The Effects of Having a Child with ADHD on Family Members and Family Management


Members of families including children with ADHD (Attention Deficit Hyperactivity Disorder) are greatly affected in their daily lives and functioning by symptoms associated with the disorder. Coping with a child’s hyperactivity, low control of impulses, learning difficulties, and low levels of emotional and behavioral regulation, can leave parents and siblings confused, exhausted, and feeling overwhelmed. A recent set of research studies by Judy Kendall and her colleagues investigated the experiences of family members affected by ADHD and examined the ways in which parents, siblings, and the children themselves spoke of the functioning of their families. The two articles reported here focused on the views of parents regarding the effects of ADHD on their own lives and the ways in which their families functioned.

**Method**

In the first study, researchers used a qualitative research approach in order to construct theories based on everyday experiences of family members as they managed the disruptive symptoms of their children with ADHD. The second investigation focused on a subset of the data in order to construct a typology of family functioning that could be of use to service providers. Both studies were based on 109 interviews with 59 family members from 15 families that included 15 mothers, 10 fathers, 20 children diagnosed with ADHD, and 14 siblings. The families were primarily European American and ranged from low to middle income. Researchers began by selecting an initial sample through service agencies and support groups. Participants were interviewed in their own homes and were tape recorded in sessions that started by asking them to reflect on what it was like to live with ADHD or with a family member having that disorder. Investigators used a grounded theory approach (Glaser & Strauss, 1967), and analyzed data from the first set of interviews for emerging themes (Strauss & Corbin, 1998). Since preliminary analyses indicated that the age of the child with ADHD had a major effect on family functioning, the later sample was designed to include families with children ranging in age from early elementary school age to later adolescence. After further analyses, the researchers interviewed family members a second time, so that participants could add to their earlier reflections, and could assist researchers in their interpretation of the findings from the first round of interviews. To strengthen the trustworthiness of their analysis and interpretations, the authors also compared their findings with observations of families recorded in their field notebooks, and reviewed their results with experts in qualitative research and with health professionals who were also parents of children with ADHD.

**Outlasting Disruption: A Theory of Coping with ADHD**

Parent interviews revealed that raising a child with ADHD is a long-term process that is marked by frequent disruptions brought about by the variability in symptoms and performance that is characteristic of the disorder. Family members identified seven different types of disruption: aggression; uncontrolled hyperactivity; emotional and social immaturity; learning difficulties and poor school performance; negative interactions with peers; family conflict; and difficult relations with members of their extended family. Outlasting disruption emerged as a central problem experienced by the parents, who then strove to manage the disruption and its consequences so that the child and the family had the best possible outcomes. In the midst of the stress and struggles, parents engaged in three simultaneous processes: making sense, recasting biography, and relinquishing the "good ending." In order to make sense of the disorder, parents had to first realize that something was really wrong and engage in a process resulting in a diagnosis, next come to an understanding of the chronic nature of ADHD, then recover from periods of being worn out as the child continued to exhibit symptoms even after treatment, and finally transfer responsibility for managing the...
consequences of ADHD to the adolescent who was becoming an adult. As they coped with challenges to their parenting, the family members also reflected on their own lives and recast their personal biographies. In an attempt to understand the feelings experienced by their children and to seek ways to protect them from stigma, they reflected upon lessons learned from their own childhood difficulties with being different or misunderstood. Their interviews also revealed the depth of guilt and grieving experienced by the parents, as they examined their disrupted family lives, and blamed themselves for not acting earlier or more decisively to seek help for their child affected by ADHD. Parents learned to separate their own feelings from those of their children, and to manage their own pain so that it did not stop them from requiring accountability on the part of the child. Finally parents came to the point of restoring a measure of peace to their own lives, could devote time to their own development as a person, and had some satisfaction with their own biography. The process of relinquishing the “good ending” involved letting go of the belief that the children affected by ADHD would attain the same goals as their peers on the same timetable. As the mainly European American participants reflected, they had to give up their culturally sanctioned idea that their hard work as parents would result in normal development for their children. Instead, recognizing the disruption produced by their child’s disorder, they worked toward realistic expectations. When all three processes were successful, parents could then reinvest their time and energy in their families including the “real” child, the child’s siblings, and themselves.

Types of Family Management Styles
Through an analysis of a subset of interview data, Kendall and Shelton (2003) also identified four subtypes of family management styles that corresponded in part to the age of the child and the length of time since a diagnosis of ADHD had been received. Seven families that were early in the process of adjusting to ADHD were categorized as operating from an ADHD controlled management style, in which the symptoms were the central factor that dictated family life and left parents feeling overwhelmed and victimized. Four of the families had moved into the surviving management style; the parents focused less on symptoms, strove to meet the needs of all of the individual members of the family, engaged in self care, and reached out to sources of support in the community. In three families with older children, a reinvested family management style had been adopted by parents. They had come to the point of recognizing that their child was affected by a neurologically-based set of behavioral challenges, and that they had not failed as parents. Since their children were fast approaching adulthood, they worked toward holding their children responsible for their own actions, and reinvested their energies in fulfilling their own goals. One other family, headed by a single parent on public assistance, was seen as falling into a separate category, a chaotic management style. The mother and child were functioning under such extreme circumstances, that their limited ability to cope with the child’s ADHD was understandable. From their clinical experience, the authors stated that chaotic family management was not rare in families that had few external supports or internal resources.

Conclusions and Implications
Parents caring for children with ADHD are forced to consciously manage their stress and confront their inadequacies in ways rarely experienced by parents of other children. Unlike some family members of children with other disabilities, they cannot normalize their daily lives by making adjustments to accommodate the needs of their children. Instead, they and their children embark on a journey toward their children’s adulthood that can be fraught with major psychosocial difficulties. Family members living with these children require services that support them and build on their strengths and coping strategies. As Kendall put it, “A comprehensive family approach must be taken…and it should emphasize services for the entire family rather than concentrating on the treatment of the disorder” (p. 855).

References