Psychiatric Times

Psychiatric Times. Vol. 27 No. 10
CHILD AND ADOLESCENT PSYCHIATRY

# Keys to Success in ADHD Treatment

## *Strategies for Effective Partnering With Families*

By Regina Bussing, MD and Ayesha Lall, MD | October 18, 2010
Dr Bussing is professor and Dr Lall is assistant professor in the department of psychiatry, division of child and adolescent psychiatry, at the University of Florida in Gainesville. The authors report no conflicts of interest concerning the subject matter of this article.

Clinicians who treat children with attention-deficit/hyperactivity disorder (ADHD) face a challenging conundrum. Although our understanding of ADHD and its evidence-based treatments has increased significantly in recent years, the number of successful treatment outcomes has not increased. Instead, treatment is characterized by high rates of discontinuation, poor adherence to quality indicators of care, and lack of documented improvements in long-term outcomes.[1]

One missing ingredient in suboptimal ADHD treatment may be insufficient partnering between families and treatment providers. Here we briefly review relevant health care concepts of partnering. We then describe a process of family-partnered ADHD treatment and identify strategies for strengthening the partnership at each stage of the process.

### Patient activation, empowerment, and patient-centered care

Several concepts enhance our understanding of effective partnerships with families: patient activation, patient empowerment, and patient-centered care.[2-6] In a clear departure from paternalistic power structures still common in much of medicine, these concepts emphasize equal partnerships between clinicians and patients or families. The Institute of Medicine of the National Academies has emphasized the importance of patient-centered care that is grounded in respect and sensitivity to patient preferences, needs, and values, and that recognizes families as equal partners with mental health or other human service professionals.[5,6]

To strengthen family-provider partnerships during all stages of treatment, we propose a series of helpful strategies (**Figure**).

### Engagement: setting the stage for partnership

Establish the team. To build effective partnerships, the provider needs to establish who will be part of the team. We recommend expanding the focus from partnering with parents to partnering with families. The child may be raised by caregivers other than the biological parents (in this article we use the term "parents" to include a variety of caregivers).

Family members who are unable to attend sessions (perhaps because of work schedules or personal health issues), may play important roles in decision making.[7] Effective partnering requires that absent team members' influence is openly acknowledged and that they are included in the treatment planning process.

Finally, partnering approaches need to include the child or adolescent in a developmentally sensitive manner, so that he or she can also have meaningful input in treatment planning.[8] For younger children, the parent or guardian may be the primary decision maker. Teenagers, on the other hand, must be actively engaged in the decision making. Identity formation and peer acceptance are vitally important to teenagers, so they may refuse to take a pill or participate in a behavior plan that may "change their personality" unless ongoing rapport and collaboration are established.

Cultural and language considerations. Although the workforce in this country is becoming more diverse, non-white patients and families are frequently served by white clinicians. To enhance partnering, clinicians need to understand culturally appropriate care for racial/ethnic groups represented in their geographic area. Apprehension and distrust of white clinicians should not be taken as a personal criticism. Patients and their families from different cultural/ethnic backgrounds may not be fluent in English. Therefore, if the clinician does not speak the patient's language, the services of a qualified medical interpreter are necessary.

In its public policy initiative on patient care and safety, the Joint Commission ( **www.jointcommission.org**)—which holds accreditation power over hospitals, clinics, and other health organizations—emphasizes the importance of effective provider-patient communication.[9] Particular emphasis is placed on ensuring language access services for patients with limited English proficiency. Providing information and assessment materials that the family can understand is another facet of setting the stage for partnering with families from diverse backgrounds.

**Partnered assessment: learning about child and family**

Listen to the stories. Children with ADHD and their families have personal stories of life with ADHD. The child's behavior may have elicited withering looks from strangers, unsolicited parenting advice from family members, frustrated phone calls from teachers, and searing parental self-recrimination after angry exchanges with a misbehaving child. Although practice guidelines emphasize the need for both parent and teacher reports of ADHD symptoms, patients have their own stories.[8,10]

Because of time constraints, clinicians may cut short individual accounts and focus on standardized questionnaires to assess symptom severity. This assessment experience, however, may not give families and children the sense that they have been heard and understood. As such, treatment suggestions subsequently offered by the clinician can more easily be discounted, especially if the recommendations are inconsistent with the family's expectations and values.

CHECKPOINTS

By including the child or adolescent in decision making as well as his or her parents, the partnering approach improves adherence to treatment and improves treatment outcomes.

To enhance partnering, clinicians need to be knowledgeable about culturally appropriate care for diverse cultural/ethnic groups and to ensure that communication between clinician and family is not compromised; a qualified medical interpreter may be needed.

In making a clinical diagnosis, the clinician needs to listen to and take into account not only the patient's story but that of relevant family members.

