution...	65
4.3	Summary .....	66

## CHAPTER 5 : CONCLUSION AND RECOMMENDATIONS

5.1	Conclusion .....	69
5.2	Critical evaluation of this study .....	70
5.3	Recommendations .....	71
5.3.1	Implications of further research .....	71
5.3.2	Implications for clinical practice .....	72

<b>BIBLIOGRAPHY</b> .....	73
---------------------------	----

### LIST OF APPENDICES:

<b>APPENDIX A</b>	Questionnaire for parents .....	81
<b>APPENDIX B</b>	Questionnaire for siblings .....	95
<b>APPENDIX C</b>	Examples of transcribed interviews .....	102

# LIST OF FIGURES AND TABLES

## LIST OF TABLES

Table 3.1	Explanation of and motivation for selection criteria .....	23
Table 3.2	Description of the children with severe disabilities .....	26
Table 3.3	Research motivating the descriptive criteria of the subjects .....	27
Table 3.4	Description of the subjects .....	28
Table 3.5	Description of the subjects for the pilot study .....	29
Table 3.6	Aims, methods and recommendations of the pilot study .....	30
Table 3.7	Explanation and motivation of the categories of the questionnaire for parents .....	34
Table 3.8	Explanation of the preformulated questions for the interviews .....	36
Table 3.9	Explanation of the categories for data analysis .....	41
Table 3.10	Inter-rater reliability on categories rated .....	45
Table 4.1	Professional support received by the families of the subjects .....	48
Table 4.2	The subjects' primary feelings about having a sibling with a disability .....	50
Table 4.3	The subjects' feelings about family interaction .....	51
Table 4.4	The subjects' social support networks .....	53
Table 4.5	The subjects' expression of their feelings regarding the sibling with a disability .....	58
Table 4.6	The subjects' feelings of guilt .....	59
Table 4.7	The subjects' future expectations regarding their siblings with disabilities .....	60
Table 4.8	The subjects' perceptions of how others view their sibling with disabilities .....	63
Table 4.9	The subjects perception of how they are viewed by their peers .....	64
Table 4.10	Familial conflict and conflict resolution .....	65

## LIST OF FIGURES

Figure 3.1	The editing analysis style .....	38
Figure 4.1	The subjects' knowledge of the disability .....	56

# CHAPTER 1

## INTRODUCTION

Raising a child with a severe disability places demands on the whole family. Traditionally the focus was primarily on supporting the parents of the child with a disability and little or no attention was given to the siblings. The last decade however, has marked a shift from parent-child centred services only, towards family-child centred services, which includes the siblings of the children with disabilities.

This move towards family-centred services for children with disabilities, has created new challenges for professionals, as the needs of the child with a disability as well as those of the other children in the family have to be addressed.

Families are also influenced by factors such as the health, development and characteristics of the child with a disability, the characteristics of the sibling with a disability, the number of siblings in the family, general stressors affecting the family, parental attitudes and the family's available social support network.

Although the siblings experience some concerns or issues regarding their brother's or sister's disability, the presence of these concerns does not imply that all their coping responses and reactions are pathological or negative. Literature has documented the positive effects that result from having a sibling with a disability (Powell & Gallagher, 1993; Siegel & Silverstein, 1994). It is, however, important to address and understand these issues and concerns experienced by siblings.

Siblings need to be well informed with regard to their sibling's disability and its consequences. They have to gain an understanding of the disability, in order to cope with the stressor of having a sibling with a disability. Siblings may experience jealousy and feelings of anger towards their brothers or sisters with disabilities, which in turn cause them to feel guilty. They may also feel that their needs are overlooked and that their accomplishments are taken for granted. This input may

Some siblings of children with disabilities experience a sense of loneliness and isolation, which is influenced by the appearance and behaviour of the child with a disability and the reactions of peers and others. The siblings' own perceptions of the disability may cause them to cope with these stressors by withdrawing or developing behavioural problems.

Factors related to the disability itself can also impact on sibling relationships. These factors include the severity of the disability, the need for specialised care, health concerns and behavioural issues. The severity of the disability and the resulting care-giving demands, as well as disruptive behaviour, appear to affect the adjustment of the other siblings (Powell & Gallagher, 1992; Frank, 1996).

In spite of the above issues raised in relation to siblings of children with severe disabilities, little is known regarding the perceptions of adolescent siblings of children without disabilities. Adolescents may perceive the situation differently from what they did in early childhood, as adolescents strive towards independence and autonomy from their family members and may employ different strategies for coping with having a sibling with a disability.

It is important to identify the responses adolescents employ in coping with the reality of having a sibling with a disability. In identifying the coping responses of the adolescent siblings of children with severe disabilities, it is also necessary to consider those factors that mediate the impact that the sibling with a disability has on their lives. These factors include parental attitudes, social support, personal beliefs, etc.

By studying the coping responses of the adolescent siblings of children with disabilities, one can identify their needs, as well as the family's needs with regard to coping with and adjusting to the stress induced by the presence of a child with a disability.

It is against this framework that the present study investigates the impact of children with disabilities on the lives of their siblings. The coping responses of the adolescent



siblings of children with severe disabilities will be described, as well as the factors that mediate the impact on their lives.

## **Outline of chapters**

*Chapter 1* is the introduction to the study and serves to state the research problem and motivate the study. It also includes a list of abbreviations and definitions of terms.

*Chapter 2* is the literature review for this study and focuses on the stress the adolescent siblings of children with disabilities may experience. Stress and coping are discussed within the framework of different theoretical models of stress and coping.

*Chapter 3* describes the method of data collection and analysis. Qualitative methods were used. The data was collected by means of interviews with the adolescent siblings of children with severe disabilities.

*Chapter 4* provides a discussion of the results according to the categories that were set for data analysis.

*Chapter 5* provides concluding remarks and recommendations for further research and clinical practice are also made.

## **Abbreviations**

**AAC** : Augmentative and Alternative Communication

**ADL** : Activities of daily living

**SES** : Socio-economic status

**TASH** : The Association for Persons with Severe Handicaps

## **Definitions of terminology**

### **Adaptation**

Adaptation takes place when an individual employs coping resources in an effort to maintain a balance in personal functioning.

### **Ambivalence**

Ambivalence can be described as a differentiated range of emotions regarding the same issue.

### **Children with severe disabilities**

Children with severe disabilities are defined as individuals who need continuous support in one or more area of life.

### **Cognitive appraisal**

Cognitive appraisal is the process by which individuals ascribe meaning to an event or encounter.

### **Coping resources**

Coping resources are factors used by individuals to mediate the adverse effects of events that are appraised as being stressful.

### **Coping responses**

Coping responses are cognitive and behavioural efforts to manage events that are appraised as being stressful.

### **Defense mechanisms**

Defense mechanisms are strategies that protect individuals from overwhelming anxiety and help the individual to maintain a psychological equilibrium under stressful conditions.

### **Egocentrism**

Egocentrism is a child's limited perspective at each new phase of development. In young adolescents it is reflected by an inability to recognise that others do not necessarily share one's own ideas.

**Social support networks**

Social support networks are social concentric structures in an individual's life of which the individual and his/her family forms the innermost level, which is embedded in broader ecological systems, including friends, relatives, etc. These structures function interchangeably.

**Stress**

Stress can be described as any event in which environmental demands, internal demands, or both, exceed the individual's adaptive resources.

**Young adolescents**

Young adolescents are 12-15 years old and this phase starts with the onset of puberty.

## CHAPTER 2

# LITERATURE REVIEW

This literature review entails a general discussion of literature regarding the impact of children with disabilities on their siblings within specific familial situations. The focus is specifically on the adolescent siblings of children with severe disabilities and their responses in adjusting to this situation. The adolescent siblings' coping responses will be discussed within the framework of different models of family stress and coping. In discussing these models, coping responses can be identified, in order to describe the responses of these siblings in coping with the fact that they have a sibling with a severe disability. These responses may include feelings of guilt, projection of negative feelings, etc.

### 2.1. Introduction

Literature dealing with the effects of having a disabled sibling, shows positive, negative and mixed results regarding the sibling relationships and possible factors contributing to the varied outcome (Lobato, 1990; Powell & Gallagher, 1992; Siegel & Silverstein, 1994). These varied outcomes in sibling relationships, can't be explained only in terms of birth order, age differences or gender. Siblings influence one another in complex and multifactorial ways. The affectionate quality of the sibling relationships, family interaction and communication style, the children's personality characteristics and the parent-child relationships impact on the process (Frank, 1996).

Sibling interaction operates as part of the family system and involves a dyadic interchange between siblings. It is rooted in ambivalence, because it encompasses

sibling rivalry and psychological closeness, care taking and socialisation (Bryant & Litman, 1987). Children's interpretations of their siblings' behaviour and problems are vitally important in understanding when and why children display problems in coping. Sibling relationships that are characterised by negative behaviour, leave siblings feeling anxious and depressed, with fewer mental coping strategies (McHale & Gamble, 1987).

## **2.2. Factors impacting on the siblings' experience of having a brother or sister with a severe disability**

Siblings' adjustment to having a brother or sister with a severe disability, seems to be influenced by variables such as family size, the family's socio-economic status and their religious beliefs (Powell & Gallagher, 1992; Marsh, 1992; Siegel & Silverstein, 1994).

In studies that have been done on siblings' adjustment and adaptation to having a brother or sister with a disability in the family, results suggest that siblings from larger families are better adjusted, provided the family has adequate financial resources. Siblings of lower socio-economic status may be overburdened with extra care giving responsibilities. A family with a better socio-economic status may be able to access care services and a range of professionals to provide in possible family needs. In general it also seems as if siblings adjusted better if the age gap between siblings is bigger (Fischer & Roberts, 1983; Dyson, 1989).

The type of disability has a marked effect on the other siblings' acceptance and adjustment to having a disabled sibling. (Fischer & Roberts, 1983; Dyson, 1989). However, Breslau (1981) found no relationship between the type and severity of disability and the psychological functioning of the siblings. According to Siegel & Silverstein (1994), the severity of the behavioural problems of the children with disabilities, seems more predicative of distress in family members, than the severity of the disability itself, although children with more severe disabilities tend to have more disruptive behaviour and require more care-giving responsibilities.

Religious beliefs affect parents' responses to the birth of a child with a disability. There is a positive correlation between religious background and parental acceptance of their child's disability (Powell & Gallagher, 1992; Siegel & Silverstein, 1994). According to McHale et al. (1986), sibling relationships are more positive, if future concerns regarding the sibling, feelings of rejection and parental favouritism are perceived as minimal by the siblings of children with severe disabilities. Children tend to adopt their parents' attitude toward the sibling with a disability. Siblings of children with a disability adjust better if they have an open channel of communication with their parents. If the siblings are able to express their feelings, misunderstandings and communication breakdown are prevented within the family system (McHale & Gamble, 1987; Powell & Gallagher, 1992; Siegel & Silverstein, 1994).

### **2.2.1 The sibling system as part of the family system**

The successful growth and development of a child with a disability requires the restructuring of roles for the entire family system. However, it is important to indicate that successful family functioning and sibling relationships can manifest in different ways. Clinicians need to be aware of the range of adaptive family functioning if they want to capitalise on family strengths in their intervention efforts (Kazak & Marvin, 1985).

A combination of factors seems to be important indicators of which families could experience stress and anxiety. These factors include the presence of multiple stressors, the life-cycle stage of the family, the family's interpretation of the situation and the integration of the family prior to the birth of the child with a disability (Byrne & Cunningham, 1985). Families use different coping strategies, which depends on the structure of the family unit, relationships within the family and the material, psychological and social resources available to the family as potential contributors to the process of coping. Familial adaptation must therefore be seen in a comprehensive and descriptive manner, which accounts for familial and individual differences and the factors that influence them (Crnic, Friedrich & Greenberg, 1983).

The coping responses of adolescent siblings of children with disabilities, should be examined in relation to the family system and other social systems (Kazak, 1987). Siblings' responses to having a brother/sister with a disability are related to parental reactions and ability to cope (Crnic et al. 1983). A particular research concern is that preadolescent children are heavily socialised by their parents in how to think and feel about their siblings with a disabilities. Parents teach their children from an early age to "compartmentalise" their negative feelings toward their siblings with disabilities. "Compartmentalisation" may influence the measuring of the siblings' perceptions, because siblings may only express what they were taught to say and results of such studies may not reflect their true feelings (Siegel & Silverstein, 1994).

Family members are forced to respond and adapt to changing roles and functions within their interfamilial relationships when an event is appraised as stressful. Adolescent social support systems consist of more than one relationship. Parental emphasis on personal growth encourages the adolescent's sense of mastery. (Seiffge-Krenke & Shulman, 1993). During the process of role taking within the family context, the self-concept is connected with social and moral norms. Role taking arouses emotions of empathy with others, as well as seeing themselves through the eyes of others. Feelings of guilt and shame are often aroused in children, if they perceive the attitudes and responses of others towards themselves as negative evaluations. Family interactions and roles influence how children come to understand themselves as individuals and to define themselves in relation to others (Abell & Gecas, 1997).

General attitudes toward active problem-solving, sensitivity toward situation-specific characteristics and a flexible response in dealing with problem situations on the part of parents are crucial for the development of adequate coping behaviour in adolescents (Seiffge-Krenke & Shulman, 1993). The coping of the adolescent siblings of children with severe disabilities can be seen as the siblings' cognitive and behavioural efforts to master the demands that are created by the stressful situation of having a sibling with a disability (Lazarus & Folkman, 1984). Adaptation to stressful conditions takes place when individuals employ coping responses in order

to develop a sense of mastery regarding their stressful life situations (Meyer, Peck & Brown, 1991).

It has to be considered that the developmental tasks of adolescents, such as physical development and peer conformation, may be a stressful encounter for adolescents and they cope with it in various ways (Newman & Newman, 1997).

Adolescent coping behaviour seems to be contradictory. On the one hand, active forms of adolescent coping are associated with an optimal family atmosphere combining closeness and individual autonomy. On the other hand, adolescent behaviour in familial conflict, shows that withdrawal, which is seen as inactive coping, is the most frequent type of behaviour. A possible solution to this contradiction, may be suggested by the fact that adolescents acquire adaptive coping strategies within the family by a two-step process. They develop an increasing ability to act autonomously and independently. In developing their individuality, young adolescents need to differentiate themselves from the rest of the family. This newly acquired independence often results in conflict with other family members, which emphasises the distinctive differences in the views and attitudes of different family members. Adolescents are usually involved in conflict situations with their parents about mundane issues such as pocket money, watching television, fashion, etc. Allowing the adolescent his own separateness, combined with closeness and support, allows them to explore ways of coping with stressful events. A supportive family atmosphere alone, however, is not enough for the adolescent to adopt effective coping responses to having a disabled sibling (Seiffge-Krenke & Shulman, 1993).

It is important to view the coping responses of adolescent siblings within the framework of theoretical models of familial stress and adaptation. All subsystems of the family system are assumed to interact with one another and are influenced by other elements. The complexity of human behaviour and social systems necessitates an integrative approach when trying to describe them. These models can be used as a basis for the description of the coping responses employed by adolescents and as tools to identify coping responses (Byrne & Cunningham, 1985).



## 2.3 Models of familial stress and adaptation

Studies provide evidence that families who have a disabled child, may experience greater stress than similar families without disabled children (Fischer & Roberts, 1983; Beckman, 1983; Kazak, 1984; McHale et al. 1987; Lobato et al. 1997). The presence of a disabled child in the family is generally associated with maladaptive coping responses, although clinical data suggests that these pathological reactions are not uniform. Therefore it is necessary to describe the adaptation of siblings and other family members of children with disabilities, according to possible coping responses, including the factors that may influence coping responses (Crnic et al. 1983).

In addressing the possible coping responses involved in the familial adaptation to the stressor of the child's disability, models of family stress will be discussed.

### 2.3.1 Lazarus' model of family stress

Monat & 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).

Lazarus & Folkman (1984), presented a stress appraisal model in which the stressful events and coping resources are inseparable (Meyer et al. 1991). The coping resources and coping responses of both the family and the individual can be placed within the framework of this model. Different families respond differently to various stressors and attention should be given to the variables that mediate the effects of stress (Crnic et al. 1983). The process of stress can be mediated by two processes, namely cognitive appraisal and coping (Lazarus & Folkman, 1985).

According to Lazarus & Folkman (1985), stress lies in the individual's appraisal of the relationship between the environmental input and its demands and the person's agendas and capabilities to meet, mitigate or alter these demands in the interest of well-being. *Cognitive appraisal* refers to the process by which the individual ascribes

meaning to an event or encounter. Nothing is considered stressful, unless the individual appraises it as stressful.

Cognitive appraisal involves two main levels of appraisal, namely primary and secondary levels of appraisal. *Primary appraisal* is used to evaluate an encounter as irrelevant, positive or negative. If a sibling has a disability, it could be judged as a negative event and then it is seen as a situation of potential harm or loss. In *secondary appraisal*, the individual evaluates his/her coping resources and options when addressing a stressful event (Lazarus & Folkman, 1985; Luiz, Fullard, Stewart, Lombard, Corna, Jansen, Wiehan, 1994). Primary and secondary appraisal function interdependently. For example, if having a disabled sibling is seen as threatening, but the child's coping resources are adequate for dealing with it, the degree of threat of a stress reaction is diminished (Lazarus & Folkman, 1985).

