Having a Brother with Emotional and Behavioral Challenges: The Experiences of Adolescent Girls


Siblings of children with mental health challenges have been described as the 'forgotten family members'. Research on siblings of children with chronic illnesses show both positive outcomes, such as higher levels of compassion and sensitivity, and negative outcomes, such as difficulties at school, loneliness, anxiety, depression, or other psychosocial problems. Less is known about the siblings of children with emotional and behavioral disorders, even though the reported incidence of emotional and behavioral disorders among school-aged children ranges from 5% to 10%. The experience of having a sibling with mental health challenges is relevant a significant number of children. This study focuses on the experiences of female siblings of boys with deficits in attention, motor control and perception (DAMP) and Asperger syndrome. These problems associated with these conditions, such as overactivity, low frustration tolerance, impulsiveness, and difficulties with social interaction, are likely to have significant consequences for the lives of family members including siblings.

Participants were recruited, with parental permission, from a resource center for families of children with a chronic disease. A total of fourteen adolescent girls (12-18 years), whose siblings had been diagnosed with either Asperger syndrome (n=7) or deficits in attention, motor control and perception (n=7) agreed to participate in the study. In-depth interviews of approximately one hour were used to collect data on the adolescent’s experiences of life at home, in school, and during leisure time, and on how she coped with her life situation in relation to her sibling. In four cases, follow-up telephone interviews were used to expand and clarify the data. The audio-taped interviews were transcribed verbatim, and coded and analyzed using a bottom-up approach to understanding the data in accordance with grounded theory and constant comparison methods.

The researchers identified two core concepts in the data to explain the how these adolescent girls experienced life with a sibling with deficits in attention, motor control and perception or Asperger. The first concept focuses on the dilemmas experienced as a sibling (dilemma of requirements and concerns) and the second concept (harmonizing) focuses on how participants deal with their life situation.

**Siblings' Experiences: Dilemma of Requirements and Concerns**

Participants described a variety of responses to having a sibling with DAMP or Asperger syndrome. These included feelings of helplessness, fear, loss, loneliness, empathy, responsibility and feelings of protection towards their sibling, and feelings of shame and guilt about feeling ashamed. This group of adolescent girls also described a range of different dilemmas that they faced arising from varying requirements of the situation. For example, they described adaptational requirements (e.g. accommodating to the needs of their disabled sibling with unpredictable behavior), conditional requirements (e.g. taking second place and having extra responsibility due to demands on the family) and self-preservation requirements (e.g. achieving their own life goals). Participants also expressed different dimensions of concern, including concern for self (e.g. goals in life), concern for family (e.g. keeping the family together), and concern for sibling (e.g. sacrificing own needs for sibling). The researchers suggest that it is essential to understand both the focus of the participant's concern and the participant's experience of the requirements of their situation and in order to understand the dilemmas they describe.
Siblings' Coping processes: Harmonizing

The researchers found that while the combination of coping processes was unique to individuals, it was related to how the individual's experienced the dilemma of requirements and concerns summarized above. Four different types of coping processes were described. These were gaining independence (e.g. focusing on own goals in life), balancing (e.g. delaying attainment of own goals), gaining understanding (e.g. finding out about the sibling's condition) and following a bonding responsibility (e.g. taking on a parenting role). Thus the adolescents in this study used a variety of coping processes ranging from maintaining distance from the situation to feeling responsible for their sibling and taking on parenting functions in the family.

Peer and sibling relationships play a significant part in children’s social and emotional development, and thus it is important that the voices of siblings are included in the design and delivery of services to families who have children with mental health challenges. In this study, the researchers conclude that a better understanding of the sibling's disability is associated with more empathetic attitudes. Thus improving access to appropriate informational resources may be one form of support. However the study also shows that it is essential to understand the individual's experience within his or her context. It is evident that there is a need for further research to advance our understanding of the experiences of siblings of children with mental health challenges within a variety of family, social, and cultural contexts.

Resources: The Sibling Support Project

Further information about resources for siblings can be found at [http://www.thearc.org/siblingsupport/](http://www.thearc.org/siblingsupport/). The Sibling Support Project is a national program set up to provide peer support and education for brothers and sisters of people with special health and developmental needs.

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Reference