

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
Siblings from the same family						

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"> • Question 1 had to be adapted, when there are only two children in the family. • Question 2 can be left out if there are only two siblings in the family. • Question 6 is only applicable if there are more than two siblings in the family. • The probes that are part of the questions, are sometimes not needed as subjects gave the answer without needing to be probed. • The subjects seemed to understand all the questions and their formulation. 	<ul style="list-style-type: none"> • Question 1. I want to talk to you about your brother/sister. * Tell me more about <u>x</u> . * How do you get along? • Question 2 Tell me more about <u>x</u>. • Question 6 Do you and your brothers/ sisters ever fight? • The probes don't have to be used if the subject has already given the information necessary. • No question's formulation was changed.
<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"> • Transcriptions of the tape recorded interviews has to be done as soon as possible after the interview. • A second transcriber has to check the accuracy of transcriptions.
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"> • The subject can choose the location of the interview. • Parents and subjects have to be given the relevant information regarding this study. • Subjects don't have to answer a question with which they're not comfortable.

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"> • How many brothers and sisters do you have? • How do you get along with each other? 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"> • 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?	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"> • How do they help your family? • How do you think they feel about x? 	According to Folkman et al. (1979), coping resources mediate stressful encounters and they include the following: <ul style="list-style-type: none"> • the individual's health, energy or morale, • problem-solving skills, • social support networks, • utilitarian resources, e.g. socio-economic status, etc. and • general and specific beliefs
The subjects' available social support networks.	7. What do you think your friends think about you? <ul style="list-style-type: none"> • Why do you think that they think that? • How do you feel about that? 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"> • What do they do to support your family? • How do you think they feel about x? 	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"> • 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? <ul style="list-style-type: none"> • 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/ sister(s)? 	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"> • 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? <p>10. What changes do you have to make in your life because of x?</p> <ul style="list-style-type: none"> • 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 before? • Do you think that it is wrong to feel this way? <p>12. Do you and x ever fight?</p> <ul style="list-style-type: none"> • 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? 	<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 & 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"> • Why? 	

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).