It is often difficult to differentiate between primary and secondary appraisal, because both are ways in which people conceptualise what is happening to them. Lazarus & Folkman (1985) did a natural experiment which provides substantial evidence for the four important principles that have to be considered when examining stressful encounters. Firstly, a stressful encounter is not a static event, but unfolds as a dynamic process. It is important to consider that a stressful event in one situation, may not be stressful in another situation, when examining the coping strategies humans employ to change a troubled person-environment relationship. Secondly, at any given stage of a stressful encounter, people might experience seemingly contradicting emotions. Thirdly, most people cope in complex ways and fourthly, individual differences in cognitive appraisal and coping are reflected by the substantial individual differences there are in emotion at any given stage of a stressful encounter.

The abovementioned principles imply that it is important to consider the multidimensional and dynamic nature of the stress of having a disabled sibling. One can hypothesise that adolescent siblings may appraise having a disabled sibling differently from how they used to in preadolescence, because adolescents are less socialised by parental attitudes. Lazarus's model of stress appraisal and coping

resources can be applied in determining whether the adolescent siblings of children with severe disabilities, appraise the situation as being stressful or not, what their available coping strategies are and what coping strategies they employ.

### 2.3.2 The Double ABCX Model of Adjustment and Adaptation

Cherry (1989), delete provides an overview of Hill's (1949) ABCX model of family stress. The *ABCX model* illustrates the family's initial response to a stressor resulting in the perception of the stressor as being a crisis or not. It includes four components: *A, the stressor event; B, the family's resisting resources; C, the family's definition of the meaning of the stressor and X, the crisis.* A crisis may occur if the family is unable to restore stability and if they give in to continuous pressure to make changes in the family structure.

McCubbin and Patterson's (1983) expanded model, the *Double ABCX Model*, takes into account that the effect of the stressor itself can compound over time and that as the family tries to cope, there is an eventual outcome of adaptation on a continuum of good to poor. The components parallel to those of the ABCX model, applied to the adolescent siblings of children with disabilities, are as follows:

- a A Factor: the compound of cumulative effects of the stressor of having a sibling with a severe disability*
- b B Factor: the family's coping resources, e.g. socio-economic status, availability of a social support network, etc.*
- c C Factor: the family's definition and perception of the whole situation, including stressor pile-up, e.g. a multiplicity of care-giving demand and old and new resources available to the family members, because over time the family begins to perceive the situation differently*
- x X Factor: adaptation through family coping efforts trying to maintain a balance in family functioning*

The Double ABCX model provides us with a matrix for conceptualizing the factors in a family's adaptation to a stressor. It enables us to understand these families' and

the individual family members' responses to stress and coping, the disability itself and its difficulties, the cumulative pile-up by the chronicity of the problem and the intra-familial and social network resources of the family affecting their adaptation (Cherry, 1989). In applying the Double ABCX Model of Adjustment and Adaptation to adolescent siblings of disabled children, it is important to account for changes in cognitive functioning with development (Seiffge-Krenke & Shulman, 1993).

### **2.3.3 An Adaptational Model**

Crnic et al. (1983) proposed an *adaptational model* which integrates three basic concepts: *stress, individual coping and ecological influences on development and functioning*. According to this model, the presence of a disabled child, is an ongoing stressor, precipitating numerous minor and major crises. The familial response to the stress will involve various coping resources available both to the individual and the family. These available coping resources are mediated by the various ecological domains in which the family members interact, as well as the interactions within and between these domains. The family's adaptation to the stressor of having a disabled child can encompass various strategies that are employed in adapting to the stressor of having a sibling with a disability, which include *defense mechanisms, coping and resilience* (Marsh, 1992).

The above mentioned adaptation strategies will be discussed in terms of their role in the coping of the siblings of children with disabilities.

#### **2.3.3.1 Defense mechanisms**

Defense mechanisms protect individuals from overwhelming anxiety and assist the individual in maintaining a psychological equilibrium under conditions of stress. Defenses often involve distortion of reality and do not facilitate problem-solving. Specific defense mechanisms may help individuals to cope, but they may also have the potential to interfere with the process of coping. Defense mechanisms generally operate unconsciously, causing little or no awareness of these strategies or of their influence on the individual's functioning (Marsh, 1992).

Siegel & Silverstein (1994), have delineated some common defense mechanisms seen in the behaviour of siblings of disabled children. They include the following: *displacement*, *reaction formation*, *projection*, *regression*, *intellectualisation* and *acting out*.

- *Displacement* occurs when an individual defends him-/herself against unpleasant feelings about another person or an issue by displacing these negative feelings on another person/ issue. Some siblings experience displacement as “survivor’s guilt”, because they are not also disabled.
- *Reaction formation* takes place when negative feelings are left unprocessed and the opposite sentiment is felt in an exaggerated form. Siblings may be influenced in major aspects of identity, such as career choice. Many siblings of disabled children become “helping professionals”, e. g. doctors, social workers, etc.
- *Projection* takes place when an individual projects unpleasant feelings, e. g. anger, on an external force.
- *Regression* occurs when the individual regresses to an earlier means of coping by becoming dependent on others. Siblings will behave in an attention seeking way. Usually these effects are subtle and sometimes they lie outside of the child’s control.
- *Intellectualisation* occurs when the individuals create a distance between themselves and their pain, by acting as if they are an uninvolved third party. They construct so many rules on how to live with the disabled child that spontaneity and individual relationships are destroyed.
- *Acting out* involves the direction of anger toward a person/ institution when doing so directly, would be socially unacceptable. Siblings may get into trouble at school, etc.

### 2.3.3.2 Coping

In studying the effect of having a sibling with a disability, it is important to consider a coping-based framework, rather than considering only pathology-based concepts of adaptation (Crnic et al. 1983). Lazarus & Folkman (1985), describe coping as *cognitive* and behavioural efforts to manage events that are appraised as being stressful. Coping varies in mode, function and outcome. Therefore it is important to identify the coping strategies used, in order to reveal the siblings' coping processes and their adaptation to having a brother/sister with a disability (Crnic et al. 1983).

Coping can be focused on the regulation of distressing emotions (*emotion-focused coping*), or it can be focused on doing something to manage the problem (*problem-focused coping*). Problem-focused coping entails problem solving, decision making and/or direct action. Emotion-focused coping, on the other hand, is used to control distressing emotion, e.g. the attitude of "living one day at a time". Individuals use emotion-focused coping more frequently when they appraise a situation as unchangeable. In contrast, problem-focused coping is used more frequently in situations appraised as changeable (Lazarus & Folkman, 1985).

Adolescents generally employ more emotion-focused coping strategies when confronted with a problem. It is difficult for them to differentiate among stressful events and defining those, which need a problem-focused coping approach and those, which need emotion-focused coping. Therefore one can assume that a supportive family atmosphere alone, does not inspire active coping in adolescents, but that the parental model of coping will also influence adolescents (Seiffge-Krenke & Shulman, 1993).

Families tend to respond differentially to stress, therefore it is important to investigate the factors that mediate the effects of stress. It is necessary to address the subject of the family's available coping resources, when looking at the members' adaptive strategies to a stressor and in dictating the possible outcome (Crnic et al. 1983).

Folkman et al. (1979), delineated five types of general coping resources, which mediates adverse effects of encounters appraised as being stressful:

- health/ energy/ morale of individuals;
- problem-solving skills which involves the ability to search for and analyse information and generate action;
- social networks including potentially supportive relationships that may facilitate positive adaptations;
- utilitarian resources, such as socio-economic status and income;
- general and specific beliefs, which include individual variables, such as feelings of self-efficacy.

Siegel & Silverstein (1994), describe four types of general coping strategies often found in the behaviour of siblings of disabled children. These strategies include *parentification*, *withdrawal*, *acting out* and *superachieving*.

*Parentified* siblings react to a disabled brother or sister by precociously taking on a parental / care taking role toward that sibling. At first parentification seems to be an adaptive way of coping. However, it causes a lack of the child's own childhood experiences. Adolescents often experience a backlash, in their search for individuality and self-identity.

*Withdrawn* siblings cope by removing themselves from family activities that increase the stress of having a disabled child in the family. Siblings *acting out* feelings of anger/ hostility, draw attention to themselves in a negative way, forcing parents and significant others to pay more attention to them. Usually this worsens with age. Adolescents that are acting out, often meet with rejection at home. This leads to his/ her self-esteem being deflated and they try to seek attention outside of the family. The negative attention the child gathers, results in the worsening of the self-esteem and an even greater need for extra-familial attention.

*Superachieving* siblings focus on being perfect. They try to prove to their parents that they are the opposite of their disabled sibling, who causes all the family's stress. There is nothing wrong with striving for a high level of achievement, except that

these superachieving siblings have the wrong motivation and there is much emotional stress involved.

## **2.4 Social support networks**

More supportive social networks are associated with better personal well being. Individuals who have supportive social networks have positive attitudes that filter through to parent-child interaction and child behaviour and development. The emotional and physical health and time demands placed upon parents of disabled children, are related positively to social support (Dunst, Trivette & Cross, 1986). Different social networks will exert different influences on the coping resources and strategies of the siblings of disabled children.

Bronfenbrenner (1979) describes social networks as concentric structures embedded within one another. The child and his/her family forms the innermost level, which is embedded in broader ecological systems, which include blood and marriage relatives, friends, neighbours and other acquaintances. These units are embedded further within larger social units, including schools, neighbourhoods, etc. This social system theory postulates that these units do not operate in isolation, but interact interchangeably (Dunst et al. 1986).

Social support is either a mediational or a causative factor in stressful encounters. It is important to determine the bi-directional influences of persons, settings and their characteristics and the influences of mediational factors should be determined for the child, family and other relevant network members. Social support is defined in terms of both the satisfaction with different sources of support and the number of sources available to the family. The family's perceived satisfaction with support and the extent to which it is considered as helpful is related to well being and other behavioural outcomes (Dunst et al. 1986).

The behaviour and attitudes of people in these various settings, seem likely to influence the parents' and siblings' beliefs, problem-solving, morale and other resources that may affect the individual and familial response to the disabled child



(Crnic et al. 1983). Social networks provide feedback and they confirm and maintain behaviour, thereby contributing to physiological functioning and the maintenance of health. Social networks are resources available to people when developing coping strategies. These strategies include behaviours and perceptions in which people engage when dealing with their life problems. The family system should therefore not only be seen as a reactor to stress, but also as a manager of support resources within the family system (Byrne & Cunningham, 1985).

Competent adolescents have parents who exercise reasonable control, but are flexible and encourage independence. Parental influence on adolescents regarding coping modes in stressful situations, is apparently derived from the parental role as definers of norms and standards, if the family atmosphere nurtures competence and autonomy in adolescents (Seiffge-Krenke & Shulman, 1993). Identity formation within adolescence, is influenced by the adolescents' educational aspirations, their expectations for the future, their level of ego development, the available support from their parents and other family members and their cognitive maturity. Adolescents who are coping well with stressors are usually able to identify at least one care giver who provides them with the necessary attention and support (Swanson, Spencer & Petersen, 1998).

Peers seem to be attractive role models for some behaviour. Female adolescents tend to rely more on social resources in coping with stressful events and are therefore more receptive than male adolescents to interpersonal influence, whether it is from parents or peers (Seiffge-Krenke & Shulman, 1993). From mid-adolescence onwards, adolescents perceive friendships as a supportive relationship and it provides a new perspective through which the adolescent discovers the power to receive validation through interaction with equals. However, the ways in which peers provide positive help in coping with stress, seem to be relatively unknown (Seiffge-Krenke & Shulman, 1993). Since peers seem to have a role in the social support network of adolescents, it is important for this study to determine the extent of peer involvement in the social support networks of the adolescent siblings of children with severe disabilities.

## 2.5 Summary

All family relationships experience some stress, but it is evident that the levels of stress are increased when there is a child with a disability in the family. Each family member experiences the stress in a different way and it affects each family member personally (Sherman, 1997). The impact of having a disabled sibling, may exacerbate the problems in the psychological adjustment of adolescents, as they appear to be prone to experiences of shame, guilt, stigma, extra care giving responsibilities, etc. (Lobato, 1990; Abell & Gecas, 1997).

In order to give a comprehensive description of adolescent siblings' perceptions of having a sibling with a disability one needs to identify coping responses in adolescents, as well as the social resources that are available to them.

It is necessary to determine whether the adolescent perceives having a sibling with a disability as being stressful or not, to identify the coping resources available to them and the coping responses they employ. These coping resources include the social support networks within their environment.

The following chapter will discuss the methodology that will be used to describe the above mentioned factors and the relationships between them.

## CHAPTER 3

# METHODOLOGY

This chapter will discuss the methodology by which the coping responses of the adolescent siblings of children with disabilities will be described.

### 3.1. Aims

#### 3.1.1 Main aim

The main aim of this study is to identify the coping responses of adolescent siblings of children with disabilities in their adjustment to the family stressor of having a sibling with a disability.

#### 3.1.2 Sub-aims

- To conduct a structured interview with adolescents with a sibling with a disability to determine the following:
  - the subjects' appraisal of the stressor of having a sibling with a disability;
  - the coping resources available to the subjects;
  - the subjects' coping responses to the impact of having a sibling with a disability.
- To apply a questionnaire to the parents of the subjects to collect biographical information and information regarding the parents' perceptions of the subjects' coping.
- To do a qualitative analysis of the emerging themes in the interviews with the subjects and to identify specific trends among the subjects.

## **3.2 Research design**

This study is a qualitative research project, following the phenomenological research method. Phenomenology tries to explain phenomena as they present themselves in the immediate subjective experience of the person who lives them (Barrell, Aanstoos, Richards & Arons, 1987). This approach aims to "understand the meaningfulness of human experience as it is actually lived" (Barrell et al. 1987, p. 446).

The qualitative researcher focuses on the ways which individuals use to interpret the reality of their life worlds, by *bracketing* the social actions that take place in their lives. Individuals have *stocks of knowledge*, consisting of ideas, images, theories, values and attitudes, which are applied to life experiences, adding meaning to it. These *stocks of knowledge* are used to interpret life experiences, determine the intentions of other people, gain inter-subjective understandings and to co-ordinate actions. *Typifications* are used to account for experiences, rendering things and occurrences to be recognised as being of a particular type (Denzin & Lincoln, 1998, p. 139).

Data will be collected by means of a structured interview with subjects. The interview should be treated as a social encounter constructing knowledge and producing reportable knowledge (Holstein & Gubrium, 1997).

## **3.3 Subject selection**

### **3.3.1 Selection criteria**

The subjects that were selected have siblings with severe disabilities, although they have different diagnoses. In literature the general assumption is made that the severity of the disability impacts on the coping responses of the other siblings, because children with severe disabilities place bigger care giving demands on the family and often they have disruptive behaviour. However there is no conclusive

evidence that the severity of the disability of a child can be associated with possible maladaptive coping responses of the other siblings (Breslau et al. 1981; Meyer et al. 1991; Powell & Gallagher, 1992; Siegel & Silverstein, 1994). It was therefore decided that the degree of disability would be important for subject selection, although the kind of disability involved was not necessarily controlled for.

Table 3.1 explains the selection criteria applied in the selection of subjects:

**TABLE 3.1: Explanation of and motivation for selection criteria**

SELECTION CRITERIA	MOTIVATION
The subject must have a brother/sister with a severe disability, who lives at home on a permanent basis, or comes home at least every weekend.	Siblings need to be in contact with the child with a disability on a regular basis, in order to identify relevant coping responses.
The subject has to be in early adolescence (12 - 15 years).	Adolescents' perceptions regarding familial adaptation to having a sibling with a disability, play an important role in the development of the adolescent's self-esteem and attitude toward problem-solving and flexibility (Harvey & Byrd, 1988).
The subject has to be willing to share their experiences with the researcher.	The siblings' willingness to share their experiences, are important if information received has to be honest. This requires a relationship of mutual trust between the subject and the researcher (Furman & Buhrmester, 1985).
The subject's parents have to be married.	Children who come from single-parent families, could be influenced by additional stressors
The subject's first language has to be Afrikaans or English.	The data collected during the structured interview has to be transcribed. The researcher is in command of both of these languages.

### 3.3.2 Method of selection

A deliberate selection of subjects was done. The selection of subjects was influenced by the availability of subjects who met the selection criteria, as well as their willingness to participate in this study. Nineteen subjects were selected.

Three schools in Pretoria and one in Johannesburg, attended by children with severe disabilities, were selected. These include schools for children with severe disabilities and a school for Autistic learners. Subjects' telephone numbers were

obtained from these schools. If the selection criteria were met, subjects were contacted telephonically and if they were willing to participate in this study, an appointment for an interview was scheduled.

### **3.3.3 Descriptive criteria**

#### **3.3.3.1 Description of the children with severe disabilities**

TASH (The Association for Persons with Severe Handicaps), defines individuals with severe disabilities as people who need continual support in one or more area of life (Meyer et al. 1991). The children with severe disabilities are described according to gender, chronological age, diagnosis, first language, whether they are speaking or whether they have little or no functional speech for communication, their physical abilities and the school they attend (table 3.2). The children's ability to perform activities of daily living (ADL), are described in the column for physical abilities. ADL include feeding, dressing, washing, going to the toilet, brushing teeth, etc. The children's main mode of communication is described in the column for communication. This column gives an idea as to whether the child is speaking or has little or no functional speech, which implies that the child has less than 15 intelligible words (Burd et al. 1988).

