Self-Perceptions of Siblings and Sibling Relationships in Families with Down Syndrome

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The diagnosis of a genetic condition is difficult not only for the affected individual, but also the entire family. The majority of current studies focus on the effects of a diagnosis on a parent; few focus on the unaffected siblings. Therefore, this study aims (1) to determine self-perception for siblings of individuals with Down syndrome (2) to determine the quality of the sibling relationship when one sibling has a diagnosis of Down syndrome and (3) to determine if the self-perception for siblings of individuals with Down syndrome differs from data on a normative sample. The exploratory aim of this study is to determine whether there are differences in self-perceptions and quality of sibling relationships based on gender of the unaffected sibling.

The study population consists of unaffected siblings of children diagnosed with Down syndrome. Participants were recruited through the Down Syndrome Association of Houston support group. Data was collected using the Self-Perception Profile for Children (Harter, 1985) and an interview containing 10 open-ended questions adapted from the Sibling Inventory of Behavior Items (Schaefer & Edgerton, 1981). A total of 14 families participated in this study.

Results of the Self-Perception Profile for Children showed a significant decrease in behavioral conduct and a statistically significant increase in global-self esteem compared to normative data. Decreased personal conduct may be explained by rebellion against increased expectations placed on children who have a sibling with special needs. In contrast, increased global self-perception may result from independence and positive self-worth that develop from additional responsibilities placed on the unaffected sibling. The quality of the sibling relationship was high due to high levels of companionship, high levels of empathy and low levels of avoidance. High quality relationships may be explained by high levels of cohesiveness within the family, positive peer relationships, and an increased sense of responsibility. In summary, this study provides evidence that having a sibling with Down syndrome creates positive self-perceptions and a positive sibling relationship. Future studies including a larger, more diverse study population could help strengthen these results.