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## **ADOLESCENTS: TYPICALLY DEVELOPING SIBLINGS AND SIBLINGS WITH SEVERE DISABILITY**

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### **ABSTRACT**

The aim of this study was to establish adolescents' perceptions of their siblings with a severe disability as well as the degree and type of social support they utilise. Seventeen adolescents with siblings with a severe disability were interviewed using a semi-structured interview. A control group of adolescents with normal functioning siblings also took part in the research project as it is essential to distinguish between perceptions and attitudes that are characteristic of sibling relations in general and those which are a direct result of the presence of a sibling with a severe disability. Interviews were conducted with 25 adolescents between the ages of 12-16. The data were analysed in a qualitative manner according to 9 categories. Results showed that guilt feelings were more frequently experienced amongst the adolescents with siblings with a severe disability and these subjects tended not to freely express their feelings about their sibling with a disability. Amongst the control group the majority of the adolescents had a positive cognitive appraisal of their normal functioning siblings, although these adolescents did express ambivalent emotions towards the sibling relationship.

### **INTRODUCTION**

Much of the research conducted in family-centred intervention has highlighted the role parents play in the intervention process (Cherry, 1989; Dale, 1996; Dunst, Trivette & Cross, 1986). Limited research has attempted to understand siblings' contributions, experiences and needs. This trend is also clearly evidenced in the research conducted to date in the field of severe disability.

Siblings serve as a child's first social group where sharing, companionship, learning, jealousy, compromise and persuasion are introduced, negotiated and practised (Lobato, 1990). These relationships may be co-operative or competitive, close or distant, harmonious or conflicting (Fuhr & Buhrmester, 1985).

Little research performed on siblings of individuals with a severe disability has focused on young adolescents. This is particularly important phase of development as it is during this phase that adolescents establish a sense of identity as well as a personal value system (Kruger, 1995). Early adolescence is a period of transition involving changes in physical development, cognitive abilities, emotional adjustment, social awareness and self-esteem. All of the above factors are potential stressors for the adolescent. Siblings in the age group of early adolescence are especially susceptible to the influence that a individual with a disability has on the family as, according to Swanson, Spencer & Peterson (1998), personal identity develops within the context of relationships.

Results from studies involving siblings of individuals with a severe disability have been controversial. Detriments to individual functioning resulting from the presence of an individual with a severe disability include, amongst others, a high degree of anxiety, conflict with parents,



lower sociability and poorer interpersonal relationships (Crnic, Freidrich & Greenberg, 1983). Wilson, Blacher & Baker (1998) concluded that many individuals with a severely disabled sibling have low self-esteem and predominantly negative perceptions regarding the family's interactions. On the other hand, Lobato (1990) found that subjects who benefited from the presence of a brother or sister with a disability were rated as having a greater understanding of people in general and disabilities in particular. They were found to be more compassionate, more sensitive of prejudice and more appreciative of their own good health and intelligence than their peers.

Emotional and cognitive appraisals of the environment of the adolescents are seen as the determining factors when rating a situation as stressful or not. If a situation or relationship is appraised by the adolescent as being stressful, then coping strategies are implemented. Coping strategies include actions, behaviours and thoughts used to handle and overcome a stress-evoking situation. Coping mechanisms may be used not only to resolve problems, but also to reduce the stress linked with them (Dale, 1996). Adaptive strategies include seeking help from friends and family, using constructive problem solving and thinking positively. Conversely, maladaptive responses include avoidance, wishful thinking and withdrawal (Swanson *et al.*, 1998).