The children with disabilities who were selected for the study, attend schools for children with severe disabilities, where an I. Q. of under 50 is a prerequisite.

The diagnoses of the children with severe disabilities vary. None of the children is primarily hearing impaired or visually impaired, although some of them have problems with auditory and visual perception as a result of their disability. Seven of the disabled siblings were female, while ten of them were male. Their ages vary between ten and eighteen years. The age difference between the disabled siblings and the subjects, doesn't exceed five years.

Only two of the disabled children are able to perform activities of daily living (ADL), independently. The rest of the children need assistance with ADL or it needs to be

done for them by someone else. None of the children with little or no functional speech makes use of an augmentative and/or alternative communication (AAC) device. Two of the children suffer from petit mal epilepsy and two of them suffer from grand mal epilepsy.

Table 3.2 provides a description of the children with severe disabilities.

**TABLE 3.2: Description of the children with severe disabilities**

CHILD	GENDER	CHRONOLOGICAL AGE	DIAGNOSIS	COMMUNICATION	PHYSICAL ABILITIES	FIRST LANGUAGE	SCHOOL
1.	Male	10 years	Mental retardation. Petit mal epilepsy	Speaking.	Able to walk; can do ADL independently.	Afrikaans	1
2.	Female	14 years	Calcifying leukodys- trophy	Speaking.	Not able to walk; can't do any ADL independently	Afrikaans	1
3.	Female	10 years	Cerebral atrophy	Speaking.	Not able to walk; needs assistance with ADL	English	1
4.	Male	14 years	Mental retardation. Grand mal epilepsy	Speaking	Able to walk; can do ADL independently	Afrikaans	2
5.	Male	10 years	Down's syndrome	Speaking.	Able to walk; needs assistance with dressing, but can do other ADL independently.	English	3
6.	Female	10 years	Cerebral palsied.	Speaking	Quadruplegic - not able to walk; needs assistance with all ADL.	Afrikaans	1
7.	Female	10 years	Mental retardation.	Speaking.	Able to walk but needs assistance with ADL.	Afrikaans	3
8.	Female	17 years	Mental retardation. Grand mal epilepsy	Speaking	Able to walk, but needs assistance with ADL.	English	4
9.	Male	17 years	Cerebral palsied. Mental retardation. Grand mal epilepsy	Little/no functional speech.	Hemiplegic - walks with difficulty and needs assistance with ADL.	Afrikaans	4
10.	Male	13 years	Autistic.	Speaking.	Able to walk, but needs assistance with ADL.	Afrikaans	5
11.	Male	10 years	Autistic.	Speaking	Able to walk, but needs assistance with ADL.	English	5
12.	Male	18 years	Autistic.	Speaking	Able to walk and perform ADL with supervision.	English	5
13.	Female	10 years	Cerebral palsied.	Little or no functional speech.	Quadriplegic - not able to walk and not able to perform any ADL.	Afrikaans	4
14.	Male	10 years	Cerebral palsied. Mental retardation.	Speaking.	Able to walk and perform ADL with assistance.	Afrikaans	1
15.	Male	13 years	Closed head injury	Functional speech	Hemiplegic; needs assistance with ADL.	Afrikaans	1
16.	Female	12 years	Mentally retarded	Intelligible speech	Able to walk and perform ADL with supervision.	Afrikaans	3
17.	Male	10 years	Cerebral palsied. Mental retardation.	Functional speech, although not intelligible to strangers.	Unable to walk or perform any ADL.	English	3



### 3.3.3.2 Description of the adolescent siblings of the children with severe disabilities

Literature emphasises that gender, age, the number of children in the family, the position of the sibling in the family and age-spacing between the sibling and the child with a disability, should be considered when the siblings are described. Therefore siblings will be described according to these criteria. Table 3.3. provides a motivation for the descriptive criteria of the adolescent siblings of the children with disabilities (Prinsloo, 1998).

**TABLE 3.3: Research motivating the descriptive criteria of the subjects**

DESCRIPTION OF SIBLING	MOTIVATION FROM LITERATURE
Gender	Gender is not uniformly associated with sibling adjustment problems, but some studies found differences in the adjustment of male and female siblings (Lobato, 1990). Some research found that sibling interaction tends to be more positive if the child with a disability is of the opposite gender from the sibling (Powell & Gallagher, 1992). Girls and boys handle their negative feelings about their siblings differently (Siegel & Silverstein, 1994).
Age	The older siblings of the child with a severe disability, seem to have less problems with coping and adjustment, because they have already started to form their own identity. (Powell & Gallagher, 1992).
Position in the family	According to Siegel & Silverman (1994), it is the older sister and younger brother of the child with the disability that are mostly affected by the child's disability. Older sisters are expected to assume more care giving responsibilities, which places age inappropriate burdens on them. Younger brothers receive less attention, which causes feelings of rejection and loneliness. Younger sibling have difficulty in understanding their older sibling's disability (Lobato, 1990).
Number of children in the family	It seems as if parents in two-child families tend to place all their hope and expectations on the sibling without a disability. In larger families these expectations can be distributed among several children, which prevents the pressure being on only one child. Siblings from larger families seem to have better psychological adjustment, if the family doesn't have financial problems (Powell & Gallagher, 1992).
Age-spacing	Siblings' behaviour and adjustment are influenced more when they are closer in age to the sibling with a disability. If the disabled child is three or more years older than the sibling, critical issues concerning his/her disability might already be resolved. The disabled child's older sibling will have had time to develop and be established before the disabled child's arrival (Lobato, 1990).

Table 3.4 provides a summary of the siblings of the children with disabilities.

**TABLE 3.4: Description of the subjects**

SUBJECT S	GENDER	AGE (years)	EDUCATIONAL QUALIFICATION	POSITION IN THE FAMILY	NUMBER OF CHILDREN IN THE FAMILY	AGE-SPACING BETWEEN SUBJECT AND DISABLED CHILD
1.	Male	13	Grade 7	First	2	3 years older
2.	Female	15	Grade 9	First	3	2 years older
3.	Male	15	Grade 9	Third	4	3 years older
4.	Female	15	Grade 10	First	2	1 year older
5.	Male	15	Grade 10	First	4	5 years older
6.	Male	15	Grade 10	First	4	5 years older
7.	Male	13	Grade 7	First	3	3 years older
8.	Female	15	Grade 9	First	3	5 years older
9.	Female	13	Grade 7	Second	3	3 years older
10.	Male	13	Grade 7	Second	3	4 years younger
11.	Male	13	Grade 7	Second	2	4 years younger
12.	Male	15	Grade 9	First	2	2 years older
13.	Male	13	Grade 7	First	2	3 years older
14.	Female	15	Grade 10	Second	2	3 years older
15.	Female	14	Grade 9	First	2	4 years younger
16.	Female	12	Grade 7	First	2	2 years older
17.	Female	14	Grade 8	Second	3	1 year older
18.	Female	15	Grade 9	First	3	3 years older
19.	Male	12	Grade 7	Second	3	2 years older
<b>Siblings from the same family</b>						

Interviews were conducted with nineteen siblings of children with severe disabilities in the age group of 12-15 years. Ten of the subjects were male, while the other nine subjects were female. Eight of the subjects' parents decided to have another child after they've had a disabled child. Sixteen of the subjects are older than the disabled sibling and the remaining three are younger.

### **3.4 Pilot study**

A pilot study was done to determine whether the preformulated questions for the structured interview were relevant. The results of a pilot study provide valuable information both on the administration of the interview and the quality of responses from the interviewees. The pilot study also provides the researcher with an extra training opportunity in interviewing (Frey & Mertens, 1995). The pilot study also served as a means to determine the technical quality of the tape recordings that were made during the interviews, in order to ensure reliability of the obtained data (Silverman, 1993). The data obtained during the pilot study, was used to determine

the relevant categories for data analysis. Subjects for the pilot study were selected according to the same selection criteria as for the main study. Table 3.5 provides a description of the subjects for the pilot study. Two subjects were selected according to the subject selection criteria in table 3.1.

**TABLE 3.5: Description of subjects for the pilot study**

SUBJECT	GENDER	AGE (years)	EDUCATIONAL QUALIFICATION	NUMBER OF CHILDREN IN FAMILY	POSITION IN THE FAMILY	AGE-SPACING BETWEEN SUBJECT AND DISABLED CHILD
1	Male	12	Grade 6	2	First	2 years older
2	Female	15	Grade 9	3	First	2 years older

The subjects for the pilot study were both born first and the age-spacing between them and the disabled child is two years in both cases. One subject was male and the other female. The parents of subject 2 decided to have another child after the disabled sibling.

Table 3.6 provides the aims, results and recommendations from the pilot study.

**TABLE 3.6: Aims, methods and recommendations of the pilot study (the questionnaire used in the pilot study, can be viewed in Appendix B)**

AIM and MOTIVATION	METHOD	RESULTS	RECOMMENDATIONS
<p>To collect reliable information during the interview, by eliminating complicated, vague, irrelevant and leading questions, Questions will be reformulated or adapted.</p>	<p>Preformulated questions were used to guide the interviewer in obtaining the relevant data, because the obtained data will be more reliable and it would simplify data analysis. . The responses of subjects were tape recorded with a Sony M-425 Microcassette-corder.</p>	<ul style="list-style-type: none"> <li>• Question 1 had to be adapted, when there are only two children in the family.</li> <li>• Question 2 can be left out if there are only two siblings in the family.</li> <li>• Question 6 is only applicable if there are more than two siblings in the family.</li> <li>• The probes that are part of the questions, are sometimes not needed as subjects gave the answer without needing to be probed.</li> <li>• The subjects seemed to understand all the questions and their formulation.</li> </ul>	<ul style="list-style-type: none"> <li>• <b>Question 1.</b> I want to talk to you about your brother/sister. * Tell me more about <u>x</u> . * How do you get along?</li> <li>• <b>Question 2</b> Tell me more about <u>x</u>.</li> <li>• <b>Question 6</b> Do you and your brothers/ sisters ever fight?</li> <li>• The probes don't have to be used if the subject has already given the information necessary.</li> <li>• No question's formulation was changed.</li> </ul>
<p>To determine the time it will take to conduct a successful interview with a subject.</p>	<p>The average time it took to complete the interviews was calculated.</p>	<p>The interview with subject 1 took approximately 20 minutes, while the interview with subject 2, took approximately 25 minutes.</p>	<p>It was decided to allow 20 minutes for each interview.</p>
<p>To improve the researcher's skill in qualitative interviewing, and the analysis and interpretation of data (De Vos, 1998).</p>	<p>The researcher conducted the two interviews for the pilot study and analysed the obtained data.</p>	<p>The researcher acquired skill in interviewing and the transcribing of the tape recordings, as well as data analysis.</p>	<p>The researcher felt competent in proceeding with the interviews for the main study, because relevant information was obtained during the interviews.</p>
<p>To determine the impact of the tape recorder on the subjects during the interview. Adolescents are at a self-conscious stage and they might feel uncomfortable revealing personal feelings if the interview is recorded on audiotape (Lloyd, 1985).</p>	<p>Before the interview was started, subjects were informed that a tape recorder will be used. The subjects were free to withdraw from the study if they felt uncomfortable.</p>	<p>All the subjects felt comfortable with the use of the tape recorder.</p>	

**TABLE 3.6 Aims, methods and recommendations of the pilot study (continued)**

AIM and MOTIVATION	METHOD	RESULTS	RECOMMENDATIONS
To ensure the technical quality of the tape recordings made during the interview.	The interviews were tape recorded with a SONY M-425 Microcassette-corder.	The quality of the tape recordings was adequate for data analysis. The cassette recorder is small, which limits distraction of the subject.	<ul style="list-style-type: none"> <li>• Transcriptions of the tape recorded interviews has to be done as soon as possible after the interview.</li> <li>• A second transcriber has to check the accuracy of transcriptions.</li> </ul>
To identify categories for data analysis.	The data collected during the interviews were transcribed and analysed according to different categories for data analysis.	The interview provided data that could be divided into meaningful units.	The meaningful units need to be grouped together into categories for data analysis According to the sub-aims of this study..
Ensuring the maximum cooperation from subjects and their parents during the interview.	<p>Subjects were allowed to choose where they want to have the interview.</p> <p>Subjects and parents were given an explanation about the aim of the study.</p> <p>Subjects were given the right to refuse to answer questions with which they didn't feel comfortable.</p>	<p>Subjects usually chose to have the interview in the living room or in their bedrooms</p> <p>Parents and subjects seemed to be content with the information given to them regarding this study.</p> <p>None of the subjects felt threatened with the questions asked during the interview.</p>	<ul style="list-style-type: none"> <li>• The subject can choose the location of the interview.</li> <li>• Parents and subjects have to be given the relevant information regarding this study.</li> <li>• Subjects don't have to answer a question with which they're not comfortable.</li> </ul>

### **3.5 Main study**

#### **3.5.1 Data collection procedures**

##### **3.5.1.1 *Data collection procedures regarding the children with severe disabilities***

- The names of possible subjects were obtained through the respective schools for children with severe disabilities and a school for autistic learners in Pretoria and a school for children with severe disabilities in Johannesburg.
- Information about the children's disabilities was obtained through a questionnaire completed by the parents.

##### **3.5.1.2 *Data collection procedures regarding the parents of the subjects***

- The researcher contacted the parents of possible subjects telephonically and the aim and motivation of this study were explained to them.
- Interviews were scheduled at a time that suited both the subject and one of the parents, which was usually in the evenings or in the late afternoons at the subject's home.
- The parents signed a form of consent for participating in this study. One of the parents was required to complete the questionnaire for parents (Appendix A). This questionnaire aims to obtain data regarding the family structure and to obtain the necessary information for the description of the children with severe disabilities and the subjects.
- The instructions for the completion of the questionnaire were given on a cover sheet with the questionnaire. The researcher was available to answer questions regarding the questionnaire, when necessary.
- The parents could complete the questionnaire in Afrikaans or English, which ever they preferred.

### **3.5.1.3 Data collection procedures regarding the subjects**

- Open-ended, structured interviews with preformulated questions (Appendix B) were conducted in the home language of the subjects. A structured interview can be described as a social interaction between individuals, where the researcher directs the interview by means of a definite research agenda (Schurink, 1998, p. 298).
- The interview started with an informal question in order to create a cordial atmosphere and to create an intellectual and emotional partnership with the subject (Schurink, 1998).
- The interviews were conducted at the subjects' homes, in the room they preferred. Subjects were given enough time to respond to questions and each interview took approximately 20 minutes.
- The aim of this research study was explained to the subject and his/her parents before the interviews. It was made clear that subjects didn't have to answer any questions with which they felt uncomfortable.
- The interviews were recorded on audiotape. Tape recordings provide the researcher with detailed representations of the interaction that took place during the interviews and it improves the accuracy of data collection (Silverman, 1997). The interviews were conducted by the researcher to ensure consistency in possible explanations of terms and questions during the interview.
- The subjects knew that the interviews were recorded on audiotape and they had the option to withdraw from the study if they felt uncomfortable about revealing personal information. They were assured that their anonymity will be protected and that the obtained information would remain confidential.
- The researcher used the same questions and procedures for each interview, which increased the intra-rater reliability of the study.
- The researcher transcribed the tape recordings. It was checked by an external rater to ensure that the transcriptions were accurate and conveyed the original information.

### 3.5.2 Material for data collection

#### 3.5.2.1 Questionnaire for parents

The questionnaire for parents aims to obtain information about the family structure, which is necessary for the description of the subjects and the children with severe disabilities (see Appendix A). Table 3.7 provides an explanation of the categories for the questions of the questionnaire for parents.

**TABLE 3.7: Explanation and motivation of the categories of the questionnaire for parents**

CATEGORIES	QUESTIONS	MOTIVATION
1. Biographical information	1, 2, 3, 4, 5, 6, 7	In order to be able to give a meaningful description of the subjects, their parents and their siblings with disabilities, it is necessary to obtain some information regarding their ages, home language, birth position, etc.
2. The parent's perception of professional support services utilised by the family.	8	It is necessary to identify the professional support networks available to the subjects in coping with the fact that they have a sibling with a disability. Collaboration between families and professionals, may lead to more effective coping responses and more creative solutions for problems (Beckman, Frank & Stepaneck, 1996)
3. The diagnosis of the child with a disability.	9	It is necessary to know what the diagnosis of the child with a disability is according to the parent, because parental attitudes influence the attitudes of siblings (Siegel & Silverstein, 1994).
4. The information given to the subject regarding his/her sibling's disability.	10, 11	Children need information regarding their sibling's disability and its consequences in order to employ effective coping responses (Marsh, 1992).
5. The parent's perception of the family's adaptation with regard to the fact that they have a family member with a disability.	12, 13	Parents need to be able to identify adaptational problems that family members might encounter. It is important for them to realise that the family is at risk of encountering some stress because of the special demands caused by the sibling with a disability (Siegel & Silverstein, 1994).

#### 3.5.2.2 Material for the interviews

" ..... the face-to-face interview helps us to understand the closed worlds of individuals, families, organisations, institutions and communities," (Schurink, 1998).

