

Lessons Learned

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We've often been told that it is impossible to listen and talk at the same time. When researchers and professionals take the time to listen to parents and families of individuals diagnosed with AD/HD, the insight into their daily struggles, concerns and triumphs is truly amazing. Here are the results of one such study.

Background

The Maryland legislature set up a task force to study the uses of methylphenidate and other drugs on school children to determine the extent of use of prescribed drugs for AD/HD in the state. The task force expanded the scope of its mission and requested that the Maryland Center for Attention and Developmental Disorders (MCADD) carry out a series of focus group discussions with parents in Maryland. The focus group would sample caretaker views on topics related to the referral and diagnosis of and intervention for children with AD/HD, as well as the economic and social burdens placed on families. Groups were held in four distinct geographical areas of the state, both rural and urban. Advertisements elicited responses from 88 parents of school-age children with AD/HD, of whom 58 were selected for participation in the groups. In all, 42 parents attended, with group size ranging from five to 20. The children of the parents who attended ranged in age from 4 to 17 and were representative of the characteristics of the AD/HD population in terms of male to female ratios, age at diagnosis, and from whom they received services.

We moderated the four two-hour discussions with the goal of encouraging all members to share their views, avoiding biased and judgmental questions and comments, and flexibly covering important topics with open-ended questions. The questions dealt with the diagnostic process, treatment with particular emphasis on medication, the effects of having a child with AD/HD on family life, and interventions that have been most helpful. The major themes that emerged are presented below.

Results

The focus group method of gathering information forced us to remove the filters of researcher, clinician and "expert." We simply listened, and in that way we were able to understand more fully the experience of families with children with AD/HD. Parents emphasized again and again the stress involved in parenting a child with AD/HD. However, we were struck by the eloquence and humor they used in describing their experiences. They needed little prompting to speak; the words poured out, varying in the elegance of their delivery but packing force, passion and persuasiveness. Also, like soldiers in battle, it seemed to help many to maintain humor, often with a "black" quality to it.

By listening, we heard several important messages, quite consistently across groups, that reoriented our thinking about this complex disorder. First, parents viewed

medication in generally positive terms, but clearly communicated ambivalent feelings about its use. Second, in statement after statement, parents conveyed to us the weight of the burden that their children with AD/HD confer, not only on them, but also on others who care for and teach them. Third, shouldering this burden demands vigilance and a position of advocacy; to function best for their children, parents feel the need to carefully monitor all aspects of their children's life and to be informed, pushy and persevering in the face of numerous obstacles and frustrations. Finally, the burden is reduced for parents when they sense that others appreciate their level of suffering and when they join with others who work with their children in a spirit of cooperation.

1. Opinions concerning medication: "I think the medicine is really a start. The medicine is a good start. It gives him the ability or the realization that he can do the work."

Parents almost universally viewed medication as an important tool in the treatment of AD/HD, although many wished that they did not have to use it. Most hoped that their children would be able to discontinue its use by developing skills to compensate for their difficulties. Some parents expressed ambivalent feelings concerning the use of medication, resulting from fears of untoward effects, stigma, worries that children would use it as a crutch and a desire to use more "natural" treatments. There was no sense from these parents that stimulants or other drugs were overprescribed. Instead, concerns were expressed over specific drawbacks of medication (e.g., uneven course of effects), seemingly random changes in dosage and medication type, negative side effects, and lack of communication with the prescribing physician. A resounding message was that medication was not the total answer to the problems of a child with AD/HD. Rather, it was seen as an important tool, but only when used with other interventions to lower the burden of the disorder on the child, family, schools and providers.

2. Burdens of AD/HD: "He's the joy of my life, but there's a love-hate relationship going on almost daily. You know you love them but you could just slam dunk them sometimes."

The sense of burden permeated the comments of the four groups of parents. This is in keeping with other findings that disruptive disorders, like AD/HD, produce the greatest burden based on their prevalence, severity, stability and impact on the individual, family and community. From the comments of parents, the burden of AD/HD results from a variety of sources including community stigma, stresses of being on guard because of the impulsiveness of the child, the need to monitor social and academic activities, lack of community and family support, family conflict and enforced isolation. Judging from

our experience, the level of burden and the response of parents and caretakers to the burden may have major significance for outcomes of children with AD/HD. Although little research exists in this area, recent studies have shown that increased levels of family-environment adversity, particularly family conflict, were associated with impaired psychosocial functioning in children with AD/HD.

Although parents were the sole voice in these focus groups, their comments also reflected the wider burden of AD/HD. Teachers are confronted with a variety of challenges including engaging children with less ability to be engaged and directing children with greater tendency to resist direction. These challenges are complicated by a higher prevalence of learning disabilities and other behavioral and emotional problems. They also demand a greater degree of out-of-class time and activities, greater contact with parents and alterations in their usual way of teaching. Parents are frustrated with the lack of response of teachers, but also realize the weight of the teachers' burdens and the lack of training and support available to meet these demands.

