

Estimating Prevalence and Detection Cost: Prerequisites for Disease State Management of Attention Deficit Hyperactivity Disorder

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Abstract

Attention deficit hyperactivity disorder (ADHD) is an expensive, vexatious, and destructive problem for patients, providers, and payers alike. The customary diagnostic method involving the use of specialty consultants to determine the significance of symptoms is imprecise and intolerably costly, especially in a capitated or managed healthcare system. A more efficient, less costly diagnostic procedure enables primary care physicians to determine symptom significance with a clinical information system before specialty consultation is considered. This procedure enables the Disease State Management process to be applied to ADHD.

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The prevalence of attention deficit hyperactivity disorder (ADHD) has been estimated to represent 3% to 20% of children and it is the leading reason for referral to child mental health programs in the United States.¹ Several studies²⁻⁵ have reported that children with ADHD use more medical services, educational services, and social agency services than those who do not have ADHD. In addition, ADHD is associated with several other painful and expensive comorbid disorders of adolescence and adulthood, including affective disorders, accidents, and alcohol abuse.^{1,6} Thus ADHD is a prime candidate for Disease State Management (DSM).

The DSM process requires precise identification of a disease, methods for selecting patients who will benefit from specific interventions, explicit plans for clinical intervention, and measurement of patient outcomes.⁷ Although DSM refers to a systematic process based on explicit definitions and objective data, the process can be applied just as effectively to imper-

fectly defined disorders (such as ADHD or depression) as to more clearly understood diseases (such as bacterial infections). In this paper, DSM refers to a systematic process of healthcare management but is not meant to imply that ADHD is understood well enough to be considered a disease.

Attention deficit hyperactivity disorder has a long history of successfully eluding each requirement of the DSM process. As to precise identification of the disorder, ADHD is ambiguously defined^{8,9} and probably includes at least two (also undefined) neurodevelopmental disorders.^{8,10-12} The etiology of ADHD and its component disorders also is unknown.^{13,14}

It is not possible to accurately identify persons with a disorder if the disorder itself is not accurately defined. It follows that without a serviceable definition of ADHD there can be little agreement on the prevalence of the disorder in the pediatric population.¹⁵ Several investigators have reported that ADHD affects boys more than girls,^{1,5,16-21} but this sex-related difference might be explained by the less-disruptive behavior of girls with ADHD compared with boys with ADHD.²² Again, clinical and epidemiological inferences about ADHD can be no more accurate than the prerequisite definition of the disorder.

To complicate matters further, about one third of children diagnosed with ADHD experience a remission of symptoms in adolescence and adulthood.¹ Remission may occur as a result of effective treatment, delayed development, or incorrect diagnosis. To date, no one has been able to predict who will experience remission of ADHD symptoms and who will not.

There is a general consensus that drug therapy is important in treating patients with ADHD.²³⁻³¹ Drug treatment usually includes a central nervous system (CNS) stimulant, such as methylphenidate, pemoline, or dextroamphetamine.^{32,33} Antidepressants are increasingly prescribed for adolescents with ADHD.^{34,35} However, since many persons function better when taking CNS stimulants even if they do not meet the diagnostic criteria for ADHD,³⁶ response

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(or lack of response) to medication is not diagnostically significant.³⁷ Not all patients with ADHD respond to drug therapy,^{1,38} and the effectiveness of a particular drug may decrease with time.³² Although drugs do play an important role in treating ADHD,³⁹ this disorder is best treated through a combination of drug therapy and consultation to develop effective mental-work and self-control habits at home and at school.⁴⁰⁻⁴⁴

Central nervous system stimulants are prescribed for 1% to 2% of elementary school children in the United States,⁴⁵ with the number of prescriptions being written rapidly increasing.²⁶ This prescription trend indicates that ADHD is a large and growing problem for the healthcare system. Yet we still have no serviceable definition of the disorder, no means of accurately identifying children with the disorder, no methods for selecting patients who will benefit from specific interventions, and no ability to plan explicit clinical interventions. From management's point of view, if persons with ADHD cannot be identified with certainty, the prevalence of the disorder cannot be determined and detection and treatment costs cannot be controlled.

The purpose of this paper is to provide a realistic estimate of the prevalence of ADHD and to estimate detection costs as the first steps in applying the DSM process to this disorder.

