

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.