Social support is important in the formation of coping strategies. Social support is a multi-dimensional construct and includes instrumental assistance, information provision, emotional empathy, psychological support and resource sharing (Dunst *et al.*, 1986). The support that an individual experiences, according to Dunst *et al.* (1986), can directly or indirectly influence the behaviour, attitudes and expectations of the individual. Support can be provided on a number of ecological levels, including intimate relationships, extended family networks, friendships and less formal neighbourhood or community contacts (Byrne & Cunningham, 1985). The family environment, however, remains an important source of social support. Well-adjusted siblings rely heavily upon parents and other family members to address their feelings, provide information, teach them how to communicate and interact with their brother or sister and enjoy an independent life. Parents of children with severe disabilities are less able to pay attention to the children without disabilities, since much of their time is spent caring for the child with a severe disability. Furthermore, these parents often have fewer social resources available to them as the social and friendship networks of families with children with a disability tend to be smaller and more dense (Cherry, 1989). The amount of parental support as well as other forms of family and peer support available to the sibling of a child with a disability is therefore often diminished.

Without information on the types of stressors that families with normal functioning children experience, it is difficult to interpret reports of stress in families with children with a disability (Kazak, 1986). Without sufficient information regarding the quality of sibling behaviour between individuals without a disability, one cannot fully understand the sibling relationships in which one of the members has a severe disability. Thus this research project aimed at identifying the coping strategies of adolescents within their family setting, where families include a sibling with or without a severe disability. The aim of this project was to explore the following research questions:

- What is the amount and type of social support available to and utilised by adolescents?
- What are the adolescent subjects' experiences of having a sibling with or without a disability?
- What are the coping resources and strategies used most frequently by adolescents to accommodate their sibling?



## METHOD

This study used a descriptive group design whereby interviews were conducted with two groups of adolescents between the ages of 12-16. Two groups of adolescents were interviewed. Group 1 consisted of 19 adolescents who had a sibling with severe disability. Group 2 consisted of 16 adolescents who had typically developing siblings. Semi-structured interviews were used as the method of data collection.

## SUBJECTS

Children with a severe disability, ranging from 10-18 years, were identified from four schools. Individuals with severe disabilities can be described as those people who need continual support in one or more areas of life (Meyer, Peck & Brown, 1991). The children with disabilities who were selected for this study attended schools for children with severe disabilities. The majority had been diagnosed with mental retardation and had an IQ below 50. This group was used as a basis for the selection of 19 adolescent participants for Group 1. All participating adolescents were within the age group 12-16 years.

Sixteen participants formed Group 2 and were chosen from three schools. The control group of adolescents interviewed attended three different schools. These siblings were matched as far as possible to the gender, number of siblings in a family, age and language of the original 19 siblings interviewed. This can be seen in Table 1 below.

**TABLE 1**  
**ADOLESCENTS PARTICIPATING IN STUDY**

Group 1					Group 2			
Number	Gender	Age	Number of siblings	Home language	Gender	Age	Number of siblings	Home language
1	Male	13	2	Afrikaans	Male	13	2	Afrikaans
2	Female	15	3	Afrikaans	Female	15	3	Afrikaans
3	Male	15	4	English	Male	15	3	English
4	Female	15	2	Afrikaans	Female	15	3	Afrikaans
5	Male	15	4	English	Male	15	3	English
6	Male	15	4	English	Male	14	3	English
7	Male	13	3	Afrikaans	Male	13	3	Afrikaans
8	Female	15	3	Afrikaans	No match	No match	No match	No match
8	Female	13	3	Afrikaans	Female	13	2	Afrikaans
9	Male	13	2	English	Male	12	2	English
10	Male	13	2	Afrikaans	Male	13	3	Afrikaans
11	Male	15	2	Afrikaans	No match	No match	No match	No match
12	Male	13	2	English	Male	13	2	English
13	Female	15	2	English	Female	15	2	English
14	Female	14	2	Afrikaans	Female	15	4	Afrikaans
15	Female	12	2	Afrikaans	Female	12	2	English
16	Female	14	3	Afrikaans	Female	16	4	Afrikaans
17	Female	15	3	Afrikaans	Female	15	3	Afrikaans
18.	Male	12	3	English	Male	12	2	English
19.	Male	10	3	English	No match	No match	No match	No match



## DATA COLLECTION

After the subjects were identified and parental permission was granted for the participants to take part in the study, an interview time was scheduled. Information was obtained using informal individual interviews with pre-formulated questions. The interviews were conducted in the home language of the subject. All the interviews were conducted by the researcher to ensure a high consistency of execution. Interviews were audio-recorded and the transcriptions were then checked by an external controller to ensure that the transcriptions were accurate and reliable.

