Learning how to live with a child with ADHD is a long process

Question
How do families with children who have attention deficit hyperactivity disorder (ADHD) manage the persistent difficulties caused by their children's symptoms?

Design
Grounded theory.

Setting
United States.

Participants
A total of 15 families (14 white) with ≥1 child with ADHD between the ages of 6 and 18 years. The ADHD child and ≥1 parent had to be willing to participate. Fifteen mothers, 10 fathers, 20 children with ADHD (mean age 11 years, 16 boys), and 14 siblings without ADHD (mean age 11 years, 8 boys) were interviewed. Five families had a single mother, 7 had both biological parents living at home, and 3 had a biological mother and a stepfather.

Methods
Altogether, 109 individual and family open-ended interviews, each lasting 30 to 90 minutes, were done in the home. Each person was asked to describe what it was like to live with ADHD or with a family member with ADHD and how their family functioned. Second individual and family interviews were done 8 to 12 weeks later.

Main findings
Outlasting disruption was the core variable. Family life was described as chaotic, conflictual, and exhausting. Disruptive behaviors were aggression, out-of-control hyperactivity, emotional and social immaturity, academic underachievement and learning problems, family conflicts, negative peer interactions, and isolation and rejection from the extended family. Parents regained control over their lives *(process of reinvestment)* using a 3-step model *(making sense, recasting biography,* and *relinquishing the good ending).*

Making sense had 4 categories. *Sinking in* dealt with being able to admit that a problem existed. *Believing* dealt with coming to terms with the child's identified problem and working toward normal functioning. *Wearing out* was a cyclical process of getting stuck, giving up, recharging, burning out, and getting stuck again. *Transferring responsibility* included relinquishing the idea that normal functioning was possible.

Recasting biography involved parents' examining their lives and developing new directions. Its categories were *remembering* their own childhood difficulties; *grieving* for past and current situations and the child's inability to become a strong and self-confident adult; *individuating,* which occurred when the mother realized that she had to "separate" from the child (often a son); and *restoring self,* in which parents put energies back into themselves and felt comfortable with who they were.

Relinquishing the good ending was the final process. It involved letting go of the belief that a child with ADHD was just like everyone else and moving beyond grief. The categories were *deintegrating stigma* by examining their own beliefs about ADHD, *gaining perspective* by changing old beliefs and fostering an emotional acknowledgment of the disorder, and *letting go of the anticipated normal child.* Once these processes were complete, parents were able to come to terms with the child's disability and engage in reinvestment in the "real" children, family, other children, marriage, and themselves.

Conclusion
Parenting a child with ADHD was a long and arduous process. Parents outlasted the disruption by making sense of the disorder, recasting biography, and relinquishing the good ending.

Kendall J. *Qual Health Res* 1998; 8:839-57.

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COMMENTARY

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ADHD, a disorder involving inattentiveness, overactivity, and impulsivity, has been the subject of recent debate in child and adolescent mental health. Much of the debate has centered on establishing diagnostic criteria and on specific interventions; Kendall's study, in contrast, centers on the experiences of those who are part of a family that has a child with ADHD.

Although Kendall identifies a specific process and constituent subprocesses in the families studied, this is not the main strength of the study. Its main strength lies in the way in which it persuasively reminds the reader that the real-life experiences of those living with a specific mental health problem are equally effective in informing practice as are more formal sources such as textbooks. As Kendall herself points out, all too often the focus of any intervention with families similar to those described in the study is on training family members to be better caregivers or parents. Issues important to the families themselves, such as offering physical or emotional support, respite, or family-centered mental health services, are rarely given the attention they deserve.

Because the study gives us insight into the experiences of only a few families with a child with ADHD, the identification of specific processes is only useful if it is set to inform rather than prescribe. Moreover, as with any research, the study raises more questions than answers:

- Are the predominantly white, "high-functioning and well-educated" families included in the study typical of other families with children with ADHD?
- Are these families different from other families caring for a family member with special needs?
- Are similar processes evident in families that appear to be comparatively stress-free?
- What about families who do not outlast disruption?

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