Attention Deficit Hyperactivity Disorder

Attention deficit hyperactivity disorder is a cluster of attentional and inhibitory impairments of unknown etiology that manifest in a variety of combinations and a range of severities. It has a destructive effect on children's ability to control themselves, relate to others, do effective mental work, and sometimes control their movement. The disorder can have profound consequences for children, their families, and the healthcare system.^{3,5,46-50}

Several other conditions, such as immaturity,⁵¹ stress, anxiety, learning disabilities,^{52,53} neurologic deficits,^{9,54} exposure to toxins,⁵⁶ and metabolic disorders⁵⁶⁻⁵⁸ have clinical presentations similar to that of ADHD. These possibilities must be explored and ruled out before an ADHD diagnosis is finalized and treatment initiated.

Detection and Diagnosis

Attention deficit hyperactivity disorder is usually, but not always, noticed in early childhood,⁵⁹ and patients typically are seen first by a primary care physician.^{16,42} The disorder generally is recognized shortly after a child enters school or a preschool program.¹

Traditionally, ADHD has been diagnosed by history and clinical observation supplemented by scores on behavior rating scales,⁶⁰⁻⁶² such as the Conners Parent Rating Scale,⁶³ completed by parents and sometimes by teachers.⁶⁴ Although several behavior rating scales are widely used, their usefulness to the DSM process varies relative to their ability to sample each of the stated symptoms of the target disorder and to document additional and alternative causal factors.

The traditional ADHD diagnostic process is time and labor intensive, as well as unreliable and imprecise.⁶⁵⁻⁶⁸ Currently available laboratory studies cannot confirm a diagnosis of ADHD.¹⁹ Although neuropsychological assessment provides an illusion of precision, no neuropsychological test profiles reliably or validly identify ADHD.⁶⁹⁻⁷⁸ Some authors even argue that no compelling evidence exists for attention deficit in ADHD, at least as attention is measured by continuous performance tests⁷⁹⁻⁸² and psychometric measures of sustained attention.⁸³

In the final analysis, the diagnosis of ADHD is usually based on the behavioral observations of adults other than the diagnosing physician. This process is disconcerting to many primary care physicians, who are trained and accustomed to observing and evaluating symptoms first hand. However, symptoms of ADHD often are not exhibited in the physician's consulting room. Neither are the ADHD symptoms of nondisruptive boys and girls obvious in the classroom. Thus behavioral observations made by parents and reported to physicians remain the most reliable data for diagnosing ADHD.⁸⁴

The *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV)*⁸⁵ provides four ADHD diagnoses derived from various combinations of 18 behavioral symptoms usually reported to the physician by a parent. Although the DSM-IV diagnostic criteria for ADHD require "clear evidence of clinically significant impairment...to a degree that is maladaptive and inconsistent with developmental level," clear evidence is hard to come by. No currently available laboratory or psychologic tests can reliably detect ADHD. Response to medication also is not conclusive or diagnostically significant.

In addition to ambiguity, the DSM-IV diagnostic criteria for ADHD do not specify normal or clinically significant values for individual symptoms or combinations of symptoms. If a "normal" reference point cannot be defined, neither can "abnormal," "maladaptive," "inconsistent with developmental level," or "clinically significant." Even if primary care physicians or specialty consultants obtain reliable information from the parent, they cannot determine

whether the behavior is abnormal or clinically significant without first defining normal.

As with other medical disorders, ADHD symptoms occur on a continuum. Consequently, until normal or average values for ADHD symptoms are specified, the point of clinical significance or abnormality cannot be determined by primary care physicians or anyone else. These two points (normal and abnormal) cannot be determined by idiosyncratic clinical interviews, no matter who does the interviewing or how long they take to do it.

The process of diagnosing ADHD involves two separate and distinct steps. The first step in the ADHD diagnostic process involves determining if an individual meets the stated ADHD diagnostic requirements at some objectively specified level of significance. In the context of clinical practice, "significant" is a relative term that describes a measurable difference from normal or average. The actual point of significance can be set at any objectively defined and justifiable value, but for it to have any useful meaning, the reference point "normal" must also be objectively specified. These points of normality and clinical significance must be specified objectively. They cannot be stated impressionally or as anecdotal reports. The second step of the diagnostic process, exclusion of diagnostic alternatives, determines if factors other than ADHD are responsible for a clinically significant report of child behavior. Several conditions can result in a behavior pattern that is qualitatively and quantitatively consistent with ADHD, and each must be considered and ruled out before an ADHD diagnosis can be established. This is the point in the diagnostic process at which the wisdom, clinical experience, and interviewing skill of physicians and consultants can be optimally employed.

