

Measuring Outcomes in Attention-Deficit/Hyperactivity Disorder

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Attention-Deficit/Hyperactivity Disorder (ADHD)¹ is a frequently encountered neurobiological disorder in childhood and has been the focus of significant scientific investigation and clinical interest over the past five decades.^{2,3} Primary care pediatricians provide a major component of the care for children and adolescents with ADHD. For the purpose of improving the care of these children, the American Academy of Pediatrics developed practice guidelines for the diagnosis and treatment of ADHD in the primary care setting for children ranging in age from 6 to 12 years.^{4,5}

Goldman et al. have noted that ADHD is one of the “best-researched disorders in medicine” and that there are compelling data to attest to the validity of the disorder.⁶ ADHD carries with it a number of symptoms including problems with attention and concentration, distractibility and impulsivity (for review see Barkley⁷). These symptoms are associated with an array of debilitating functional impairments in individuals with ADHD. Epidemiological studies have been somewhat variable with regard to the prevalence of ADHD; estimates range from approximately 7% to 10% percent although fewer children receive treatment for the disorder (for review see American Academy of Child and Adolescent Psychiatry²). Contrary to previous clinical lore that ADHD represents a maturational lag that children would eventually out grow,³ compelling data from follow-up studies suggest that 60 to 85% of children with ADHD continue to meet diagnostic criteria for the disorder at adolescence and that a significant percentage of adults suffer from functional impairment, although they evidence fewer symptoms of the disorder (for review see Barkley⁷).

In recent years, growing evidence supports a main genetic basis for ADHD, with approximately 76% of the variance of symptoms attributed to genetic factors.⁸ Neuropsychological studies have demonstrated that children with ADHD frequently have deficits in executive functions that involve impairments in response

inhibition, vigilance, working memory, and planning ability.⁹ Neuroimaging studies have generally found children with ADHD to have decreased frontal and temporal lobe volume relative to normally developing controls,¹⁰ while functional imaging studies have revealed differences in brain activation in the frontal lobes, the caudate, and anterior cingulate relative to comparison controls.¹¹ With regard to the treatment of the disorder, there has been an array of new pharmacotherapies tested by careful controlled clinical trials that include long-acting stimulant medications and novel delivery approaches including a methylphenidate transdermal patch.² Finally, a major investigation sponsored by the National Institute of Mental Health examined the unitary and combined effects of stimulant medication and behavioral treatments on ADHD symptoms and associated academic and social impairments.¹² The Multimodal Treatment Study of Children with ADHD (MTA) trial also provided a 22 month follow-up of these children after active treatment had been terminated.^{13,14}

Thus, most experts now recognize ADHD as a chronic illness for which there is clearly compelling empirical evidence to drive both the assessment and management of the disorder. Because primary care pediatricians provide a major component of the care for children and adolescents with ADHD, an understanding of recent research developments of the disorder is critical in both assessment and management and hence this supplement on ADHD.

The American Academy of Pediatrics hosted a conference in the summer of 2005 to consider new evidence and methods for measuring outcomes in ADHD. The conference brought together a diverse group of clinicians from several disciplines as well as researchers investigating a wide variety of issues in ADHD, including its prevalence, manifestations, and impact on children and families. Developed by a planning committee chaired by one of us (JMP), the conference synthesized critical new knowledge about ADHD, its outcomes, and its

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treatment. This supplement provides a series of articles arising from the conference, related to the natural history of the disorder, functional impairments associated with ADHD, issues related to treatment outcome, and finally matters pertaining to health services research in children and adolescents with the disorder including service use patterns and the economic impact of the disorder to society.

The first series of articles in this supplement pertain to the etiology, natural history, and academic and peer functioning of children and adolescents with ADHD. Spencer, Biederman and Mick provide an evidence-based overview of ADHD that includes diagnosis, prevalence, presentation of symptoms within a developmental context, heterogeneity of functional outcome, psychiatric comorbidity, pathophysiology, genetics, psychosocial and biological risk factors and neurobiology of the disorder.¹⁵ They conclude that ADHD is an early-onset, highly prevalent neurobehavioral disorder that persists into adolescence and adulthood with several etiologies including those that are genetic, environmental and biologic. Although Spencer et al. conclude that there is high diagnostic reliability and clear evidence for the robust validity of the disorder, several lines of research merit continuing attention, including the impact of development on diagnostic criteria, the impact of gender on symptom expression, and the identification of specific risk and protective factors that are associated with functional impairments. Loe and Feldman have meticulously reviewed the academic and educational outcomes of children with ADHD and conclude that the disorder has dramatic associations with poor grades, poor reading and math standardized test scores and increased grade retention.¹⁶ The disorder also is associated with increased utilization of school-based services, increased rates of detention and expulsion, and low rates of high school graduation and post-secondary education. The authors observe that while pharmacotherapy and behavior management typically lead to a reduction in the core symptoms of ADHD and enhanced academic productivity, these treatments have failed to enhance educational attainment. For the purpose of improving the academic and educational outcomes of children with ADHD, Loe and Feldman recommend the use of conceptually-based outcome measures that may be employed in prospective, longitudinal and community-based studies. Finally, Hoza reviews the extant literature pertaining to the peer relationships of children with ADHD including the role of the disorder in problematic relationships with peers and how peers' reactions to these problems may serve