According to Holstein & Gubrium (1997, p. 114), interviewing is a process of meaning making which actively involves the construction of knowledge by both the



interviewer and the interviewee. Interviews provide us with information about social worlds and language shapes the meanings people construct, but it also gives intersubjectivity to the meaningful "worlds" they construct. It allows the researcher to describe segments of the subjects' lives in which we are the most interested (Denzin & Lincoln, 1998).

Data collection occurred by means of structured interviews with preformulated, open-ended questions. The questions were arranged as to obtain data relatively systematically and to facilitate data analysis (Schurink, 1998). Fourteen preformulated questions were compiled in order to identify the responses present in the behaviour of the adolescent siblings of children with severe disabilities. Open-ended questions were formulated, because they allow the subjects to construct their worlds as they experience it and they eliminate yes/no answers. Open-ended questions create an informal atmosphere and probes serve the means of eliciting additional information. Each question has probes to facilitate the interviewer in obtaining the necessary information.

During the interview, the researcher used a form with the preformulated questions on it. The number of the subjects was also recorded on this form. All interviews were recorded on audiotape with a SONY M-425 Microcassette-corder. The obtained data was transcribed by means of a SANYO Memoscriber TRC 8070 Microprocessor Control.

The possible responses of the siblings were divided into categories (table 3.8). The questions are based on the components of models of stress and adaptation (Crnic et al. 1983; Lazarus & Folkman, 1985; Cherry, 1989) and on sub-headings in Marsh (1992) and Siegel & Silverstein (1994).

Table 3.8 provides an explanation of the preformulated questions that were used for the interviews. The complete questionnaires in Afrikaans and English as they were used for the interviews, can be seen in Appendix C.

**TABLE 3.8: Explanation of the preformulated questions for the interview**

CATEGORIES	QUESTIONS	MOTIVATION
The subject's appraisal of the stressor of having a sibling with a disability.	4. I want to talk to you about your brother(s) and/ sister(s). <ul style="list-style-type: none"> <li>• How many brothers and sisters do you have?</li> <li>• How do you get along with each other?</li> </ul> 2. Tell me more about <u>  x  </u> . 3. Has anyone ever told you what exactly is wrong with <u>  x  </u> ? <ul style="list-style-type: none"> <li>• Have you ever tried to find out more about the disability on your own?</li> <li>• What do you think will happen to him/her in the future?</li> </ul> 4. How do you feel about having a brother/sister like that?	According to Lazarus & Folkman (1985), cognitive appraisal is the process by which individuals ascribe meaning to events or encounters. Individuals experience stress during events or encounters, if the situation is appraised as being stressful. Therefore it has to be determined whether the subjects appraise the situation of having a disabled sibling as being stressful.
The subjects' available coping resources.	8. Are there family members outside of your immediate family circle, e.g. your grandparents and uncles/aunts, that sometimes do things to help your family with <u>  x  </u> ? <ul style="list-style-type: none"> <li>• How do they help your family?</li> <li>• How do you think they feel about x?</li> </ul>	According to Folkman et al. (1979), coping resources mediate stressful encounters and they include the following: <ul style="list-style-type: none"> <li>• the individual's health, energy or morale,</li> <li>• problem-solving skills,</li> <li>• social support networks,</li> <li>• utilitarian resources, e.g. socio-economic status, etc. and</li> <li>• general and specific beliefs</li> </ul>
The subjects' available social support networks.	7. What do you think your friends think about you? <ul style="list-style-type: none"> <li>• Why do you think that they think that?</li> <li>• How do you feel about that?</li> </ul> 1. What other people, e.g. neighbours, family friends or people from the church, support your family with x? <ul style="list-style-type: none"> <li>• What do they do to support your family?</li> <li>• How do you think they feel about x?</li> </ul>	Social support networks are part of families' coping resources. These social support networks include extended family, professionals, family friends, people from the church, parent support groups, etc. Families with more supportive social networks, are associated with better personal well-being, more positive attitudes and more positive influences on parent-child interaction and child development (Dunst & Trivette, 1986, p. 403).
The subject's coping responses to the impact of the stressor of having a disabled sibling, on the subject's life.	5. What do you tell your friends / strangers when they ask you about x? <ul style="list-style-type: none"> <li>• Why do you tell them that?</li> <li>• How do you think they feel about x?</li> </ul> 6. Do you and your brother(s) and/ sister(s) ever fight? <ul style="list-style-type: none"> <li>• What usually causes a fight?</li> <li>• What usually happens when you fight?</li> <li>• How do you usually act in a situation like that?</li> <li>• How do your parents react when you fight with your brother(s) and/ sister(s)?</li> </ul>	Families who have a child with a disability as a member, seem to experience greater stress than similar families without children with disabilities (Luiz et al. 1994). It is necessary to investigate the coping of siblings of children with disabilities with regard to the range of positive and negative coping strategies, which include factors that mediate adaptation (Crnic et al. 1983). Coping can be emotion-focused or problem-focused.

**TABLE 3.8: Explanation of the preformulated questions for the interview (continued)**

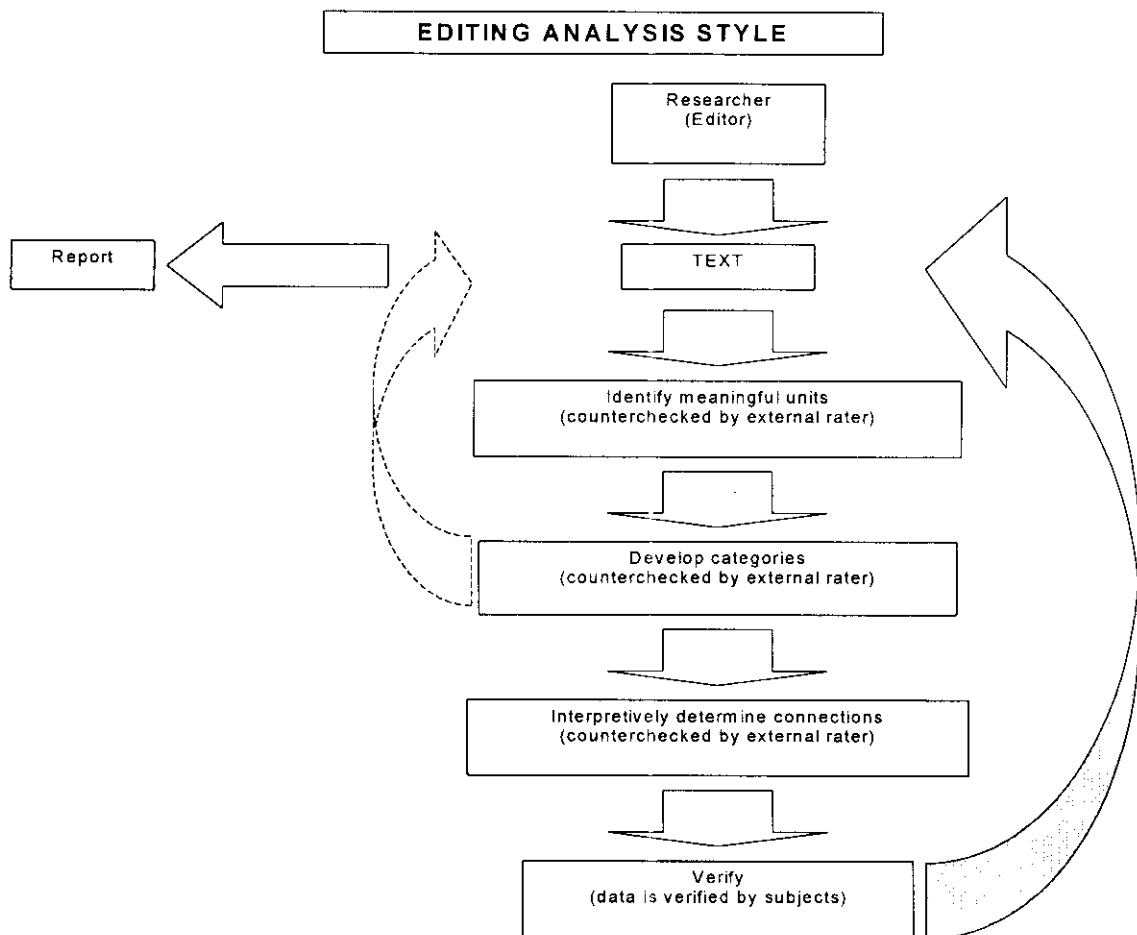
CATEGORIES	QUESTIONS	MOTIVATION
<p>The subject's coping responses to the impact of the stressor of a disabled sibling on the subject's life.</p>	<p>9. Do you and your parents ever talk about x?</p> <ul style="list-style-type: none"> <li>• What do you discuss when you talk about him/her?</li> <li>• Are there things that you sometimes disagree on?</li> <li>• What usually happens in a situation like that?</li> </ul> <p>10. What changes do you have to make in your life because of x?</p> <ul style="list-style-type: none"> <li>• How do you feel about that?</li> <li>• Are there things that you can't do because of x? (Yes) What are they?      or (No) Are there things that are difficult to do because of x?</li> <li>• Are there things about x that irritate you now more than before?</li> <li>• Do you think that it is wrong to feel this way?</li> </ul> <p>12. Do you and x ever fight?</p> <ul style="list-style-type: none"> <li>• What usually causes a fight?</li> <li>• What usually happens when you fight?</li> <li>• How do you usually act in a situation like that?</li> <li>• How do your parents react when you and x fight?</li> </ul>	<p>Problem-focused coping entails problem solving, decision making and/or direct action. Emotion-focused coping, on the other hand, is used to control distressing emotion, e.g. the attitude of "living one day at a time". Individuals use emotion-focused coping more frequently when they appraise a situation as unchangeable. In contrast, problem-focused coping is used more frequently in situations appraised as changeable (Lazarus &amp; Folkman, 1985).</p>
<p>The subject's coping responses to the impact of the stressor of a disabled sibling on the subject's life.</p>	<p>2. If you could change your life, which three things would you like to change/ which three things would you wish for?</p> <ul style="list-style-type: none"> <li>• Why?</li> </ul>	

### 3.6. Data analysis and interpretation

Tesch (1990), identifies three core steps common to qualitative data analysis methods:

- developing a system to organise data;
- segmenting the data;
- and making the necessary connections.

Based on these core steps, Miller & Crabtree (1998, pp.302-303), identified four idealised analytic styles, of which the editing analysis style seems the most appropriate for this study. Figure 1 gives a diagrammatic representation of the editing analysis style according to Miller & Crabtree (1992).



**FIGURE 3.1: The editing analysis style (Miller & Crabtree, 1998)**

According to this analysis style, the researcher serves as the interpreter and organises the editing of data. The text is edited and meaningful units are identified. Data is considered to be a meaningful unit if the subjects ascribe meaning to it within the context of the interview. An external rater counterchecked the identified meaningful units.

These meaningful units are divided into categories for data analysis. In order to create categories and sub-categories, the researcher needs to discover the links between data. The researcher then has to interpret this data and determine possible connections. The categories for data analysis, as well as the connections made, have to be counterchecked against the original transcripts of the interviews.

A second observer counterchecked the categories for data analysis as the researcher identified them. The second rater also has to verify the interpreted information with regard to the tape recordings.

- All the interviews were transcribed in order to facilitate the analysis of the obtained data. Transcripts allow the researcher to return to the data during data analysis and to identify additional lines of analysis and it has presentational purposes (Silverman, 1993). Appendix C provides examples of the transcriptions.
- The analysis of these transcripts involves the attentive reading of transcripts to get a feeling of unity for each interview. It is important to consider different topics, interpretations and ideas when doing this (Silverman, 1993).
- The semiotic analysis of data is based on the assumption that all units are related to an underlying structure. Semiotic clustering was used to analyse the meaningful units and it involves the noticing of recurring themes and writing up of all the various ways in which the concepts of interest were mentioned by the subjects (Feldman, 1993).
- All the above-mentioned strategies toward the analysis of data, were checked by a second rater. The second rater is a clinical psychologist. Differences in ratings and analysis were discussed and decided upon.

- The various meanings derived from the data are then organised according to connotative meanings, in order to increase the significance of data and to determine the connections between the categories (Feldman, 1993).
- A system for categorisation was developed in order to organise the obtained data for data analysis and interpretation.
- The categories include the following:
  1. The subject's primary feeling about having a sibling with a disability.
  2. The subject's feelings about family interaction regarding the influence of the sibling with a disability.
  3. The social support networks that are available to the subject.
  4. The subject's knowledge of the disability.
  5. The subject's expression of his/her feelings about the sibling with a disability.
  6. The subject's future expectations for the sibling with a disability.
  7. The subject's perception of how others view the sibling with a disability.
  8. The subject's perception of how he/she is viewed by their peers.
  9. Conflict situations within the family and conflict resolution.

Table 3.9 provides a description of the categories.

**TABLE 3.9: Explanation of the categories for data analysis**

Category	Explanation of the content of each category	Sub-categories within each category	Rating scales for each category
1. The subject's primary feeling about having a disabled sibling.	This includes any factors suggesting that the subject experiences the situation of having a sibling with a disability as being positive or negative, or that he/she have ambivalent feelings about the situation or if he/she are uncertain about their appraisal of the situation. The primary appraisal of the situation, classifies it as being positive, negative or irrelevant (Lazarus & Folkman, 1985).	<ul style="list-style-type: none"> <li>A positive appraisal of the situation, implies that the subject appraises the overall situation as being positive. Responses include: <i>"I think it's great having a sister like that..."</i> (subject 3; 15 years).</li> <li>A negative appraisal of the situation, implies that the subject appraises the overall situation as being negative. Responses include: <i>"She gets a lot of attention from my dad and that makes me jealous..... she knows she gets all the attention."</i> (subject 8; 15 years).</li> <li>The ambivalent appraisal of the situation, implies that the subject's appraisal of the overall situation varies between positive and negative appraisal. Responses include: <i>"It's.... sometimes it's difficult for me and sometimes it's nice...."</i> (subject 1; 13 years).</li> </ul>	1. Yes 2. No 3. Ambivalent
2. The subject's feelings about family interaction regarding the influence of the sibling with a disability.	The subject might feel that the presence of the sibling with a disability influences the family interaction that takes place.	<ul style="list-style-type: none"> <li>Places increased socio-economical demands on the family.</li> <li>Unrestricted family interaction takes place.</li> <li>The subject has to deny his/her own needs because of the sibling with a disability.</li> <li>The subject has unexpressed emotions with regard to having a sibling with a disability.</li> <li>The subject admits to not participating in family activities and preferring to do things on his/her own.</li> <li>The subject is dissatisfied with the amount of care giving responsibilities he/she has, regarding the sibling with a disability.</li> </ul>	1. Yes 2. No 3. Ambivalent
3. The social support networks that are available to the subject.	Social support networks are part of families' coping resources. These social support networks include extended family, professionals, family friends, people from the church, parent support groups, etc. Families with more supportive social networks, are associated with better personal well-being, more positive attitudes and more positive influences on parent-child interaction and child development (Dunst & Trivette, 1986, p. 403).	<ul style="list-style-type: none"> <li>The subject's parents support him/her regarding his/her sibling's disability, e.g. discussing the disability.</li> </ul>	1. <i>Very little support</i> – the parents and the subject seldom discuss the sibling's disability. 2. <i>Reasonable support</i> – the parents and the subject discuss sibling's disability occasionally. 3. <i>Well supported</i> – the parents and the subject often discuss issues regarding the sibling's disability.

**TABLE 3.9: Explanation of the categories for data analysis (continued)**

Category	Explanation of the content of each category	Sub-categories within each category	Rating scales for each category
3. The social support networks that are available to the subject.		<ul style="list-style-type: none"> <li>Other family members, e.g. grandparents, uncles or aunts, support the family with the sibling with a disability.</li> </ul>	1. <i>Very little support</i> - the family receives almost no support from other family members. 2. <i>Reasonable support</i> - the family occasionally receives support from other family members. 3. <i>Well supported</i> - other family members are involved with the disabled sibling and give support on a regular basis when needed.
		<ul style="list-style-type: none"> <li>The family is supported by other people, e.g. neighbours, family friends, other families with a disabled member, regarding the sibling with a disability.</li> </ul>	1. <i>Very little support</i> - the family receives no support from, e.g. friends/ neighbours. 2. <i>Reasonable support</i> - the family is supported by e.g. only one friend / neighbour on occasion. 3. <i>Well supported</i> - the family receives support from a lot of other people on a regular basis.
		<ul style="list-style-type: none"> <li>Professionals, e.g. teachers, doctors and therapists, support the family with the sibling.</li> </ul>	1. <i>Very little support</i> - the family receives almost no support from professionals. 2. <i>Reasonable support</i> - the family occasionally receives support from professionals. 3. <i>Well supported</i> - the family receives support from professionals, e.g. teachers at the disabled sibling's school on a regular basis.
		<ul style="list-style-type: none"> <li>The subject is supported by peers, regarding the sibling with a disability.</li> </ul>	1. <i>Very little support</i> - the subject has no friends and doesn't receive any support from peers. 2. <i>Reasonable support</i> - the subject is supported by one/two friends. 3. <i>Well supported</i> - the subject receives a lot of support from two friends or more.
4. The subject's knowledge of the disability.	In order for the subject to employ effective coping strategies, it is necessary for him/her to understand the disability and its consequences. He/she has to realise that he/she needs to be involved in a process of meaning-making regarding the disability of his/her sibling.	<ul style="list-style-type: none"> <li>The subject knows what exactly is wrong with the sibling with a disability.</li> </ul>	1. <i>Very little</i> - the subject seems to have limited knowledge about the disability. 2. <i>Simplistic</i> - the subject knows some general things about the disability, but is not well informed. 3. <i>Satisfactory</i> - the subject knows the diagnosis of the disabled sibling and the main characteristics of the disability.