## MATERIAL

Open-ended semi-structured interviews were conducted using a pre-formulated questionnaire and probes were necessary to elicit additional information. The questionnaire consisted of 15 questions that could be divided into various categories which were used during the data analysis procedure. The questionnaire for Group 2 was adapted from that of Group 1. Out of the original 13 questions, 12 remained essentially the same. The questions specifically designed to obtain information regarding the adolescents' knowledge of their sibling's disability and future expectations for the sibling were adapted.

## DATA ANALYSIS

An editing analysis style (Miller & Crabtree, 1998) was used during which meaningful units were identified and categories were developed accordingly. From the audio-tapes and the transcriptions interviews were analysed according to 9 categories developed. These categories allowed the researcher to answer the research questions posed above (see Table 2 below).

**TABLE 2**  
**RELATIONSHIP BETWEEN RESEARCH QUESTIONS AND DATA ANALYSIS CATEGORIES**

RESEARCH QUESTIONS	CATEGORIES USED FOR DATA ANALYSIS
Social support available to the adolescents.	<ul style="list-style-type: none"> <li>• Category 3: Social support available to the adolescents</li> <li>• Category 8: Adolescents' perception of how they are viewed by their peers</li> <li>• Category 9: Conflict situation within the family and conflict resolution by parents</li> </ul>
Subjects' experience and attitudes towards their sibling.	<ul style="list-style-type: none"> <li>• Category 1: Subjects' primary attitude towards the siblings</li> <li>• Category 2: Subjects' feeling about family interaction</li> <li>• Category 4: Subjects' acceptance of sibling differences and knowledge of the disability</li> <li>• Category 5: Subjects' primary feelings about and coping strategies towards their siblings</li> <li>• Category 6: Subjects' future expectation for their siblings</li> <li>• Category 7: Subjects' perception of how others view their siblings</li> </ul>
Subjects' coping responses to the stress inherent in sibling relationships.	<ul style="list-style-type: none"> <li>• Category 5: Subjects' primary feelings about and coping strategies towards their siblings</li> </ul>



The researcher's transcriptions and data analysis were checked by an external rater in order to ensure that the data were accurately represented and described. Inter-rater reliability was ensured by having samples of the data checked by an external rater who categorised a sample of the responses. The external rater checked 40% of the sample by rating it according to the 9 data analysis categories discussed above. A discussion followed between the external rater and the researcher in order to clarify differences obtained on each of the 9 categories. A final comparison was made according to the reliability formula of Miles and Huberman (1994:64) and an inter-rater reliability of 95% was obtained.

## RESULTS AND DISCUSSION

Results of the study can be viewed in Table 3 below and are discussed according to the research questions posed above.