to sustain these difficulties.¹⁷ Here too, she finds quite substantial impact of ADHD on peer relationships. Based on her review of the extant literature and the conceptualization of ADHD and how this impacts peer relationships, Hoza recommends more intensive interventions and novel approaches for the purpose of addressing peer problems among children with ADHD. The large impact of ADHD on both educational performance and peer relationships indicates the importance of assessing these domains in the treatment of ADHD.

The second set of articles in this supplement addresses treatment issues for children with ADHD. Hinshaw discusses specific moderators and mediators of treatment response from the MTA.¹⁸ Key moderator variables include comorbid anxiety disorder, public assistance, severity of ADHD, parental depressive symptomatology, and IQ. Mediator processes reviewed include negative/ineffective parental discipline. Based on his review, Hinshaw concludes that future treatment research must specifically consider moderator and mediator variables that may explain clinical trials and specify the next steps for intervention research. In the further assessment of outcomes for children with ADHD, Cunningham has identified parenting and familial factors that can help the planning and measurement of interventions for children with ADHD.¹⁹ These factors include parenting and parent-child relationships, parental cognitions, parental adjustment, marital interactions, familial relationships and adaptive child functioning within the family. Cunningham notes opportunities to enhance measures of treatment outcome for children with ADHD by the use of multiple informants, the development of tools with greater content and contextual validity, the reliance on observational instruments, and finally, the identification of measures that are of greatest importance to families.

The final set of articles relate to ADHD and health services research. Leslie and Wolraich review health services use by children and adolescents with ADHD.²⁰ Primary care, mental health and educational service system sectors each play an essential role in caring for youth with ADHD. Studies also suggest an increase in the use of psychotropic medication including stimulants, a decrease in mental health visits and finally, a number of barriers that impede care coordination for ADHD children across primary care, mental health and schools. They recommend greater research regarding the context in which the service use occurs, operationalizing evidence-based care for real-world settings, and the identification of variables that change clinician and

educator behavior. Finally, Pelham, Foster, and Robb examined the economic impact of ADHD using a cost of illness framework.²¹ They estimate an annual cost of illness of ADHD in children and adolescents at nearly \$11,000 per individual in 2005 dollars. Using a conservative prevalence rate of 5%, Pelham et al. estimate the annual society cost of illness for ADHD in children and adolescents to range from \$16.2 billion to \$51.0 billion with a mean of approximately \$32.1 billion.

Finally, Stein has provided a thoughtful commentary on the articles in this supplement that relate to the definition of ADHD and its manifestations, the natural history of the disorder and the morbidity that it causes, the choice of outcomes and their relative importance, the nature of the treatments, the implementation of treatment research, and research priorities.²² She notes that the highest research priority should be the development of a reliable method for identifying and classifying ADHD without impairment or more specifically to separate the measurement of ADHD as a health condition from the impairment that it causes. Related to the notion of impairment, Stein has astutely observed that public health approaches to environmental modification may reduce the level of impairment of many children. Finally, Stein recommends that researchers and caretakers focus on the long-term outcomes of children with ADHD and not solely on short-term symptoms.

We are pleased to have this collaboration between pediatric psychology and pediatrics by publishing this special series in both *Ambulatory Pediatrics* and the *Journal of Pediatric Psychology*. These papers provide guidance to critical needed research in the measurement of outcomes for children and youth with ADHD. They also document well the substantial burden of illness that ADHD causes, especially in educational performance, peer relationships, and family life. Improving these domains should be a central focus of treatment, and practice guidelines should address these areas in the development of treatment targets and monitoring the effects of care. We hope that the collaboration of pediatricians and pediatric psychologists will lead to fruitful research efforts and thereby improve diagnostic and intervention efforts that will result in improved outcomes and quality of life for children with ADHD and their families.

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