Education is bi-directional and ongoing: the clinician provides evidence-based information about attention-deficit/hyperactivity disorder (ADHD) and its impact on academics and peer and social development, and family members provide information about their personal experience with ADHD, their needs, and their preferences.

Understand explanatory models. Partnering with families requires an attitude of respect and sensitivity to patient preferences, needs, and values. One useful way to elicit this important information is by identifying the family's "explanatory model" of their child's problem. This term was coined by Kleinman[11] in the mid-1970s as a means of exploring patients' understanding of their condition, for comparing the perspectives of clinicians and patients, and for cross-cultural comparisons. Six brief, open-ended questions address parental worries and beliefs about the causes, expected time course, severity, preferred treatments, and desirable treatment outcomes.

Explanatory models of ADHD vary by race/ethnicity in the United States. Black parents tend to be less sure of potential causes of and treatments for ADHD than white parents, and they are less likely to connect ADHD to their child's school experiences.[12] Briefly gathering the family's explanatory model of ADHD provides good indications of the family's psychoeducational needs and their willingness to consider various treatment options.

ADHD in family members. Because of its frequent genetic etiology, ADHD in a child is likely foreshadowed by ADHD in other family members. The chances of successful treatment will be adversely affected if the parent responsible for implementing the treatment has untreated ADHD. However, targeted ADHD education in the context of respectful family-oriented communications may open the door to parental treatment or reveal the need for ADHD assessment of the patient's siblings.

**Education**

Target education to learning needs. Education is a bidirectional and ongoing process: the clinician provides evidence-based information about ADHD and its impact on academics and peer and social development. Family members provide information about their personal experience with ADHD, their needs, and their preferences. By listening to their "story," the clinician learns where each family member is on his respective ADHD journey; for example, the child may have been given a diagnosis of ADHD years ago and has tried numerous medication and behavioral therapy trials, or he may be faced with a new diagnosis.

Bidirectional and ongoing education paves the road for future collaborative decision making and enhances rapport and treatment adherence. Clinicians need to work diligently to withhold biased judgments. Experienced clinicians know that parents may hold on to feelings of guilt or inadequacy and may project these feelings onto the clinician. Notably, parents of children with ADHD report having higher levels of self-blame as well as depression, social isolation, and marital discord.[13,14] They may feel stigmatized because of concerns about ADHD and its negative implications for behavior, including danger to self or others.[15-17] More than 40% of respondents in the recent National Stigma

Study-Children (NSS-C) believe that children will face rejection in school for receiving mental health treatment and that negative ramifications will continue into adulthood. More than half expected psychiatric medications to cause zombie-like affect.[17]

Provide resources. It is essential to increase the family's understanding of evidence-based treatment. This potentially time-consuming process may be aided through referral to national advocacy groups, such as the National Alliance on Mental Illness (NAMI; www.nami.org) and Children and Adults with Attention Deficit/Hyperactivity Disorder (CHADD; www.chadd.org), and by offering a selection of reputable Web sites and bibliotherapy suggestions (**see Table for list of educational resources**). It may be important to caution families about unselective use of Internet resources or blogs: these resources are often, at best, anecdotal.

Educational implications and laws. ADHD affects a child's academic and social functioning and thus mandates regular communication with the child's school. This communication is vitally important not only to monitor a child's progress but also to identify any areas of potential concern. The clinician works with the child to develop a positive self-image and attitude toward school. The clinician also provides families with education about relevant education laws and encourages advocacy for school-based ADHD interventions, such as 504 Plans or Individualized Educational Plans (IEPs).[18]

**Partnered treatment plan development**

Identifying evidence-based treatments. Rather than simply recommending the best treatments, clinicians intent on partnerships work to increase the family's ability to understand research-based efficacy concepts. The recent NAMI publication Choosing the Right Treatment: What Family Members Need to Know About Evidence-Based Practices is an excellent resource for the partnering process that can be used to educate families. Incorporating evidence-based treatments within the treatment plan and shared understanding of the disorder is key.

Pharmacotherapy offers multiple evidence-based choices. Stimulant medications are first- and second-line treatments for ADHD. Nonstimulant options (such as atomoxetine(Drug information on atomoxetine)) may be first line for patients with comorbid tics, anxiety disorders, or substance abuse. In any case, the initial pharmacological choice should be an FDA-approved agent.[19] The Multimodal Treatment Study of Children with ADHD (MTA) suggests that pharmacological treatment of ADHD is more effective than behavioral therapy alone. However, behavioral training for parents and behavioral classroom management have also been shown to be well-established treatments for children with ADHD.[20-22]

Communicate about alternative treatments and assessments. Questions often arise about the role of alternative therapies for ADHD. Such therapies may include specialized diets (eg, avoiding dyes/sugars, the Feingold diet), vitamins, biofeedback, hypnosis, and herbal therapy to improve concentration and to treat behavioral disruptions.[23] Some parents may inquire about an "ADHD test" that includes brain imaging techniques (eg, single photon emission CT, positron emission tomography, electroencephalography, or MRI). These techniques are neither valid nor reliable diagnostic tools for ADHD and have no evidence-based recommendations for clinical use. It is important to convey that an ADHD diagnosis is made clinically.