**TABLE 3**  
**RESULTS OF THE STUDY ACCORDING TO THE RESEARCH QUESTIONS**

<b>RESEARCH QUESTION 1: SOCIAL SUPPORT</b>	<b>GROUP 1</b>	<b>GROUP 2</b>
Parental support	5% well supported	25% well supported
Peer support	11% well supported	50% well supported
Sibling conflict	63% actively avoided conflict	100% were engaged in sibling conflict
Parental conflict resolution	55% dissatisfied	32% dissatisfied
<b>RESEARCH QUESTION 2: EXPERIENCE AND ATTITUDE TOWARDS SIBLING</b>	<b>GROUP 1</b>	<b>GROUP 2</b>
Cognitive appraisal of sibling	32% had a negative appraisal of sibling 47% ambivalent appraisal 21% had a positive appraisal	32% had a negative appraisal of sibling 47% an ambivalent appraisal 21% had a positive appraisal
Expressing emotion towards sibling	58% could not freely express emotions	6% could not freely express emotions
Family interaction as a result of sibling influences	32% unrestricted family interaction took place	100% unrestricted family interaction takes place
Adolescents' future expectation for sibling	47% had appropriate future expectations	81% had appropriated future expectations
<b>RESEARCH QUESTION 3: ADOLESCENTS COPING RESPONSES</b>	<b>GROUP 1</b>	<b>GROUP 2</b>
Guilt feelings	58% experienced guilt feelings	44% experienced guilt feelings
Transference of negative emotions	42% projected negative feelings about sibling onto other issues.	Not experienced by this group

Results indicated that in Group 1 good parental support was experienced by only 5% of the group, while good peer support was experienced by 11% of the group. Amongst the adolescents in Group 2 it was also clear that peers were perceived as providing more support than parents. Thus,



although parental support is important during the adolescent years, adolescents are relying more heavily on peers in order to gain the support they need, since they feel that information from a parent may no longer be as relevant as advice from other support sources (O'Koon, 1997). 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). According to Cotterell (1996), adolescents need these friendships to help them establish their identity. Parents, however, do remain as influential socialisation agents, as research has shown that the family environment including the parent-adolescent relationship has profound effects on the development of adolescents' self esteem (Harvey and Byrd, 1998). Peer group support is thus complementary to parental support and not in conflict with it.

A larger percentage of adolescents in Group 2 rated their parents as being supportive compared to the adolescents in Group 1. This perception by the adolescents in Group 1 can also be related to the fact that they have unexpressed emotions regarding the sibling with a disability and this impacts negatively on family interaction.

Analysis of the support available to the individual adolescents in Group 2 revealed that if parental support was high then extended family support was also rated as high and vice versa. These results support the literature, which indicates that family cohesiveness, or a close family network, can foster a sense of cohesiveness and support (Dunst *et al.*, 1986). Often parents and adolescent siblings of children with a severe disability have smaller, more dense support networks (Cherry, 1989). Close family networks, however, may also lead to a limitation of access to other resources and different viewpoints as well as fewer opportunities to engage in other social support options (Byrne & Cunningham, 1985).

Analysis of the data reveals that 63% of these adolescents in Group 1 actively avoided conflict with their sibling with a disability, while none of the adolescents in Group 2 reported doing so with their siblings without disabilities. Fisher and Roberts (1983) state that under ordinary circumstances siblings are often involved in conflict and competition with one another. Adolescents in Group 1, however, may actively avoid conflict involving their sibling and this may lead to a negative perception of family interaction. Reasons for conflict avoidance might be that adolescents take on a more parental role towards a sibling with a disability and do not treat them as equal partners in a conflict situation. The wish to protect the sibling with a disability might also be reflected here. Another reason might relate to the finding that 55% of the adolescents in Group 1 were dissatisfied with the way in which their parents resolved conflict situations relating to the sibling relationship. Avoidance of conflict with the sibling might be a strategy to avoid conflict with parents.

In Group 1 32% of the participants felt that unrestricted family interaction took place compared to the 100% of Group 2. The fact that the participants in Group 1 reported limited family interaction can be attributed to their perceived lack of parental support and their inability to freely express emotions. According to Seligman & Darling (1989), the presence of a child with a severe disability does indeed inhibit family communication and places additional stress on the family interaction. According to Lobato (1993), good communication between parents and adolescents and unrestricted family interaction lay the foundation for healthy adjustment for adolescents with siblings who have a severe disability.

Of the adolescents in Group 1, 32% had a negative appraisal of their sibling, whilst 47% expressed an ambivalent appraisal of their sibling. The same results were obtained for Group 2.