... PATIENTS AND METHODS ...

A total of 150 consecutive patients undergoing an annual physical examination in the pediatric clinic of a medical center affiliated with a health maintenance organization were enrolled in the trial. The average age (\pm standard deviation) of the patients was 10.0 ± 3.6 years. Ninety patients (60%) were boys and 60 (40%) were girls. The average age for boys was 9.8 ± 3.6 years and for girls 10.3 ± 3.5 years. Ninety-nine percent of the patients were white.

Each child's behavior was assessed by using both the Conners Parent Rating Scale (CPRS-48) and the ADD-C. Parents completed these two rating instruments while in the physician's waiting room.

The CPRS-48,⁶³ a well-known behavior rating scale used to identify behavior problems in children,⁸⁶ consists of five scales (conduct problem, learning problem, psychosomatic, impulsive-hyperactive, and anxiety). A shortened version of the CPRS-48, called the Hyperactivity Index (HI), contains the ten most highly loaded items from factor analytic studies. The CPRS-48 HI provides a broad measure of behavior problems.

The ADD-C (E.T. Heck, PhD, unpublished data, 1995) is a clinical information system, one component of which is a brief questionnaire completed by parents. The questionnaires are sent to a computer processing center where the parents' responses are compared with local population norms. A report prepared for the primary care physician provides the most likely DSM-IV diagnosis and code, a list of confirmatory and alternative diagnoses, four behavior scales, and treatment recommendations. Periodic reports of aggregate experience also are provided to the clinic or medical group. The ADD-C is used to identify children who meet the diagnostic significance requirements for an ADHD diagnosis, to document alternative or additional diagnostic possibilities, to suggest specific clinical interventions for each child, and to provide behavior scales for monitoring treatment progress.

... RESULTS ...

The percentage of boys and girls with significant scores (≥ 1.5 standard deviations) on the CPRS-48 HI and the ADD-C are shown in Table 1. Sixteen percent of the children in this clinic population had significant behavior problems according to the CPRS-48 HI. Nearly twice as many behavior problems were identified in boys as in girls. Parents rated their sons signifi-

Table 1. Percentage of Boys and Girls with Significant* Behavior Problems According to Parental Reports

	Boys (n = 90)	Girls (n = 60)
CPRS-48 HI	18.8	10.0
ADD-C	8.8	8.3
High stress	4.4	5.0

CPRS-48 = Conners Parent Rating Scale.
*CPRS-48 \geq 95th percentile; ADD-C \leq 5th percentile; high stress \geq 95th percentile (by parent's report that the child had experienced high stress in the past year)

cantly worse than their daughters on every item of the CPRS-48 Hyperactivity Index and the ADD-C. This pattern was still seen when children with ADHD were removed from the sample.

The ADD-C identified 8.6% of children whose parents' reports were clinically significant for ADHD. That is, these parents' ADD-C ratings were more than 1.5 standard deviations below average or in the lowest 5th percentile of all responses at their clinic. This excludes children for whom an alternative medical diagnosis (such as head injury or seizure disorder) was reported but includes social and behavioral diagnostic possibilities (such as a parental report of high stress in the past year). All children whose parents' reports were clinically significant for ADHD also had significantly high (at or above the 95th percentile) scores on the CPRS-48 HI.

Prevalence refers to the total number of cases of a disease or disorder in a population. If we assume that one half of the behavior problems resulted from causes other than ADHD⁸⁷ (such as high stress), the prevalence of ADHD in this clinic population is approximately 6.4%.

Incidence refers to the number of new cases of a disease or disorder identified each year. If we assume that the patient turnover rate (for payers) is 0.25, the incidence of ADHD in this clinic population is approximately 1.6%. That is, payers can expect that 1.6% of children in this patient population will be diagnosed with ADHD.

Parents reported that 23% of boys and 8.3% of girls had attention problems and were receiving treatment for them. These parental reports support the CPRS-48 data that boys have more behavior problems than girls. However, whether the boys' higher rate of behavior problems is attributable to or associated with a significantly higher rate of attention problems remains unresolved. In this clinic population, only 8.8% of boys and 8.3% of girls met the ADD-C criteria for an ADHD diagnosis (the required number of symptoms at or below the 5% level). Yet, while most children who met the ADD-C criteria for an ADHD diagnosis were receiving treatment for attention problems (92% of the boys and 71% of the girls), 75% of the boys but none of the girls were being treated with CNS stimulants. The reason for this sex difference in treating ADHD is an important but unresolved question.