**TABLE 3.9: Explanation of the categories for data analysis (continued)**

Category	Explanation of the content of each category	Sub-categories within each category	Rating scales for each category
5. The subject's expression of his/her feelings about the disabled sibling.	The subject's ability to freely express his/her feelings about the disabled sibling and the disability, allows for more effective adjustment (Marsh, 1992).	<ul style="list-style-type: none"> <li>The subject freely expresses his/her feelings regarding the disabled sibling during the interview, according to the raters.</li> </ul>	1. The subject freely expresses his/her feelings about the disabled sibling. 2. Rationalisation of the issue, by acting as if he/she has mostly positive feelings regarding the disabled sibling. 3. Ambivalent - the subject has mixed feelings regarding his/her disabled sibling.
		<ul style="list-style-type: none"> <li>The subject places his/her possible negative feelings onto other issues, e.g. someone at school, etc.</li> <li>The subject only expresses positive feelings regarding the sibling with a disability and doesn't state any negative feelings according to the raters.</li> </ul>	1. Yes 2. No
	Subjects may experience feelings of anger and guilt towards the sibling with a disability.	<ul style="list-style-type: none"> <li>The subject experiences feelings of guilt about his/her feelings about the disabled sibling.</li> <li>The subject understands why he/she is feeling guilty about the way he/she feels about the disabled sibling.</li> </ul>	1. Yes 2. No
6. The subject's future expectations for the disabled sibling.	Siblings of severely disabled children often experience anxiety and fear when thinking about the child with a disability's future, as well as their own (Marsh, 1992).	<ul style="list-style-type: none"> <li>The subject has appropriate future expectations for the disabled sibling.</li> <li>The subject sees him-/herself playing an active role in the future of the sibling with a disability, e.g. that the sibling is living with him/her.</li> <li>The subjects feels uncertain about what might happen to the sibling with a disability in the future.</li> <li>The subject is uncertain about the way having a sibling with a disability, will influence his/her own future, e.g. the subject doesn't know who will take care of the sibling when their parents are no longer there.</li> </ul>	1. Yes 2. No
7. The subject's perception of how others view the disabled sibling.	Siblings of disabled children are often confronted by what strangers, other family members and family friends, etc. think about the disabled sibling.	<ul style="list-style-type: none"> <li>Others accept the sibling with a disability without any prejudice. Responses can include: "..... the boy told a lot of other people and they started to tease him... I don't like that...." (subject 1; 13 years).</li> <li>People don't know how to act in the company of the sibling with a disability. Responses can include: "The people next door treat him as if he is stupid....." (subject 12; 15 years).</li> </ul>	1. Yes 2. No

**TABLE 3.9: Explanation of the categories for data analysis (continued)**

Category	Explanation of the content of each category	Sub-categories within each category	Rating scales for each category
8. The subject's perception of how he/she is viewed by his/her peers.	The coping responses employed by adolescents are related to how they perceive themselves and their perception of how others view them (Spencer et al. 1999).	<ul style="list-style-type: none"> <li>• The subject is uncertain about his/her friends' perception of him/her.</li> <li>• The subject feels that his peers think of him/her as a good friend.</li> <li>• The subject feels that peers admire him/ her for coping with a sibling with a disability.</li> </ul>	1. Yes 2. No
9. Conflict situations within the family and conflict resolution.	Adolescent behaviour shows that in situations of familial conflict, they tend to withdraw, which can be seen as ineffective coping (Seiffge-Krenke & Shulman, 1993).	<ul style="list-style-type: none"> <li>• The subject is involved in conflict situations with the disabled sibling from time to time.</li> <li>• The subject avoids conflict situations involving the disabled sibling.</li> <li>• The subject feels satisfied with the way the parents handle conflict situations with the disabled sibling.</li> <li>• The subject is involved in conflict situations with his/her parents, about issues concerning the disabled sibling.</li> <li>• The subject avoids conflict situations involving the sibling with a disability.</li> <li>• The subject avoids conflict situations involving the sibling with a disability.</li> <li>• The subject is involved in conflict situations with his/her parents, about issues concerning the sibling with a disability.</li> </ul>	1. Yes 2. No

### 3.6.1 Reliability and validity of category ratings.

- It is essential to ensure reliability and validity during the categorisation and thematic analysis of data. The reliability of the individual categories for data analysis was ensured by using intra- and inter-rater reliability.
- Inter-rater reliability checks were done by a registered psychologist who also categorised the responses. Results were compared and adapted when necessary.
- The analysed data of approximately 25% of the subjects (subjects 3, 6, 9, 12 and 15) were counterchecked. These subjects provided the researcher with adequate information to provide answers to the aims of the study.
- Validation for categorisation of data was obtained by means of conversation between the researcher and the psychologist during the process of discussing the reliability and validity of the data and the identified categories.
- A final comparison was made between the identified categories. The comparison was made according to the reliability formula of Miles & Huberman (1994, p. 64):

$\text{RELIABILITY} = \text{Number of agreements} / (\text{total number of agreements} + \text{disagreements})$
---

- The above mentioned formula was used and an inter-rater reliability of 95% was obtained. Table 3.10 provides the data that was used.

**TABLE 3.10: Inter rater reliability on categories rated**

Subjects	Similarities between raters	Differences between raters
3	9	1
6	17	1
9	12	1
12	10	0
15	21	1
<b>TOTAL</b>	<b>69</b>	<b>4</b>

The responses were analysed by the SAS programme.

- A qualitative study aims to describe the information obtained from the subjects. Proportional percentages were therefore used to describe individual responses and to highlight specific trends that emerged from the data.
- The proportional percentages of the results were calculated according to the data sheets produced by the SAS programme,

### **3.7 Summary**

This chapter consists of a discussion of the main aim and sub-aims of the study. It also describes the methods for data collection as well as the methods for data analysis.

## CHAPTER 4

# RESULTS AND INTERPRETATION

The responses of the subjects were analysed in order to identify meaningful units, which were categorised according to specific categories. The information obtained will therefore be discussed within the framework of these categories. The information obtained from the questionnaires for parents will be discussed according to the specific questions of the questionnaire. These results will be integrated with the results from the interviews with the subjects in order to address the specific sub-aims for this study.

### 4.1 Results as obtained from the questionnaire for the parents

Although the focus of this study is on the young adolescents and their experiences, some information from the parents and their perspective seemed relevant in providing a context for understanding. The questionnaire for parents (Appendix B), was filled in by one of the parents of the subjects. The information, will be discussed according to some of the categories of the questionnaire which are relevant for the interpretation of the responses of the adolescents, because it provides background regarding the results. This information serves as relevant data to compare the results as obtained during the interviews with the siblings. It is possible that the subjective perspectives of the subjects and their parents may be dissimilar or similar and it is important to recognize these differences and similarities.

The categories are as follows:

- The parent's perception of the family's adaptation with regard to the fact that they have a family member with a disability.
- The parent's perception of professional support services utilised by the family.

- The information given to the subject regarding his/her sibling's disability.
- **The parents' perceptions of the family adaptation with regard to the fact that they have a family member with a disability**

Twelve (63%) of the subjects' parents consider their families to be well adapted to the stressor of having a sibling with a disability. The other seven (37%) subjects' parents feel that they are well adapted only at times.

According to most of the parents (88%), their families don't need additional help in adapting to the fact that one of the family members is disabled. Only two (12%) of the parents felt that their children need additional support in coping with having a sibling with a disability. One of the parents felt that although the subject doesn't need professional help in adjusting to the sibling with a disability at this stage, it would have helped the family to receive some professional support at an earlier stage.

- **Professional support services utilised by the family**

According to the responses of the parents, only seven (41%) of the seventeen families have received professional help in order to help them adapt to the fact that they have a child with a severe disability. The percentages of support services received from professionals by these families, are provided in table 4.1:

**Table 4.1: Professional support received by the families of the subjects**

<b>Professionals</b>	<b>Proportional percentage (n=17)</b>
Doctors	58% (n=10)
Therapists	71% (n=12)
Teachers	58% (n=10)
Others (e.g. parental support groups)	58% (n=10)

Of the 41% of the families that did receive professional support regarding the sibling with a disability, most of them (71%), received support from therapists. Although

these parents received some professional support, it is not necessarily indicative of the amount of professional support that was given to the subjects.

- **The information given to the subject regarding his/her sibling's disability**

Ten of the subjects (53%) were given information regarding their siblings' disabilities by both their parents, while six (32%) of them were given information by their mothers alone. According to their parents, two (11%) of the siblings weren't given any information regarding their siblings' disabilities, because "*they grew up with it.*"

According to the questionnaire filled in by the parents, the information that was given to the subjects, can be described as follows:

- *The sibling with a disability is special and has to be treated differently.*
- *The sibling with a disability doesn't have the same abilities as "normal" children to learn how to read and write.*
- *The subjects were told the exact truth about the sibling's disability.*
- *They have to accept their sibling's disability.*
- *They have to pray for the sibling with a disability.*
- *The sibling with a disability has to be treated as "normal" as possible.*

#### **4.2 Results as obtained during the interviews with subjects**

The results obtained during the interview with the subjects, will be discussed within the following categories:

1. The subject's primary feelings about having a sibling with a disability.
2. The subject's feelings about family interaction regarding the influence of the sibling with a disability.
3. The social support networks that are available to the subject.
4. The subject's knowledge of the disability.
5. The subject's expression of his/her feelings about the sibling with a disability.
6. The subject's future expectations for the sibling with a disability.
7. The subject's perception of how others view the sibling with a disability.

8. The subject's perception of how he/she is viewed by his/her peers.
9. Conflict situations within the family and conflict resolution.

#### 4.2.1 The subject's primary feelings about having a sibling with a disability

The subjects' responses were judged according to the following sub-categories:

- a positive appraisal of the overall situation,
- a negative appraisal of the overall situation and
- an ambivalent appraisal of the overall situation.

Table 4.2 provides a summary of the subjects' primary feelings about having a sibling with a disability (table 3.9 explains the sub-categories).

**TABLE 4.2: The subjects' primary feelings about having a sibling with a disability**

Primary feelings	Proportional percentage (n=19)
A positive appraisal of the overall situation.	21% (n=4)
A negative appraisal of the overall situation.	32% (n=6)
An ambivalent appraisal of the overall situation.	47% (n=9)
<b>TOTAL</b>	<b>100%</b>

Even though it is known that adolescents change their thoughts and ideas as adolescence progresses and tend to lodge ambivalent feelings about most issues, the percentage of ambivalent responses seem to be high. This reaction to the stress of having a sibling with a disability, might be an attempt to regulate the stressful effect and negative emotions associated with having a sibling with a disability. This implies that ambivalence might be a mode of coping used to work through their emotions regarding the issue.

The stressor of having a sibling with a disability may cause a changed perception of what the sibling relationship should be like. It is possible that the subjects' personal identities were influenced, explaining their ambivalent feelings regarding the sibling



with a disability, because bereavement can cause young adolescents to show ambivalence about close relationships (Cotterel, 1996).

On the other hand, almost one third (32%) of the subjects appraises the overall situation as being negative. The negative appraisal of the situation can also be caused by adolescent egocentrism, by which the subjects might feel that they have unique sibling relationships and that they are the only ones having these experiences (Lloyd, 1985; Newman & Newman, 1997). These results raise questions regarding the family interaction.

#### 4.2.2 The subjects' feelings about family interaction, regarding the influence of the sibling with a disability

The subjects' feelings regarding the influence the sibling with a disability has on family interaction, varied considerably. Table 4.3 provides an explanation of the sub-categories and the subjects' responses.

**TABLE 4.3: The subjects' feelings about family interaction**

Subjects' feelings	Proportional percentages			
	Yes	No	Ambiva- lent	TOTAL (n=19)
The sibling's disability places increased socio-economical demands on the family.	16% (n=3)	53% (n=10)	31% (n=6)	100%
Unrestricted family interaction takes place.	32% (n=6)	26% (n=5)	42% (n=8)	100%
The subject has to deny his/her own needs because of the sibling with a disability.	26% (n=5)	47% (n=9)	26% (n=5)	100%
The subject has unexpressed emotions with regard to having a sibling with a disability.	58% (n=11)	26% (n=5)	16% (n=3)	100%
The subject admits to not participating in family activities and preferring to do things on his/her own.	63% (n=12)	37% (n=7)	0% (n=0)	100%
The subject is dissatisfied with the amount of care giving responsibilities he/she has, regarding the sibling with a disability.	37% (n=7)	63% (n=12)	0% (n=0)	100%

From table 4.3 it is evident that most of the subjects didn't see the child with a disability as a socio-economic burden on the family. They also didn't feel that their needs were denied because of the child with a disability. However, they do have

unexpressed emotions regarding the issue and they do feel ambivalent about family interaction.

58% of the subjects have unexpressed emotions regarding their sibling with a disability. The responses of the subjects who have unexpressed emotions regarding their siblings with disabilities, include the following:

"I don't like talking about my brother, because then..... maybe I will say the wrong thing... then I'll be in trouble....." (subject 1; 13 years).

Most of the subjects (63%) admit to not participating in family activities and doing things on their own, while 42% of the subjects feel ambivalent about whether unrestricted family interaction takes place. According to a study done by Prinsloo (1998), the siblings of children with disabilities experience limited family interaction. The quality and nature of family interaction is strongly associated with the coping responses employed by adolescents and their level of adjustment (Seiffge-Krenke & Shulman, 1993).

Adolescents are characterised by the ambivalence of their feelings, but one has to decide whether they are generally ambivalent to this extent and which factors cause the ambivalence. According to Newman & Newman (1997), family interaction continues to be the most central support during early adolescence, although adolescents tend to strive towards independence. Adolescents sometimes experience feelings of loneliness arising from traumatic events. One might hypothesise that adolescents who are securely attached to their families, might experience lower levels of family-related loneliness, than their peers who are not securely attached (Marcoen & Goossens, 1993).

Thirty seven percent (37%) of the subjects feel that they have too many care-giving responsibilities regarding the sibling with a disability. The fact that most of the subjects (63%), feels positive about care giving responsibilities, shows that they are either not involved in any of these activities, or that they really don't mind. Lloyd (1985), states that adolescents usually perceive inequities in household responsibilities, which leads to familial conflict situations. Therefore it is possible that

some of them are avoiding the issue and using ambivalence as a coping response. It is also possible that some of them might feel guilty about their feelings regarding the sibling with a disability and therefore they maintain that they don't mind the care giving responsibilities.

#### 4.2.3 The available social support networks

The social support networks available to the subjects form part of their coping resources. Coping resources empower families to cope with stressful encounters. One might hypothesise that individuals who have more social networks, will have more effective coping resources. Young adolescents need a growing social network to develop social competencies (Cottrell, 1996). Table 4.4 provides a description of the social support networks available to the subjects.

**TABLE 4.4: The subjects' social support networks**

Social support networks	Proportional percentages			
	Very little support	Reasonable support	Well supported	TOTAL (n=19)
The subject is supported by his/her parents regarding the sibling's disability.	42% (n=8)	53% (n=10)	5% (n=1)	100%
The family is supported by other family members, e.g. grandparents, aunts/uncles.	21% (n=4)	47% (n=9)	32% (n=6)	100%
Other people, e.g. family friends, neighbours, etc. support the family.	32% (n=6)	53% (n=10)	16% (n=3)	100%
Professionals, e.g. therapists, doctors and teachers, support the family.	47% (n=9)	37% (n=7)	16% (n=3)	100%
Peers support the subject regarding the sibling with a disability.	16% (n=3)	74% (n=14)	11% (n=2)	100%

Only 5% of the subjects feel that they are well supported by their parents, regarding their sibling with a disability and issues concerning the disability. This finding has relevance if one considers the fact that adolescents who employ effective coping responses, are able to identify a parent or care giver that provides them with the necessary support and attention (Swanson, Spencer & Petersen, 1998).

Family members give reasonable support to 47% of the subjects, by occasionally offering support to the family regarding the sibling with a disability. 32% of the subjects are well supported by their extended family. Extended family form part of the family's social support network. Parents who have more supportive social networks, perceive having a child with a disability as being less stressful, which in turn affects the attitudes of the siblings of the child with a disability (Frank, 1996).

The young adolescent siblings and their families receive help from their grandparents, aunts and uncles. The means of support include baby sitting the children with disabilities, teaching them new things and generally uplifting them and treating them as if they were not disabled. Responses include the following:

*"... they're always uplifting him...."* (subject 6; 15 years).

*"I think they help him most by treating him like a normal child....."* (subject 1; 13 years).

*"..... when we stay with them (grandparents) .... they sit with her to teach her how to read and write...."* (subject 9; 13 years).

Adolescents value their grandparents' gentle attitude, their care and their interest for them. They generally have a positive opinion about their grandparents (Tyskowa, 1993).