Assess treatment willingness. Generally, parents express less willingness for medication treatments than for behavioral interventions. Non-white families are generally less willing to accept medication than their white counterparts.[17,24,25] In the recent NSS-C, 86% of the respondents believed that physicians overmedicate children for behavioral problems.[17] Psychiatrists are trained to emphasize the

effectiveness of ADHD medications and may not be inclined to explore a family's resistance to pharmacotherapy. Yet when recommended care is inconsistent with family values and preferences, this conflict needs to be resolved if the partnering process is to continue and a successful treatment plan implemented.

After they have received all the information about treatment, some families may still choose behavioral interventions over pharmacotherapy. In this setting, treatment goals should be identified and monitored to assess progress. If families opt out of recommended treatments altogether, the clinician should invite open dialogue about the family's underlying reasons for their choice. Constructing a careful time line of all past treatments and their results will help build a shared knowledge base for future treatment decisions.

**Partnered implementation and monitoring**

Collaborate on outcome. Once a joint treatment plan is developed, discussion as to how progress will be monitored is vital. It is important to consider what outcomes matter to the family in addition to what the clinician views as most important. A youngster may be acting impulsively and hitting his siblings, which, in turn, causes increased parental stress. Perhaps the family's desired outcome is eating dinner together without the risk of physical injury, not just obtaining a lower score on a rating scale. Therefore, monitoring specific patient- and family-desired outcomes along with ADHD symptoms captured through standardized rating scales (such as the SNAP-IV and Vanderbilt) may help keep families engaged in the treatment process.[26,27]

Anticipate adverse effects and adherence barriers. A proactive monitoring stance for adverse effects will increase the family's confidence in the clinician and help maximize outcomes. If the child is underweight and a picky eater, appetite-enhancement strategies should be implemented along with medication treatment. Sleep hygiene should be regularly monitored and discussed. Problem-solving potential barriers to adherence and timely follow-up should be assessed over time. Key elements of successful collaboration include anticipating and addressing the needs of the child and his family.

Emphasize need for school feedback. As the MTA study has taught us, direct feedback from teachers and school—such as teacher rating forms, copies of report cards, and IEP or testing results—can critically enhance treatment monitoring and outcomes.[21] Families vary in their inclination and ease regarding contact with schools, in part as a result of their socioeconomic background or perhaps because of their own memories of school. Clinicians need to proactively raise the topic, encourage solutions for potential communication barriers, and play an active role in the ongoing communication process. The chances of success can be increased, for example, by offering an office fax to which teacher ratings can be sent; this saves the parents the need to pick them up and avoids having a forgetful child fail to bring them back to the office. Support groups, such as those offered by CHADD, can provide a social network and the opportunity to learn from families who have mastered effective school communication skills.

**Summary**

Families and clinicians have many evidence-based therapies at their disposal to treat children with ADHD. Family-partnered ADHD treatment may be the key for successful implementation and optimal outcomes, with ongoing dialogue paving the way. We have outlined potential elements to enhance the family-clinician relationship, and we encourage clinicians to listen to the family's story and set up the groundwork for effective partnerships.