Cost of Detecting ADHD

Because the rate of noteworthy behavior problems in this clinic population exceeded the number of children who were ultimately diagnosed and treated,

we can assume that 1.5 times the incidence of ADHD approximates the percentage of children who must be screened each year to identify all cases of ADHD in the population.

Every child suspected of having ADHD in this clinic population was referred for medical specialty consultation or neuropsychological assessment to confirm the diagnosis. The average specialty consultation cost was estimated at \$320 per patient referred. This cost includes three interview sessions per patient and 4 hours of psychological testing for every tenth patient. Assuming an ADHD incidence of 1.6% and an optimal screening rate of 1.5 times the incidence, the ADHD detection cost using specialty consultants for screening is \$.64 per pediatric member per month ($\$320 \times .016 \times 1.5/12 = \$.64$). The ADHD detection cost using primary care physicians and a clinical information system or screening instrument with a \$20 unit cost would be \$.04 per pediatric member per month ($\$20 \times .016 \times 1.5/12 = \$.04$). Reimbursing primary care physicians \$55 to administer each survey would cost \$.15 per pediatric member per month ($\$55 + \$20 \times (.016 \times 1.5)/12 = \$.15$).

... DISCUSSION AND CONCLUSION ...

Attention deficit hyperactivity disorder is a perplexing and expensive problem for patients, providers, and payers alike. The DSM-IV diagnostic criteria for ADHD are ambiguous and probably include at least two component disorders yet to be identified. Although ADHD symptoms range from significantly adaptive ability to significantly maladaptive ability, points of normality and clinical significance have not been defined. In addition, the drugs used to treat ADHD yield variable results. The customary practice of using specialty consultants to determine whether a patient meets the diagnostic criteria for ADHD (rather than ruling out alternative explanations) is inaccurate and intolerably expensive.

Because ADHD is considered a medical problem and consumers demand a large volume of healthcare services to treat it, ADHD is a prime candidate for the disease state management process. To implement the DSM process, the target disorder and the patients who have it must be precisely identified. For disorders such as ADHD, whose symptoms occur on a continuum, the diagnostic process involves two steps: (1) determining whether the symptoms are significant by some objective criterion; and (2) ruling out alternative or additional explanations for the symptoms. The first step involves statistical methodology and cannot be accomplished by idiosyncratic clinical

interviews or clinician intuition. The second step involves clinical methodology that relies heavily on interviews, intuition, and experience. Ideally, patients should first be screened by a primary care physician to determine whether the symptoms are significant. If so, the primary care physician can either complete the diagnostic process and begin treatment or refer the patient to a specialist to rule out alternative diagnoses.

In the study presented here, the prevalence of ADHD was estimated by determining the significance of symptoms in a sample of patients from a pediatric clinic affiliated with a health maintenance organization. Symptom significance was arbitrarily defined as a parental report at or below the 5% level for that symptom or group of symptoms. The prevalence of ADHD in this clinic population was estimated to be 6.4%, with an incidence of 1.6%. Based on these estimates, the cost of screening patients using primary care physicians to determine the significance of ADHD symptoms was estimated at \$.15 per pediatric patient per month (assuming a \$55 reimbursement to the physician and a survey or clinical information system unit cost of \$20). The screening cost would be \$.04 per pediatric patient per month without physician reimbursement. In contrast, the usual and customary method of diagnosing ADHD using specialty consultants to determine symptom significance was estimated at \$.64 per pediatric patient per month.

Providing coverage for a popular but poorly defined disorder can be risky business for capitated physician groups, capitated mental health providers, and payers because standard diagnostic methods yield equivocal results at great expense. On the other hand, ADHD probably is being paid for even if placed outside the reimbursement cap because ambiguous diagnostic criteria allow physicians to include its symptoms under other equally ambiguous, but covered, disorders. Increased claims for healthcare services associated with ADHD are covered, as are comorbid conditions.

The problem of ADHD cannot be solved by restricting access to coverage. If data are not adequate to provide coverage with certainty, they probably are not adequate to restrict coverage either. The optimal long-range solution will require coordinated application of the DSM process by payers, primary care physicians, and mental health professionals. Through effective healthcare management, this solution can be achieved. Applying the DSM process to ADHD will benefit patients, physicians, and payers and is long overdue.

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