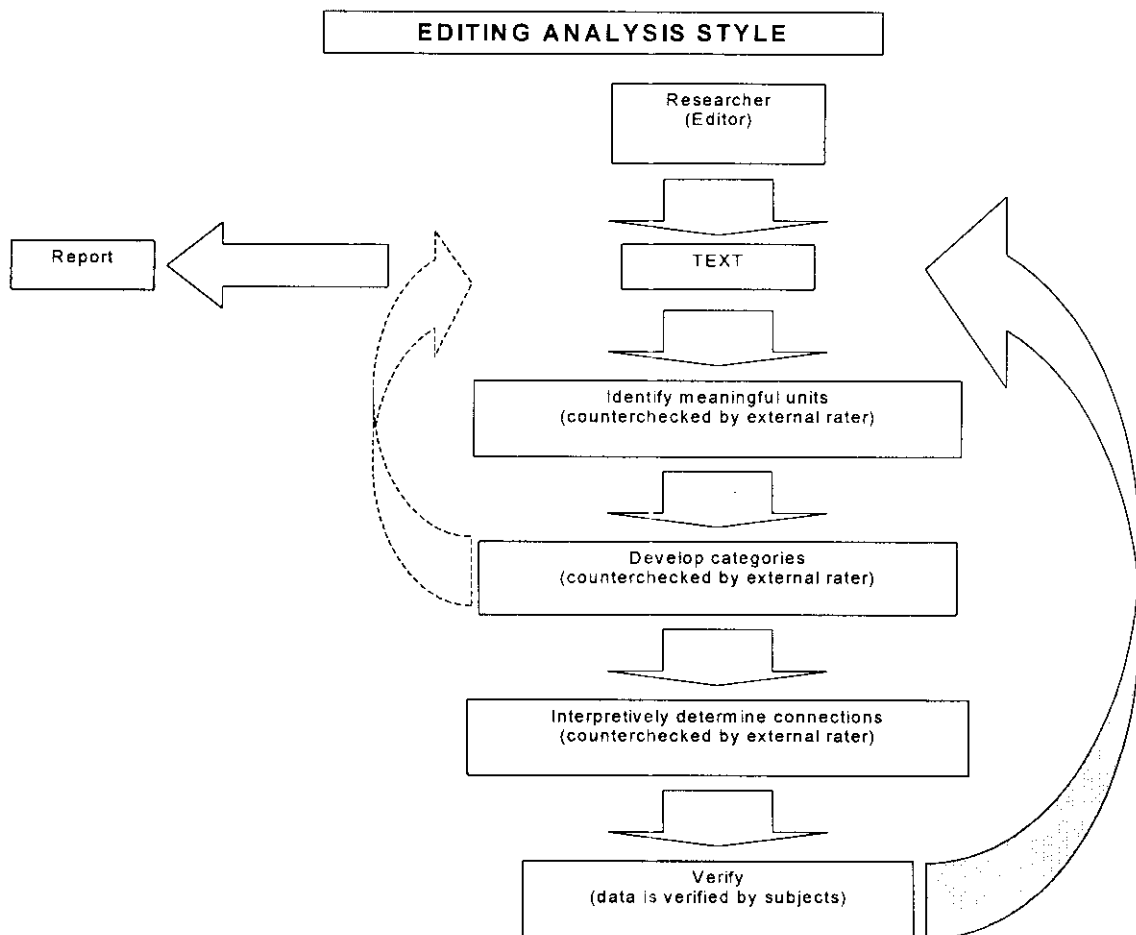


FIGURE 3.1: The editing analysis style (Miller & Crabtree, 1998)

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"> • 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). • 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). • 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). 	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"> • Places increased socio-economical demands on the family. • Unrestricted family interaction takes place. • The subject has to deny his/her own needs because of the sibling with a disability. • The subject has unexpressed emotions with regard to having a sibling with a disability. • The subject admits to not participating in family activities and preferring to do things on his/her own. • The subject is dissatisfied with the amount of care giving responsibilities he/she has, regarding the sibling with a disability. 	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"> • The subject's parents support him/her regarding his/her sibling's disability, e.g. discussing the disability. 	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"> Other family members, e.g. grandparents, uncles or aunts, support the family with the sibling with a disability. 	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"> The family is supported by other people, e.g. neighbours, family friends, other families with a disabled member, regarding the sibling with a disability. 	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"> Professionals, e.g. teachers, doctors and therapists, support the family with the sibling. 	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"> The subject is supported by peers, regarding the sibling with a disability. 	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"> The subject knows what exactly is wrong with the sibling with a disability. 	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"> The subject freely expresses his/her feelings regarding the disabled sibling during the interview, according to the raters. 	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"> The subject places his/her possible negative feelings onto other issues, e.g. someone at school, etc. The subject only expresses positive feelings regarding the sibling with a disability and doesn't state any negative feelings according to the raters. 	1. Yes 2. No
	Subjects may experience feelings of anger and guilt towards the sibling with a disability.	<ul style="list-style-type: none"> The subject experiences feelings of guilt about his/her feelings about the disabled sibling. The subject understands why he/she is feeling guilty about the way he/she feels about the disabled sibling. 	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"> The subject has appropriate future expectations for the disabled sibling. 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. The subjects feels uncertain about what might happen to the sibling with a disability in the future. 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. 	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"> 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). 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). 	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"> • The subject is uncertain about his/her friends' perception of him/her. • The subject feels that his peers think of him/her as a good friend. • The subject feels that peers admire him/ her for coping with a sibling with a disability. 	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"> • The subject is involved in conflict situations with the disabled sibling from time to time. • The subject avoids conflict situations involving the disabled sibling. • The subject feels satisfied with the way the parents handle conflict situations with the disabled sibling. • The subject is involved in conflict situations with his/her parents, about issues concerning the disabled sibling. • The subject avoids conflict situations involving the sibling with a disability. • The subject avoids conflict situations involving the sibling with a disability. • The subject is involved in conflict situations with his/her parents, about issues concerning the sibling with a disability. 	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
TOTAL	69	4

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.