**References**

**1.** Zima BT, Hurlburt MS, Knapp P, et al. Quality of publicly-funded outpatient specialty mental health care for common childhood psychiatric disorders in California. *J Am Acad Child Adolesc Psychiatry.* 2005;44:130-144.
**2.** Hibbard JH, Stockard J, Mahoney ER, Tusler M. Development of the Patient Activation Measure (PAM): conceptualizing and measuring activation in patients and consumers. *Health Serv Res.* 2004;39(4, pt 1):1005-1026.
**3.** Green CA, Perrin NA, Polen MR, et al. Development of the Patient Activation Measure for mental health. *Adm Policy Ment Health.* 2010;37:327-333.
**4.** Fitzsimons S, Fuller R. Empowerment and its implications for clinical practice in mental health: a review. *J Ment Health.* 2002;11:481-499.
**5.** Institute of Medicine of the National Academies. Improving the Quality of Health Care for Mental and Substance-Use Conditions: Quality Chasm Series. November 1, 2005. http://www.iom.edu/Reports/2005/Improving-the-Quality-of-Health-Care-for-Mental-and-Substance-Use- . Accessed August 23, 2010.
**6.** National Academies Press. Crossing the Quality Chasm: A New Health System for the 21st Century. 2001. http://www.nap.edu/catalog.php?record_id=10027. Accessed August 23, 2010.
**7.** Bussing R, Koro-Ljungberg ME, Gary F, et al. Exploring help-seeking for ADHD symptoms: a mixed-methods approach. *Harv Rev Psychiatry.* 2005;13:85-101.
**8.** Williamson P, Koro-Ljungberg ME, Bussing R. Analysis of critical incidents and shifting perspectives: transitions in illness careers among adolescents with ADHD. *Qual Health Res.* 2009;19:352-365.
**9.** The Joint Commission. What Did the Doctor Say?: Improving Health Literacy to Protect Patient Safety. 2007. http://www.jointcommission.org/NR/rdonlyres/D5248B2E-E7E6-4121-8874-99C7B4888301/0/improving . Accessed August 23, 2010.
**10.** Bell L, Kellison I, Garvan CW, Bussing R. Relationships between child-reported activity level and task orientation and parental attention-deficit/hyperactivity disorder symptom ratings. *J Dev Behav Pediatr.* 2010;31:233-237.
**11.** Kleinman A. *The Illness Narratives: Suffering, Healing, and the Human Condition*. New York: Basic Books, Inc; 1988.
**12.** Bussing R, Gary FA, Mills TL, Garvan CW. Parental explanatory models of ADHD: gender and cultural variations. *Soc Psychiatry Psychiatr Epidemiol.* 2003;38:563-575.
**13.** Johnston C, Mash EJ. Families of children with attention-deficit/hyperactivity disorder: review and recommendations for future research. *Clin Child Fam Psychol Rev.* 2001;4:183-207.
**14.** Vierhile A, Robb A, Ryan-Krause P. Attention-deficit/hyperactivity disorder in children and adolescents: closing diagnostic, communication, and treatment gaps. *J Pediatr Health Care.* 2009;23(1 suppl):S5-S23.
**15.** Norvilitis JM, Scime M, Lee JS. Courtesy stigma in mothers of children with attention-deficit/hyperactivity disorder: a preliminary investigation. *J Atten Disord.* 2002;6:61-68.
**16.** Pescosolido BA, Fettes DL, Martin JK, et al. Perceived dangerousness of children with mental health problems and support for coerced treatment. *Psychiatr Serv.* 2007;58:619-625.
**17.** Pescosolido BA, Perry BL, Martin JK, et al. Stigmatizing attitudes and beliefs about treatment and psychiatric medications for children with mental illness. *Psychiatr Serv.* 2007;58:613-618.
**18.** Walter HJ, Berkovitz IH. Practice parameter for psychiatric consultation to schools. *J Am Acad Child Adolesc Psychiatry.* 2005;44:1068-1083.
**19.** Pliszka S; AACAP Work Group on Quality Issues. Practice parameter for the assessment and

treatment of children and adolescents with attention-deficit/hyperactivity disorder. *J Am Acad Child Adolesc Psychiatry.* 2007;46:894-921.
**20.** The MTA Cooperative Group. Moderators and mediators of treatment response for children with attention-deficit/hyperactivity disorder: the Multimodal Treatment Study of children with Attention-deficit/hyperactivity disorder. *Arch Gen Psychiatry.* 1999;56:1088-1096.
**21.** The MTA Cooperative Group. A 14-month randomized clinical trial of treatment strategies for attention-deficit/hyperactivity disorder. Multimodal Treatment Study of Children with ADHD. *Arch Gen Psychiatry.* 1999;56:1073-1086.
**22.** Pelham WE Jr, Fabiano GA. Evidence-based psychosocial treatments for attention-deficit/hyperactivity disorder. *J Clin Child Adolesc Psychol.* 2008;37:184-214.
**23.** Weber W, Newmark S. Complementary and alternative medical therapies for attention-deficit/hyperactivity disorder and autism. *Pediatr Clin North Am.* 2007;54:983-1006; xii.
**24.** Johnston C, Hommersen P, Seipp C. Acceptability of behavioral and pharmacological treatments for attention-deficit/hyperactivity disorder: relations to child and parent characteristics. *Behav Ther.* 2008;39:22-32.
**25.** Dosreis S, Zito JM, Safer DJ, et al. Parental perceptions and satisfaction with stimulant medication for attention-deficit hyperactivity disorder. *J Dev Behav Pediatr.* 2003;24:155-162.
**26.** Bussing R, Fernandez M, Harwood M, et al. Parent and teacher SNAP-IV ratings of attention deficit hyperactivity disorder symptoms: psychometric properties and normative ratings from a school district sample. *Assessment.* 2008;15:317-328.
**27.** Wolraich ML, Lambert W, Doffing MA, et al. Psychometric properties of the Vanderbilt ADHD diagnostic parent rating scale in a referred population. *J Pediatr Psychol.* 2003;28:559-567.