Judging from the parents' experiences with prescribing physicians, treating the child with AD/HD involves significant demands that their practice style has difficulty accommodating. Parents want their physician to hear their concerns and confusion about the diagnostic process, to conduct comprehensive evaluations, to provide advice on behavior management, school issues and family conflict, as well as to carefully monitor medication. Comments by parents also implied the sense of burden that their child with AD/HD carries above and beyond dealing with the core symptoms and associated problems. They often are shut out of community activities such as Boy Scouts and sports teams. Their lives are restricted by the increased need for structure and their parents' vigilant attitude. They carry stigmatizing labels like "bad kid" and often engender negative comments from adults and peers.

3. Need for advocacy: "You need to stay on top of these teachers, these professionals Ñ you need to be educated, you need to know what's going on and you need to know your rights."

A significant aspect of the burden that parents carry is the need to be an advocate for their child. It was clear to nearly all the participants that they needed to develop a "siege" mentality to get needed help for their child. Our sense was that there was a developmental progression towards advocacy that was similar to stages identified in families dealing with members with severe mental illness. First is a stage that can be called, "What's wrong?" This occurs prior to diagnosis and involves rationalizing ("he's only a boy"), anger and stress over the symptoms, and finally a search for information

and support. Once a diagnosis is achieved, a stage of recognition occurs when the behaviors can be finally labeled. A range of emotions can occur at this time, including relief at finding an "answer" and guilt over prior responses to the child's problems. A critical coping stage then ensues that involves adjusting to frequent crises and disruptions as well as the development of despair and pessimism as the chronic nature of the disorder becomes evident. The family's response at this stage appears critical in adapting to the burden of AD/HD. Parents who are most successful seem to move into a stage of advocacy which involves increased assertiveness, decreased self-blame, and efforts to change the system at all levels. Helping parents move toward such an advocacy position may have important effects on outcomes for children with AD/HD. Although these stages appear to represent a developmental progression, it was our feeling that parents often shift back and forth between different stages, depending on external events and as their children with AD/HD met new challenges at different developmental and academic stages.

4. Need for acknowledgment and cooperation: "What happens is, every once in a while there's a gem; a teacher is there and knows how to do it and you just say, 'wow, we're going to have a good year.' And then the next year, if you get somebody who doesn't want to do those things or doesn't know how intuitively to do it, you just pay the price, and the kid pays the price. Our son paid a heck of a price. In our experience, you just hope that you'll make it through that year without too much damage."

Strength, self-confidence and a sense of mastery derive from an advocate's stance. However, it was clear from our parents that their crusade for their children is helped markedly by an acknowledgment of their burden by others coupled with a desire to collaborate and cooperate. The message was simple and direct. The genuine feelings conveyed by teachers, therapists, providers and others in the community were just as important as the content of the interventions. The need for interventions aimed at different aspects of the lives of children with AD/HD (e.g., school, family life, community activities) and the coordination of these interventions was a strong message that emerged from the focus groups. Parents' understanding of the comprehensive types of treatment strategies needed to make effective progress with children with AD/HD is in keeping with emerging literature indicating that single treatments alone are unlikely to yield long-term, clinically significant gains.

Directions

Listening to parents participating in the focus groups allowed us to recognize that we need a shift of emphasis in the way we approach the diagnosis and treatment of AD/HD in school-aged children. There is far more research conducted on AD/HD than any other

disorder affecting children and adolescents, concentrating on topics such as diagnostic reliability and validity, neuropsychological and neurobiological etiologies, medication effects and specific therapeutic interventions. However, according to our parents, these topics do not have as much relevance to the day-to-day functioning of children with AD/HD as the stresses and burdens that accrue to their families, teachers and providers. What we heard from parents and evidence from recent surveys reveal a disturbing trend in the treatment of AD/HD that suggests less rather than more effective interventions. Although the amount of medication dispensed has increased over the last eight years, the provision of psychosocial interventions and support services has generally declined.

Oddly, this change has occurred amidst calls for a broader model of intervention for childhood disorders. There has been a move away from emphasizing symptom reduction to including general adaptation, consumer perspectives (e.g., quality of life, satisfaction with care, family stress), environments (aspects of home, classroom, neighborhood, availability of social support) and systems (use of services, accessibility, coordination and costs). The focus group findings point to the need to develop interventions that directly address these broader outcomes. We need to expand our focus to a more systemic level, particularly within the health and education government programs, to have impact on this major public health problem. Care has tended to be in pieces, concentrating on symptom management. We have neglected the pain of families as they strive to do the best thing for their children. We feel that there is a strong need for support and cooperation to reduce the burden on all involved in the life of a child with AD/HD.

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