Most of the subjects' families (53%) receive reasonable support from other people, e.g. neighbours, family friends, and people from the church, who will support the family on occasion.

Kazak et al. (1984), state that it is beneficial for families with a member with a disability to have a highly developed network of friends. This network can include family friends, neighbours or the parents of other children with disabilities. It is important to encourage families to join family support groups, because discussing common problems and solutions can expand available resources. Members of these support networks may also act as models affecting parenting styles if the network members have effective and nurturing parenting styles.

Most of the subjects (74%) have one/two peers supporting them with issues regarding the sibling with a disability (Seiffge-Krenke & Shulman, 1993). From mid-adolescence onwards, adolescents tend to replace their parents with peers as trustworthy addressees for personal problems. Peer relationships provide the adolescent with a new perspective through which they can co-construct ideas and receive validation from equals (Seiffge-Krenke & Shulman, 1993). However, some of the subjects experience some difficulties with peers who don't understand the issues regarding a child with a disability. Responses include the following:

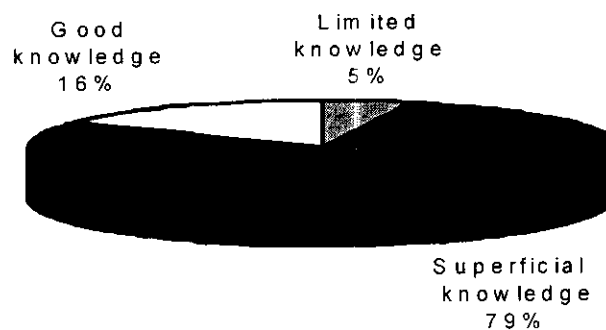
*"Some of them think I'm making up a story.... that my brother isn't really disabled...."*  
(subject 1; 13 years).

*"..... some of them will give me a difficult time because I have a sister like that ....."*  
(subject 10; 13 years).

The results of this study clearly indicate the poor professional support received by the families of the subjects. According to 21% of the subjects, their families are well supported by professionals, such as doctors, therapists and teachers on a regular basis. However, according to the responses of the questionnaire for parents, 41% of the families received professional support regarding the sibling's disability (table 4.1). The discrepancy in the perceived professional support as reported by the subjects and their parents, identifies the limited support given by professionals to the siblings regarding the child with a disability. It appears as if the siblings were not included in the professional support that parents might have received. One of the major needs of families of children with disabilities is to cope with the personal and familial implications of the disability. The limited professional support raises the question whether the subjects and their families had the opportunities to work through powerful feelings of loss, meet each other's needs, resolve problems and conflicts and manage the emotional climate in the home (Siegel & Silverstein, 1994). The limited professional support also impacts on the family members' knowledge of the disability.

#### **4.2.4 The subjects' knowledge of the disability**

Figure 4.1 provides a representation of the subjects' knowledge of the disability.



**FIGURE 4.1: The subjects' knowledge of the disability**

Most of the subjects (79%) have superficial knowledge about their siblings' disabilities, meaning that they know mostly general things about the disability, but they can't name the disability and they don't know its consequences. Responses include the following:

*"Uhm.... she is impaired from her neck downwards. She can't use her hands.... She can only speak a little bit...."* (subject 7; 13 years).

*"Nobody's told me, but I do know that her teacher said that she will never be able to go to a normal school..... okay.... and she can't concentrate very well....."* (subject 9; 13 years).

The fact that most of them don't have detailed knowledge about their sibling's disability, could demonstrate that the subjects have superficial understanding of the sibling's disability and its consequences. This superficial understanding could be related to the fact that the subjects and their families received limited professional support regarding the sibling's disability and consequences (table 4.1).

16% of the subjects have a good knowledge of their siblings' disabilities, because they know the diagnosis and the main characteristics of the disability.

The responses of subjects with good knowledge of their siblings' disabilities, include the following:

*"My parents have told me exactly what is wrong with her. Her right brain is damaged... there was a lack of oxygen when she was born..... and it's impaired her muscles a little bit and her balance and her ability to excel academically." (subject 3; 15 years).*

*"She has a disease... it has a long name I can't remember. If I have to explain it on a low level..... it is a disease that destroys the white gyrus of the brain..... it is not a general thing...." (subject 2; 15 years).*

In summarising the subjects' knowledge of the disability, it appears as if the subjects have a general idea about their siblings' disabilities and the general implications it has regarding education and ability to learn. It is necessary for siblings of children with disabilities to understand the nature and consequences of the disability, in order to employ effective coping strategies (Marsh, 1992).

The subjects in this study's knowledge of the disabilities of their siblings, seems to be associated with both the parental and professional support they receive, which in turn influences their overall appraisal of the situation.

#### **4.2.5 The subject's expression of his/her feelings about the sibling with a disability**

Table 4.5 gives a description of the ease with which the subjects expressed their feelings about their sibling with a disability during the interview according to the raters.

**TABLE 4.5: The subjects' expression of their feelings regarding the sibling with a disability**

The subject's expression of feelings	Proportional percentage		
	Yes	No	TOTAL (n=19)
The subject freely expresses his/her feelings regarding the sibling with a disability according to the raters.	32% (n=6)	68% (n=13)	100%
The subject only expresses positive feelings regarding the sibling with a disability and doesn't state any negative feelings according to the raters.	37% (n=7)	63% (n=12)	100%
The subject projects his/her negative feelings about the sibling with a disability onto other issues, e.g. someone at school, etc.	42% (n=8)	58% (n=11)	100%

According to the raters, the subjects' responses show that only 32% of the subjects freely express their feelings regarding the sibling with a disability.

It is possible that the 37% of the subjects who seemingly only express positive feelings regarding their sibling with a disability, may still be socialised by their parents' attitude regarding the issue, because children tend to adopt their parents' attitude toward the sibling with a disability. This implies that they will say only positive things about the sibling with a disability, because it is expected by their parents (McHale & Gamble, 1987; Powell & Gallagher, 1992; Siegel & Silverstein, 1994).

Subjects could also be rationalising their thoughts regarding their feelings about the sibling with a disability, as they experience guilt and shame because of their feelings. Adolescents who experience guilt, usually try to do a reparative act towards the victim and when it is not possible, their guilt is prolonged (Hoffman, 1980).

Table 4.6 provides an overview of the subjects' responses regarding their feelings of guilt towards the sibling with a disability.



**TABLE 4.6: The subjects' feelings of guilt**

Subjects' feelings of guilt	Proportional percentage		
	Yes	No	TOTAL (n=19)
The subject experiences feelings of guilt about his/her feelings about the sibling with a disability.	58% (n=11)	42% (n=8)	100%
The subject understands why he/she is feeling guilty about the way he/she feels about the sibling with a disability.	32% (n=6)	68% (n=13)	100%

More than half of the subjects (58%) feel guilty about the way they feel about the sibling with a disability. However, only 32% of the subjects understand why they feel guilty about the way they feel about their siblings with disabilities.

Responses of subjects who experienced guilt, included the following:

*"Yes.. sometimes I feel that I'm too selfish and irritable ..... In the evening I wonder if I could have been nicer to her, or have done more..... and sometimes I feel that I could have..."* (subject 2; 15 years).

*"If they treat him as he was made out of gold, because he is disabled, it makes me jealous..... or he thinks he can get away with anything..."* (subject 1; 13 years).

Often subjects experience feelings of anger and guilt towards the sibling with a disability. In normal adolescents these feelings are usually related to the amount of special demands the sibling with a disability places on the family (Lloyd, 1985; Newman & Newman, 1997). Since only a few of the subjects are dissatisfied with the amount of care giving responsibilities they have (table 4.3), these feelings of anger, guilt and jealousy, could be related to the quality of family interaction and the subjects' superficial understanding of the disability and its consequences (Powell & Gallagher, 1992; Siegel & Silverstein, 1994).

According to the subjects' responses, only 32% understand why they experience feelings of guilt about their feelings towards their siblings with disabilities. Once again these results emphasise the subjects' superficial understanding of the disability and its consequences. These feelings of guilt cause loneliness and isolation in the young adolescent, which in turn, cause the adolescent to shy away

from other close relationships, e.g. sibling relationships and peer relationships (Newman & Newman, 1997).

#### 4.2.6 The subjects' future expectations regarding their siblings with disabilities

Linked to the subjects' feelings regarding the sibling with a disability, are their future expectations for themselves as well as the sibling with a disability

Table 4.7 provides us with the responses of the subjects regarding their future expectations for themselves as well as their siblings with disabilities.

**TABLE 4.7: The subjects' future expectations**

Subjects' future expectations	Proportional percentage		
	Yes	No	TOTAL (n=19)
The subject has appropriate future expectations for the sibling with a disability regarding education and employment according to the raters.	47% (n=9)	53% (n=10)	100%
The subject sees him-/herself playing an active role in the future of the sibling with a disability, e.g. providing financial support or taking care of the sibling.	37% (n=7)	63% (n=12)	100%
The subject feels uncertain about what might happen to the sibling with a disability in the future.	58% (n=11)	42% (n=8)	100%
The subject is uncertain about the way having a sibling with a disability, will influence his/her own future.	47% (n=9)	53% (n=10)	100%

More than half of the subjects' (53%) future expectations for their siblings with disabilities regarding issues of education and employment, don't seem to be appropriate according to the raters. Their future expectations are not compatible with the nature and severity of their siblings' disabilities. Responses include the following:

*"He can be anything if he really wants to.. maybe he can be a mechanic...."*

(Subject 1; 13 years, whose brother has severe mental retardation.)

This could be attributed to the fact that they possibly didn't receive adequate information about the disability and its consequences, because most of the subjects and their families didn't receive adequate professional support in terms of their sibling's disability and its consequences. It can also be because they avoid the issue of their siblings' future, by creating unrealistic expectations regarding their education and employment (Marsh, 1992).

Fifty three percent of the subjects (58%) feel uncertain about what might happen to the sibling with a disability in the future, which include responses like:

*"Actually I don't know if he has a future.... it looks as if they don't do much at school.... so I don't know...."* (subject 4; 15 years).

Lack of knowledge and information about the disability and its consequences, can not only cause subjects to have unrealistic future expectations, but also uncertainty regarding issues concerning the future of their sibling with a disability. These issues include the prognosis for the disability, the specialised services that may be required and the possible impact on family relationships (Powell & Gallagher, 1993).

Some of the subjects (47%) are uncertain about how their own future will be influenced by the fact that they have a sibling with a disability. They are not sure about what their role will be in the future of the sibling with a disability, whether or not they will also have child with a disability and how it will influence their relationships with members of the opposite sex (Powell & Gallagher, 1993). Responses include the following:

*"... hopefully I will have a wife and children who'll love him..."* (subject 5; 15 years).

*"I've had a boyfriend or two..... but sometimes when I have a male friend that keeps his distance.... I wonder if he thinks that I'm going to have a child like that..."* (subject 2; 15 years).

One third of the subjects (37%), see themselves playing an active role in the sibling with a disability's future. This include them providing financial support for the sibling

with a disability or taking care of the sibling in future. Responses include the following:

*"I will change my whole lifestyle to suit him... I'll change the way I do things, my timetables for work....."* (subject 5; 15 years).

*"I plan to look after her when we're grown up....."* (subject 8; 15 years).

These perceptions of the subjects can also be because of adolescent egocentrism. Egocentrism implies that the subjects are at the beginning of a new phase of development (early adolescence) and they still have a limited perspective regarding their life plans. They haven't yet realised that their own life plans need to be adapted to the needs and expectations of relevant others (Newman & Newman, 1997). Therefore these subjects still think that their way of thinking is unique and that they are the only ones responsible for the sibling with a disability.

The fact that so few of the subjects see themselves playing an active role in their sibling's future, is also influenced by the fact that they have superficial knowledge regarding the disability and its future implications. The subjects' perceptions regarding their siblings with disabilities' future, influence not only their ability to cope, but also their perceptions of how others might view them, as well as their sibling with a disability (Siegel & Silverstein, 1994).

#### **4.2.7 The subjects' perceptions of how others view their siblings with disabilities.**

The siblings of children with disabilities are often confronted by the attitudes of strangers, other family members and family friends towards the sibling with a disability. Table 4.8 provides a summary of the subjects' perceptions.

**TABLE 4.8: The subjects' perceptions of how others view their siblings with disabilities**

Subjects' perceptions	Proportional percentages		
	Yes	No	TOTAL (n=19)
They accept the sibling without prejudice.	11% (n=2)	89% (n=17)	100%
People don't know how to act in the presence of the sibling with a disability.	84% (n=16)	16% (n=3)	100%

89% percent of the siblings feel that others do not accept the sibling with a disability without prejudice. Responses include the following:

*"I get frustrated when someone just stares at her when she is sitting in her wheelchair...."* (subject 2; 15 years).

*"... the boy told a lot of other people and they started to tease him.... I don't like that."* (subject 1; 13 years).

The subjects seem to be aware of social realities regarding equity for people with disabilities, because most of the subjects (84%) feel that other people don't know how to act in the presence of the sibling with a disability. The following are examples of the responses:

*"The people next door treat him as if he's stupid....."* (subject 12; 15 years).

*"It's a bit distressing sometimes, because people..... they don't know about her and they tease me about her...."* (subject 10)

The fact that the subjects feel that people are prejudiced in their acceptance of their siblings with disabilities, can cause the adolescents to feel lonely and isolated. These feelings of loneliness and isolation could reflect a distance between the subjects and their siblings. Normally some adolescents also encounter feelings of loneliness and isolation, because of the unique set of social expectations encountered by them and they need support in handling these circumstances (Marcoen & Goossens, 1993).

#### 4.2.8 The subjects' perceptions of how they are viewed by their peers

The coping responses employed by adolescents are related to how they perceive themselves and their perception of how others view them (Spencer et al. 1999). Table 4.9 provides a description of the subjects' perceptions of their peers' view about them.

**TABLE 4.9: The subjects' perception of he/she is viewed by their peers**

Subjects' perceptions	Proportional percentages		
	Yes	No	TOTAL (n=19)
The subject is uncertain about his/her friends' opinion of him/her.	42% (n=8)	58% (n=11)	100%
The subject feels that his peers think of him/her as a good friend.	63% (n=12)	37% (n=7)	100%
The subject feels that his/her peers admire him/her for coping with a sibling with a disability.	63% (n=12)	37% (n=7)	100%

Most of the subjects (63%) feel that their peers think of them as being good friends, while 42% of the subjects feel uncertain about their friends think about them. Responses include the following:

*"They really think I'm a nice guy. They like me because I'm always fun.... always making jokes and stuff...."* (subject 6; 15 years).

*"....uhh.... they think I'm a good friend... uh... that I'm friendly.... and that I work hard..."* (subject 7; 13 years).

These perceptions can be interpreted as being positive, with regard to the fact that adolescents need peer support in order to establish psychological autonomy. Being positively evaluated by peers, is a source of higher self-esteem among adolescents (Lloyd, 1985)

Some of the siblings (63%) also feel that their peers admire them for having to cope with a sibling with a disability. *"They think I'm a good person for coping with a brother like that....."* (subject 19; 12 years).

This perceived admiration may enhance self-esteem, but it is also directly linked to the egocentrism of adolescents (Lloyd, 1985).

It seems as if most of the subjects feel that they have at least one good friend. By participating in social and interpersonal relationships, adolescents are provided with coping resources for developmental tasks and possible stressful encounters. Peers provide adolescents with opportunities for observing others' coping responses and how effective these responses are. The peer group provides the adolescent with emotional support, without which they may feel lonely and insecure (Kirchler, Palmonari & Pombeni, 1993).

#### 4.2.9 Conflict situations within the family and conflict resolution

Table 4.10 provides us with the subjects' responses regarding the conflict situations in which they are involved in with their siblings with disabilities, their parents and how these situations are usually resolved.

**TABLE 4.10: Familial conflict and conflict resolution**

Familial conflict and conflict resolution	Proportional percentage		
	Yes	No	TOTAL (n=19)
The subject is involved in conflict situations with the sibling with a disability from time to time.	42% (n=8)	58% (n=11)	100%
The subject avoids conflict situations involving the sibling with a disability.	37% (n=7)	63% (n=12)	100%
The subject feels satisfied with the way the parents handle sibling conflict situations with the sibling with a disability.	47% (n=9)	53% (n=10)	100%
The subject is involved in conflict situations with his/her parents, about issues concerning the sibling with a disability.	42% (n=8)	58% (n=11)	100%

According to the responses of subjects, only 42% of the subjects are involved in conflict situations with their siblings with disabilities and the same percentage of

subjects are involved in conflict situations with their parents about issues concerning the sibling. The following illustrates their views on the conflict situations with their siblings with disabilities:

*"If I look at other children.... how they fight.... Maybe it's because he is disabled.... we never fight... I do get irritated with him..."* (subject 4; 15 years).

*"We don't actually fight, but we do have our differences.... but mostly we're friends.."* (subject 7; 13 years).

Conflict between adolescents and their parents normally tends to be about mundane issues such as performing household chores, doing homework, or spending money, rather than on family values (Newman & Newman, 1997). However, the subjects in this study reported conflict situations with their parents regarding issues concerning the sibling with a disability. It is possible that sibling conflict might evolve into conflict between the subjects and their parents with regard to issues concerning the sibling with a disability (Powell & Gallagher, 1992).

