

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.