According to Fuhr and Buhrmester (1985), many siblings do express ambivalent feelings regarding their siblings. The high presence of ambivalent feelings amongst these adolescents may



be an attempt to regulate the stressful effects associated with having a sibling with a severe disability.

In Group 1 47% of the adolescents had appropriate future expectations for their siblings. According to Seligman and Darling (1989), individuals often have unrealistic future expectations regarding their sibling with severe disability due to insufficient information regarding their sibling's specific disability. Insufficient knowledge about the disability and its consequences may also bring about uncertainty regarding issues concerning the future of the sibling with a disability and the subject's role in caring for their sibling. Of the adolescents in Group 2, 81% expressed appropriate future expectations for their siblings based on sibling interests and abilities.

A large percentage of adolescents with siblings with a disability (84%) felt that other people are prejudiced towards their sibling. They stated that others do not know how to interact with individuals with a disability. This indicates the need for greater public awareness of issues surrounding disabilities as well as an increase in the amount of support available to the adolescent siblings and their families in order to help them understand these prejudices.

These adolescents in Group 1 employed a variety of coping mechanisms in order to reduce the stress involved in coping with a sibling with a disability. Rationalisation of feelings in order to highlight only the positive aspects and feelings towards their sibling with a severe disability (Dale, 1996) and transference of negative emotions onto other issues were the main coping strategies employed by these adolescents. Of the adolescents in Group 1, 63% only expressed positive emotions towards their siblings. A further 42% transferred their negative emotions onto other issues. All of the adolescents in Group 2, however, stated their negative feelings about their siblings freely.

According to Dale (1996), adolescents with siblings who have a severe disability may be inhibited from expressing negative emotions towards the child with a severe disability by the parents. As a result these adolescents projected their negative feelings about their sibling onto other issues or expressed only positive feelings regarding their sibling with a disability as discussed in the data above.

Guilt feelings were present in just over half (58%) of the adolescents in Group 1. Just under half of the participants in Group 2 (44%) experienced guilt feelings about their siblings. All of these adolescents in Group 2, however, stated that these feelings form a normal part of interpersonal contact. A high percentage of adolescents with siblings with a severe disability experience guilt feelings regarding their sibling as well as guilt about their own good health and abilities (Lobato, 1990). Few of these adolescents feel comfortable with the expression of their guilt feelings. According to Seligman and Darling (1989), adolescents are not free to express their emotions if they feel that their emotional needs are insufficiently met within the family. Lacking parental support as evident in Group 1 would thus pre-empt the reluctance to express emotions.

Guilt feelings play an important role in self-control, because they reflect how individuals think about themselves in relation to their social and moral responsibilities. Knowledge of the role that guilt feelings play in the socialisation of adolescents is critical for the implementation of a family-centred intervention programme. Experience and expression of these feelings by adolescents is essential for the individual's well-being as well as for healthy family dynamics.

## CONCLUSIONS

When looking at adolescents and their perceptions of their siblings, it appears that a variety of complex feelings about siblings and sibling relationships exist. Coping with complex feelings



about a sibling is an important part of adolescence. According to Kruger (1995), adolescents negotiate stress with varying degrees of mastery. Some develop appropriate and successful coping skills, whilst others use less successful coping strategies. The difference in coping strategies utilised by the two groups of adolescents is evidenced in the results above.

Adolescents experience increased stress related to the presence of a sibling with a severe disability. Knowledge of the factors which influence sibling interaction and adolescents' attitude towards their sibling with a disability lays the foundation for the provision of family-centred intervention. This knowledge is necessary in order to minimise this perceived stress and increase adaptive coping responses. The adoption of healthy coping responses to stressful situations by the family of children with severe disabilities is essential for the facilitation of healthy interpersonal relationships and socialisation skills. Furthermore, a better understanding of the social support networks utilised by the adolescents and their families enables service providers to actively involve these individuals in the intervention process.

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