There is a rather low incidence of conflict situations between the subjects and their siblings with disabilities, although normally adolescents are involved in increased sibling conflict (Newman & Newman, 1997). This could be explained by the subjects' superficial knowledge about their sibling's disability, which inhibits their understanding of the disability. In turn this superficial understanding causes the subjects to have varying feelings (ambivalence) regarding sibling interaction, which might be responsible for some distance in the relationship.

### **4.3 Summary**

In summarising the results and interpretation of this study, there are a few trends that have emerged. These themes provide us with information regarding the way the adolescent subjects experience the situation of having a sibling with a disability.



The young adolescent subjects of this study, together with their parents seem to have received little professional support. In turn, this limited professional support to the families is reflected by the subjects' superficial knowledge about the sibling's disability and its consequences. This superficial knowledge of the disability could impact on their level of understanding and contribute to the ambivalent feelings they have towards the sibling with a disability. It also influences their future expectations for their siblings with disabilities.

Subjects' feelings of guilt about their feelings towards their siblings with disabilities, manifest in their projection of negative feelings onto other issues and the rationalisation of their feelings by highlighting only the positive aspects regarding the sibling relationship. They have unexpressed emotions regarding the sibling with a disability, which lead to feelings of guilt and fear, and in turn they may cause young adolescents to feel lonely and isolated. Feelings of loneliness and isolation are widespread in adolescents and this could arise from emotionally traumatic events, such as the stressor of having a sibling with a disability (Cotterel, 1996). Most of the subjects perceive other people to be prejudiced against the sibling with a disability and they feel that most people don't know how to act in the presence of the sibling. Fear of rejection due to the sibling's disability, can cause the adolescents to feel lonely and isolated and is linked to adolescent egocentrism (Lloyd, 1985).

Subjects seem to feel that their peers support them better than their parents. During early adolescence peer relationships take on a new importance, because they provide the adolescent with opportunities for emotional intimacy, support, and understanding, as well as companionship and fun. However, adolescents typically maintain an emotional attachment to their families and their family value orientations, because positive interactions with parents at home provide adolescents with a sense of well-being (Newman & Newman, 1997). The subjects' perception that they receive more peer support than parental support, can also be related to the fact that they have unexpressed emotions regarding the sibling with a disability and they have limited family interaction, leaving them with fewer opportunities to express their point of views.

Newman & Newman (1997) state that parents and adolescents can communicate more effectively if they have frequent interactions and allow for the expression of conflict. There seem to be relatively few conflict situations between the subjects and their siblings with disabilities. However, there seems to be an association between the conflict with the sibling with a disability and the conflict situations between the subjects and their parents regarding the siblings with disabilities. Increased familial conflict is normal for adolescents, but it is usually about mundane issues, such as money, watching television, dating, etc. (Lloyd, 1985).

## CHAPTER 5

# CONCLUSION AND RECOMMENDATIONS

Children with severe disabilities have a definite impact on the lives of their family members. The majority of the adolescents with a sibling with a disability, together with their parents, have received limited professional support. The limited professional support received by them, manifests in the adolescents' superficial knowledge of the sibling's disability and its consequences. Their superficial knowledge of the disability and its consequences, affects their understanding of the disability and it increases their feelings of uncertainty regarding the sibling with a disability. Crnic et al. (1983), confirms the importance of professional support in the understanding of the disability.

Most of the adolescents are not freely expressing their feelings regarding the sibling with a disability and, combined with their superficial knowledge of the disability, it adds to their feelings of guilt. They feel guilty about their feelings towards the sibling with a disability, which leads the young adolescents to feel lonely and isolated (Cotterell, 1996; Abell & Gecas, 1997).

According to the perceptions of the young adolescents, members of their peer group support them better than their parents. It is normal for adolescents to rely on the support of peers, although they still have an emotional attachment to their families. The subjects of the study report limited family interaction, which links to their perceived limited parental support and their inability to freely express emotions. This inability to express their emotions, leads to the projection of negative feelings onto other issues and the avoidance of any negative emotions.

Adolescent siblings need adequate professional and parental support to cope with the stressor of having a sibling with a disability. They need to have the opportunity to voice their feelings regarding the issue. Powell & Gallagher (1992) state that support groups for siblings of children with disabilities might facilitate coping responses and help in the process of adjustment.

## **5.2 Critical evaluation of this study**

- Little is known about the coping behaviour of the adolescent siblings of children with disabilities and the study focused exclusively on children in early adolescence (12-15 years).
- The open-ended, unstructured interview provided the subjects with the opportunity to voice their exact feelings regarding the stressor of having a disabled sibling, although it complicated the data analysis.
- Approximately 25% of the analysed data was counterchecked by an external rater, which improves the reliability of the data obtained. However, if there was a larger data set and if more than one method of measurement were used, these strategies could have added to the reliability of the results.
- If more than one interview could have been conducted with each of the subjects over a period of time, it would have enhanced the data, especially when considering the dynamic nature of stress and coping.
- Although adolescents are at a self-conscious age that might have influenced the reliability of the information obtained regarding their personal feelings, caution was taken to ensure that all participants felt at ease before the interviews were conducted. The interviews were conducted within an informal atmosphere at the homes of the subjects.

### **5.3 Recommendations**

Recommendations regarding further research and clinical practice are outlined in the next section:

#### **5.3.1 Implications for further research**

- A study on the sibling relationships of young adolescents with normal siblings can be done in order to identify trends within sibling relationships of adolescents who don't experience the stressor of having a sibling with a disability. The results can be compared with the results of this study.
- Research on the nature of the interaction between the young adolescents and their siblings with disabilities can be done.
- Research to determine the knowledge and understanding of siblings and parents regarding the disability of the sibling and its consequences might provide valuable insight into the lives of families with a member with a disability.
- A study can be done to determine the needs of the families of children with severe disabilities, with regard to professional support services, e.g. counselling, family support groups, etc.
- Specific siblings of children with severe disabilities can be studied over a longer period of time, e.g. early childhood to adolescence and a comparison could be drawn between their coping responses during different developmental stages.
- A study can be done specifically about the social support the siblings with disabilities receive from their peers. Especially in the case of adolescents, it will provide valuable information regarding the exact influence peers have on them and how they mediate or impede the coping responses of the siblings.
- The adolescent siblings of children with disabilities experience feelings of guilt about their feelings regarding the sibling with a disability. A study that examines these feelings of guilt can be conducted.

### 5.3.2 Implications for clinical practice

- In general the parents of children with severe disabilities are responsible for informing the other siblings about the disability and its consequences. Parental attitudes towards the disability influences the siblings' perceptions and coping responses, which highlights the importance of the following:
  - the parents need to be provided with adequate and accurate information regarding the disability and its consequences, in order to provide the other siblings with information about issues concerning the child with a disability;
  - the parents need more professional support, especially regarding issues concerning the disability and its consequences, as well as the acceptance of the disability and coping with the stressor.
- The adolescent siblings of children with severe disabilities are not freely expressing their feelings, they have feelings of guilt about the sibling with a disability and they receive limited professional and parental support. These issues can be addressed as follows:
  - professionals need to focus on the needs of young adolescents with regard to their siblings' disabilities and its consequences;
  - siblings need guidance on active coping responses in coping with the stressor of having a sibling with a disability;
  - sibling support groups may provide siblings of children with disabilities with peer support, as well as models of coping with the situation.

## BIBLIOGRAPHY

- Abell, E. & Gecas, V.** (1997). Guilt, Shame and Family Socialization: A retrospective study. *Journal of Family Issues*, 18(1), pp. 99-122.
- Alper, S. K., Schloss, P. J. & Schloss, C. N.** (1994). *Families of Students with Disabilities: Consultation and Advocacy*. Boston: Allyn & Bacon.
- Barrel, J. B.; Aanstoos, C.; Richards, A. C. & Arons, M.** (1987). Human Science Research Methods. *Journal of Humanistic Psychology*, 27(2), pp. 424-457.
- Beckman, P. J.** (1983). Influence of Selected Child Characteristics on Stress in Families of Handicapped Infants. *American journal of Mental Deficiency*, 88(2), pp. 150-156.
- Beckman, P. J., Frank, N. & Smith Stepanek, J.** (1996). "Resolving Conflicts with Families" in Beckman, P. J. (Ed.): *Strategies for Working with Families of Young Children with Disabilities*. Baltimore: Paul H. Brookes Publishing Company.
- Breslau, N., Weitzman, M. & Messenger, K.** (1981). Psychologic Functioning of Siblings of Disabled Children. *Pediatrics*, 67(3), pp. 344-353.
- Bronfenbrenner, U.** (1979). *The ecology of human development: Experiments by nature and design*. Cambridge: Harvard University Press.
- Bryant, B. K. & Litman, C.** (1987). "Siblings as teachers and therapists" in Schachter, F. F. & Stone, R. K. (Ed.): *Practical concerns about siblings: Bridging the research-practice gap*. New York: Haworth Press.

- Burd, L.; Hammes, K.; Bornhoeft, D. & Fisher, W. (1988).** A North Dakota prevalence study of nonverbal school-age children. *Language, Speech, and Hearing Services in Schools*. 19 (4), 371 - 383.
- Byrne, E. A. & Cunningham, C. C. (1985).** The Effects of Mentally Handicapped Children on Families - A Conceptual Review. *Journal of Child Psychology and Psychiatry*, 26(6), pp. 847-864.
- Cherry, D. B. (1989).** Stress and Coping in Families with Ill or Disabled Children: Application of a Model to Pediatric Therapy. *Physical & Occupational Therapy in Pediatrics*, 9(2), pp. 11-32.
- Cotterell, J. (1996).** *Social Networks and Social Influences in Adolescence*. Routledge: London.
- Crnic, K. A., Friedrich, W. N. & Greenberg, M. T. (1983).** 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.
- Dale, N. (1996).** *Working with Families of Children with special Needs: Partnership and Practice*. London: Routledge.
- Denzin, N. K. & Lincoln, Y. S. (1998).** "Introduction: Entering the Field of Qualitative Research" in Denzin, N. K. & Lincoln, Y. S. (Eds.): *Strategies of Qualitative Inquiry*. London: SAGE Publications.
- Dunst, C. J., Trivette, C. M. & Cross, A. H. (1986).** Mediating Influences of Social Support: Personal, Family and Child Outcomes. *American Journal of Mental Defficiency*, 90(4), pp. 403-417.
- Dyson, L. L. (1989).** Adjustment of Siblings of Handicapped Children: A comparison. *Journal of Pediatric Psychology*. 14(2), pp. 215-229.



- Feldman, M. S.** (1995). *Strategies for interpreting Qualitative Data*. London: SAGE Publications Incorporated.
- Fischer, J. & Roberts, S. C.** (1983). The Effect of the Mentally Retarded Child on his Siblings. *Education*, 103, pp. 399-401.
- Folkman, S., Schaefer, C. & Lazarus, R. S.** (1979). "*Cognitive processes as mediators of stress and coping*" in Hamilton, V. & Warburton, D. W. (Eds.): *Human stress and cognition*. New York: John Wiley.
- Frank, N.** (1996). "*Helping Families Support Siblings*" in Beckman, P. J. (Ed.): *Strategies for Working with Families of Young Children with Disabilities*. Baltimore: Paul H. Brookes Publishing Company.
- Frey, J. H. & Mertens, O. J.** (1995). *How to conduct interviews by telephone and in person*. London: SAGE Publications Incorporated.
- Furman, W. & Buhrmester, D.** (1985). Children's Perceptions of the Qualities of Sibling Relationships. *Child Development*, 56, pp. 448-461.
- Gath, A. & Gumley, D.** (1987). Retarded Children and their Siblings. *Journal of Child Psychology*, 28(5), pp.715-730.
- Grothberg, E.** (1995). A Guide to Promoting Resilience in Children: strengthening the Human Spirit. *Early Childhood Development: Practice and Reflections*, 8, pp. 10-19.
- Harvey, M. & Byrd, M.** (1998). The Relationship between Perceptions of Self-esteem, Patterns of Familial Attachment, and Family Environment During Early and Late Phases of Adolescence. *International Journal of Adolescence and Youth*, 7, pp. 93-111.

**Hill, R. (1949).** *Families Under Stress*. New York: Harper.

**Holroyd, J. & McArthur, D. (1976).** Mental Retardation and Stress on the Parents: A Contrast between Down's Syndrome and childhood Autism. *American Journal of Mental Deficiency*, 80(4), pp. 431-436.

**Holstein, J. A. & Gubrium, J. F. (1998).** "Phenomenology, Ethnomethodology, and Interpretive Practice" in Denzin, N. K. & Lincoln, Y. S. (Eds.): *Strategies of Qualitative Inquiry*. London: SAGE Publications.

**Kazak, A. E. (1986).** Families with Physically Handicapped Children: Social Ecology and Family Systems. *Family Process*, 25, pp. 265-281.

**Kazak, A. E. & Marvin, R. S. (1984).** Differences, Difficulties and Adaptation: Stress and Social Networks in Families with a Handicapped Child. *Family Relations*, 33, pp. 67-77.

**Kirchler, E., Palmonari, A. & Pombeni, M. L. (1993).** "Developmental Tasks and Adolescents' Relationships with their Peers and their Family" in Jackson, S. & Rodriguez-Tome, H. (Eds.): *Adolescence and its Social Worlds*. Hove: Lawrence Erlbaum Associates Publishers.

**Kruger, N. (1995).** A proposed model for the identification and handling of stress in adolescents. *Educare*, 24(2), pp. 70-77.

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

**Lazarus, R. S. & Folkman, S. (1985).** If It Changes It Must Be a Process: Study of Emotion and Coping During Three Stages of a College Examination. *Journal of Personality and Social Psychology*, 48(1), pp. 150-170.

**Lazarus, R. S, De Longis, A, Folkman, S. & Gruen, R. (1985).** Stress and Adaptational Outcomes: The Problem of Confounded Measures. *American Psychologist*, 40(7), pp. 770-779.

**Lloyd, M. A. (1985).** *Adolescence*. Harper & Row Publishers: New York.

**Lobato, D. J. (1990).** *Brothers, Sisters and Special Needs*. USA: Maple Press Company.

**Lobato, D. J. (1990).** *Brothers, sisters and special needs: Information and activities for helping young siblings with chronic illnesses and developmental disabilities*. Baltimore: Paul H. Brookes Publishing Company.

**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.

**Luiz, D. M.; Fullard, J. P. P.; Stewart, R.; Lombard, M.; Corna, L. G.;**

**Jansen, J. M. & Wiehan, C. T. (1994).** *Stress patterns in families with a mentally handicapped, physically handicapped or chronically ill child*. Pretoria: Human Sciences Research Council.

**Marcoen, A. & Goossens, L. (1993).** "Loneliness, Attitude towards Aloneness, and Solitude: Age Differences and Developmental Significance During Adolescence" in Jackson, S. & Rodriguez-Tome, H. (Eds.): *Adolescence and its Social Worlds*. Hove: Lawrence Erlbaum Associates Publishers.

**Marsh, D. T. (1992).** *Families and Mental Retardation*. USA: Greenwood Publishing Group.

**McCubbin, H. I. & Patterson, J. M. (1983).** *"The family stress process: The double ABCX model of adjustment and adaptation"* in McCubbin, H. I., Sussman, M., Patterson, J. (Eds.): *Social Stress and the Family: Advances and Developments in Family Stress Theory and Research*. New York: The Haworth Press.

**McHale, S. M. & Gamble, W. C. (1987).** *"Sibling relationships and adjustment of children with disabled brothers and sisters"* in Schachter, F. F. & Stone, R. K. (Ed.): *Practical concerns about siblings: Bridging the research-practice gap*. New York: Haworth Press.

**McHale, S. M., Sloan, J. & Simeonsson, R. J. (1986).** Sibling Relationships of Children with Autistic, Mentally retarded, and Nonhandicapped Brothers and Sisters. *Journal of Autism and Developmental Disorders*, 16(4), pp. 399-413.

**Meyer, L. H., Peck, C. A. & Brown, L. (1991).** *Critical Issues in the Lives of People with Severe Disabilities*. Baltimore: Paul H. Brookes Publishing Company.

**Miles, M. B. & Huberman, A. M. (1994).** *Qualitative Data Analysis: An Expanded Sourcebook*. London: SAGE Publications.

**Miller, N. B. (1994).** *Nobody's Perfect: Living and Growing with Children Who Have Special Needs*. Baltimore: Paul H. Brookes Company.

**Miller, W. L. & Crabtree, B. F. (1998).** *"Clinical Research"* in Denzin, N. K. & Lincoln, Y. S. (Eds.): *Strategies of Qualitative Inquiry*. London: SAGE Publications.

**Monat, A. & Lazarus, R. S. (1991).** *Stress and coping: Some current issues and controversies*. In Monat, A. & Lazarus, S. (Eds.): *Stress and Coping: An Anthology* (third edition). Columbia University Press: Mew York.

**Newman, P. R. & Newman, B. M. (1997).** *Childhood and Adolescence*. Brooks/Cole Publishing Company: Pacific Grove.

**Powell, T. H. & Gallagher, P. A. (1993).** *Brothers & Sisters: A Special Part of Exceptional Families*. Baltimore: Paul H. Brookes Publishing Company.

**Prinsloo, T. (1998).** Bepaling van die belewenisse van sibbe waar 'n erg gestremde boetie/sussie teenwoordig is. Unpublished B.Communication Pathology dissertation, University of Pretoria.

**Schurink, E. M. (1998).** *"The Methodology of unstructured face-to-face interviewing"* in De Vos, A. S. (Ed.): *Research at grass roots: A primer for the caring professions*. Pretoria: J.L. van Schaik Publishers.

**Seiffge-Krenke, I. & Shulman, S. (1993).** *"Stress, Coping and Relationships in Adolescence"* in Jackson, S. & Rodriguez-Tome, H. (Eds.): *Adolescence and its Social Worlds*. Hove: Lawrence Erlbaum Associates Publishers.

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

**Sherman, M. L. (1997).** *Asperger's Disorder as experienced by siblings*. Unpublished Masters dissertation, University of Pretoria.

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

**Silverman, D. (Ed.), (1997).** *Qualitative Research: Theory, Method and Practice*. London: SAGE Publications.

**Silverman, D. (1993).** *Interpreting Qualitative Data: Methods for Analysing Talk, Text and Interaction*. London: SAGE Publishers.

**Spencer, M. B.** (1995). "Old Issues and New Theorizing About African-American Youth: A Phenomenological Variant of Ecological Systems Theory" in Taylor, R. L. (Ed.): African-American Youth: Their Social and Economic Status in the United States. Westport CT: Praeger.

**Stevens-Long, J. & Cobb, N. J.** (1983). *Adolescence and Early Adulthood*. Mayfield Publishing Company: California.

**Stoneman, Z, Brody, G. H., Davis, C. H. & Crapps, J. M.** (1987). Mentally Retarded Children and Their Older Same-sex Siblings: Naturalistic In-home Observations. *American Journal of Mental Retardation*, 92(3), pp. 290-298.

**Swanson, D. P., Spencer, M. B. & Petersen, A.** (1998). "Identity Formation in Adolescent Years" in Borman, K. & Schneider, B. (Eds.): The Adolescent Years: Social Influences and Educational Challenges. Ninety-seventh Yearbook of the National Society for the Study Of Education, Part 1, pp. 18-41. Chicago: University of Chicago Press.

**Tesch, R.** (1990). *Qualitative Research: Analysis types and software tools*. Falmer Press: New York.

**Tyskova, M.** (1993). "Adolescents' Relationships with Grandparents: Characteristics and Developmental Transformations" in Jackson, S. & Rodriguez-Tome, H. (Eds.): Adolescence and its Social Worlds. Hove: Lawrence Erlbaum Associates Publishers.

**Wishart, M. C., Bidder, R. T. & Gray, O. P.** (1981). Parents' report of family life with a developmentally delayed child. *Child: care, health and development*, 7, pp. 267-279.

## APPENDIX A

**QUESTIONNAIRE FOR PARENTS**

**For office  
use only**

1. Respondentnumber

V1

--	--

2. Card number

V2

--

**Please mark the applicable answer**

3. Question 1

Age of father

30 – 35	1
36 – 40	2
41 – 45	3
46 – 50	4
Older than 50	5

V3

--

4. Question 2

Age of mother

30 - 35	1
36 - 40	2
41 - 45	3
46 - 50	4
Older than 50	5

V4

--

5. Question 3



Number of children in the family

One	1
Two	2
Three	3
Four	4
Five	5
More than five	6

V5

6. Question 4

Birth position of the disabled child in the family.

First	1
Second	2
Third	3
Fourth	4
Fifth	5
Fifth +	6

V6

7. Question 5

Birth position of the brother/sister in the family

First	1
Second	2
Third	3
Fourth	4
Fifth	5
Fifth +	6

V7

8. Question 6

Home language

Afrikaans	1
English	2

V8

9. Question 7

Where does the disabled child live?

At home	1
At boarding school and comes home for weekends and holidays	2
At boarding school and only comes home for holidays	3

V9

10. Question 8

Did any member of your family ever receive help in order to adapt to the fact that one of the children is disabled?

Yes	1
No	2

V10

If yes, from whom?

Doctors	1
Therapists	2
Teachers	3
Other parents of disabled children	4
Other Specify	5

V11

V12

V13

V14

V15

**Answer the following questions**

11. Question 9

Describe your child's disability

---



---



---



---

V16

V17

V18

12. Question 10

Who informed the other children about their brother's/sister's disability?

\_\_\_\_\_ V19

13. Question 11

What was the brothers/sisters told regarding the disability of their disabled sibling?

\_\_\_\_\_ V20

\_\_\_\_\_ V21

\_\_\_\_\_ V22

**Mark the applicable answer**

14. Question 12

How will you describe your family in terms of their adaptation to the fact that one of the children is disabled?

Very well adapted	1
Well adapted at times	2
In general it is difficult	3

V23

15. Question 13

Do you think that at this stage your family needs additional help in adapting to the fact that one of the family members is disabled?

Yes	1
No	2

V24

If yes, please explain why you think so?

V25

---

V26

---

V27

---

## VRAELYS VIR OUERS

### Slegs vir kantoorgebruik

1. Respondentnommer

V1

2. Kaartnommer

V2

**Merk asseblief wat van toepassing is**

3. Vraag 1

Ouderdom van vader

30 - 35	1
36 - 40	2
41 - 45	3
46 - 50	4
Ouer as 50	5

V3

#### 4. Vraag 2

Ouderdom van moeder

30 - 35	1
36 - 40	2
41 - 45	3
46 - 50	4
Ouer as 50	5

V4

#### 5. Vraag 3

Aantal kinders in die gesin

Een	1
Twee	2
Drie	3
Vier	4
Vyf	5
Meer as vyf	6

V5

6. Vraag 4

Geboorte posisie van die gestremde kind in die gesin

Eerste	1
Tweede	2
Derde	3
Vierde	4
Vyfde	5
Vyfde +	6

V6

7. Vraag 5

Geboorte posisie van die broer / suster

Eerste	1
Tweede	2
Derde	3
Vierde	4
Vyfde	5
Vyfde +	6

V7

8. Vraag 6

Huistaal

Afrikaans	1
Engels	2

V8



9. Vraag 7

Waar bly die gestremde kind?

By die huis	1
In die koshuis en kom naweke en vakansies huis toe	2
In die koshuis en kom slegs vakansies huis toe	3

V9

10. Vraag 8

Het u gesin ooit hulp gehad om aan te pas by die feit  
dat een

Van die kinders gestremd is?

Ja	1
Nee	2

V10

Indien ja, van wie het u hulp ontvang?

Dokters	1
Terapeute	2
Onderwysers	3
Ander ouers van gestremde kinders	4

V11

V12

V13

V14


Ander	5
Spesifiseer	

V15

--

**Beantwoord die volgende vrae asseblief volledig**

11. Vraag 9

Beskryf u kind se gestremdheid

---

---

---

---

V16

--	--

V17

--	--

V18

--	--

12. Vraag 10

Wie het die ander kinders in die gesin ingelig oor die gestremdheid van hul broer / suster?

---

V19

--	--

13. Vraag 11

Wat is aan die gestremde kind se broers / susters gesê aangaande die gestremdheid?

	V20	
	V21	
	V22	

**Merk wat van toepassing is**

14. Vraag 12

Hoe sal u u familie beskryf in terme van aanpassing by die gestremdheid?

Baie goed aangepas	1
Goed aangepas met tye	2
Oor die algemeen is dit moeilik	3

V23

15. Vraag 13

Dink u dat u gesin op hierdie stadium addisionele hulp nodig het om aan te pas by die feit dat een van die gesinslede gestremd is?

Ja	1
Nee	2

V24

Indien ja, verduidelik asseblief waarom u so dink?

V25

---

---

V26

---

---

V27

---

## **APPENDIX B**

## VRAE VIR DIE ONDERHOUD MET DIE SIBBE

1. Ek wil vandag met jou gesels oor jou broer(s) en/of suster(s). Hoeveel broer(s) en/of susters het jy?

- Vertel my meer van hulle
- Hoe kom julle oor die weg?

2. Vertel my meer van naam van gestremde kind.

3. Het iemand jou al ooit vertel wat presies fout is met \_\_\_\_\_ ?

- Het jy al op jou eie meer probeer uitvind daaroor?

- 

Wat dink jy sal in die toekoms gebeur met \_\_\_\_\_ ?

4. Hoe voel jy daaroor om so 'n broer/suster te hê?

5. Wat sê jy vir jou vriende of vreemde mense as hulle jou uitvra oor \_\_\_\_\_ ?

- Hoekom sê jy dit vir hulle?
- Hoe dink jy voel hulle oor \_\_\_\_\_ ?

6. Baklei jy en jou broer(s) en/of suster(s) ooit?

- Wat veroorsaak gewoonlik dat julle baklei?
- Wat gebeur gewoonlik as julle baklei?
- Hoe tree jy gewoonlik op in so 'n situasie?
- Hoe reageer jou ouers as julle baklei?

7. Wat dink jy dink jou vriende van jou?

- Hoekom dink jy dink hulle so?
- Hoe voel jy daaroor?

8. Is daar van julle familieledede buite julle gesin, bv. 'n ouma/oupa en ooms/tannies wat soms help met \_\_\_\_\_ ?

- Hoe help hulle julle gesin?
- Hoe dink jy voel hulle oor \_\_\_\_\_ ?

9. Praat jy en jou ouers ooit oor \_\_\_\_\_ ?

- Wat bespreek julle as julle oor hom/haar praat?
- Is daar soms sake waaroor julle nie saamstem nie?
- Wat gebeur gewoonlik in so 'n situasie?

10. Wat se veranderings moet jy in jou lewe maak as gevolg van \_\_\_\_\_ ?

- Hoe voel jy daaroor ?
- Is daar dinge wat jy nie kan doen nie as gevolg van \_\_\_\_\_ ?
- (Ja) Soos wat?

of

- (Nee) Is daar dinge wat moeilik is as gevolg van \_\_\_\_\_ ?
- Is daar dinge wat jou nou meer irriteer as toe jy jonger was?
- Dink jy dat dit verkeerd is om so te voel?

11. Watter ander mense, bv. die bure, vriende of die kerk, ondersteun julle gesin?

- Wat doen hulle om julle te ondersteun?
- Hoe dink jy voel hulle oor \_\_\_\_\_ ?

12. Baklei jy en \_\_\_\_\_ ooit?

- Wat veroorsaak gewoonlik dat julle baklei?
- Hoe tree jy gewoonlik op in so 'n situasie?
- Hoe reageer jou ouers as julle baklei?

13. As jy jou lewe kon verander het, watter drie dinge sou jy wou verander of vir watter drie dinge sou jy wens?

- Hoekom?



## QUESTIONNAIRE FOR SIBLINGS

1. I want to talk to you about your brother(s) and sister(s).

- How many brother(s) and sister(s) do you have?
- How do you get along with each other?

2. Tell me more about x.

3. Has anyone ever told you what exactly is wrong with x ?

- Have you ever tried to find out more about the disability on your own?
- What do you think will happen to him/her in the future?

4. How do you feel about having a brother/sister like that?

5. What do you tell your friends/strangers when they ask you about x ?

- Why do you tell them that?
- How do you think they feel about x ?

6. Do you and your brother(s) and sister(s) ever fight?

- What usually causes a fight?
- What usually happens when you fight?
- How do you usually act in a situation like that?
- How do your parents react when you fight with your brother(s) and/or sister(s)?

7. What do you think your friends think about you?

- Why do they think that?
- How do you feel about that?

8. Are there family members outside of your immediate family circle, e.g. your grandparents and uncles/ aunts, that sometimes do things to help your family with x ?

- How do they help your family?
- How do you think they feel about x ?

9. Do you and your parents ever talk about x ?

- What do you discuss when you talk about him/her?
- Are there things that you sometimes disagree on?
- What usually happens in a situation like that?

10. What changes do you have to make to your life because of X ?

- How do you feel about that?
- Are there things that you can't do because of x ?
- (Yes) What are they?

or

(No) Are there things that are difficult to do because of x ?

- Are there things about x that irritate you now more than it did before?
- Do you think it is wrong to feel this way?

11. What other people, e.g. neighbours, family friends and people from the church, support your family with x ?

- What do they do to support your family?
- How do you think they feel about x?

12. Do you and x ever fight?

- What usually causes a fight?
- What usually happens when you fight?
- How do you usually act in a situation like that?
- How do your parents react when you and x fight?

13. If you could change your life, which three things would you like to change/ which three things would you wish for?

- Why?

## APPENDIX C

## **RESULTS – SUBJECT 3; 15 YEARS**

### **1. *I want to talk to you about your brothers and sister.***

- *How many brothers and sisters do you have?*

Uhhh.. I have two older brothers .. and one older half brother .... and my sister, younger sister.

- *How do you get along with each other?*

Oh we get along very well, because uhm ..... oh .. there's a big line of respect. I respect my brothers and they respect me and I respect my little sister and she respects me. So we hardly squibble .. it's very rare.

### **2. *Tell me more about Mpepu.***

Oh, I think she's a very great thing in all our lives, because she is ... she reminds us of the simplicity of life. We don't really need all the things that we think we need... and uh... she's a very important part of our lives.

### **3. *Has anyone ever told you what exactly is wrong with Mpepu?***

My parents have told me exactly what is wrong with her. Her right brain is damaged .. there was a lack of oxygen when she was born .... and it's impaired her muscles a little bit and her balance and her ability to excel academically .... I don't know, she's going to ..... she's pretty big for her age, you know? She uhh.... mentally I think she's growing, she's growing pretty slowly. We still refer to her as "Baby", because that's .. she's got around a three, four years old ... mentality .. so .....

- *Have you ever tried to find out more about the disability on your own?*

Uhhh.. I feel that I know enough about it.

- *What do you think will happen to her in the future?*

That's a real tough question, because .... ai..... especially in South Africa .... I mean the schools here are, aren't really ... the ... developed and are .... uh .. it's just not good enough, because I don't know..... while we were staying in the US, even in one year she developed so quickly ... she was so self-sufficient. I don't know, ever since she's come back here, she's just ... she's regressing....

**4. *How do you feel about having a sister like that?***

I think it's great, because it's just ... uhm .. like I said... it reminds me to just stay simple and to learn what actually counts most.

**5. *What do you tell your friends or strangers when they ask you about Mpepu?***

Oh, I'm very honest. I'm not ashamed of her at all. I tell them .. what's wrong with her and ... how much I love her and how much I like being around her. I've never been ashamed of my sister.

- *How do you think they feel about Mpepu?*

Uhm.... it's one thing I've learnt ... you shouldn't really care ..'cause if you do, it will affect my ... the way I treat my little sister. So I don't really think about that.

**6. *Do you and your brothers ever fight?***

Not at all. We disagree, but we respect each other.

- *How do your parents react when you do fight?*

Uhm .. it depends on the situation, if my parents feel that I have been disrespectful towards my older brothers, they will reprimand me for the way I behaved, but they wouldn't allow my brothers to react in any way they would like to.

**7. *What do you think your friends think about you?***

They think of me as a successful person ... they know I am serious and that I know what I want .....

- *How do you feel about that?*

I guess I don't mind.

**8. *Are there family members outside of your immediate family circle, e.g. your grandparents and uncles/aunts, that sometimes do things to help your family with Mpepu?***

No, they live too far. My grandmother does love her, but she lives too far to really help.

**9. *Do you and your parents ever talk about Mpepu?***

Not really, but we will talk about her character ... you know ... she has a sly character ...

- *Are there things that you sometimes disagree on?*

I get irritated very easily and I don't like it if they go on about things.

**10. What changes do you have to make to your life because of Mpepu?**

No, I've never had to miss out on something because of Mpepu .....

- *Are there things that you can't do because of Mpepu?*

No .. not that I'm aware of..

- *Are there things about Mpepu that irretate you now more than before?*

There's never been a situation that I had to stay home because of Mpepu, so there has never been a situation in which i have been irretated.

**11. What other people, e.g. the meighbours, family friends or people from the church, support your family with Mpepu?**

Nobody comes to mind .... but my aunts and uncles ... they just really enjoy her company, but there is no actual financial support .. or maybe more moral support when she was younger .... just to deal with the situation ...

**12. Do you and Mpepu ever fight?**

Oh we used to, but I think she has matured a little bit now. Sometimes she just doesn't really want to do anything ..... so we fight a bit ..... but we don't really fight ....

- *What usually causes a fight?*

Uhhh..... I ..... sometimes she is disobedient. You have to know her character ... she's very ... she's very stubborn.



- *What usually happens when you fight?*

She's got very strong hands .... Being a very short person, she relies on them. She can't really rely on her feet, but she relies on her hands. She scratches ..... but this doesn't really happen since she's matured.

- *How do you usually act in a situation like that?*

When I was younger ... not in serious, but I would scratch backb but now I just walk away from her.

- *How does your parents react when you fight?*

Uhm .... my mother .... she'd be more angry at me, because ... she knows that I could control my impulses more....

**13. *If you could change your life, which three things would you like to change or which three things would you wish for?***

I'd like to see my brothers more often .. because .. they're not around the house a lot. Uhm ... I'd like to be more mobile. My parents work a lot ... like right now ..... they'll be back after seven .... there goes my Friday afternoon