

Common Dilemmas in the Diagnosis and Treatment of ADHD. *Experts' Opinions for the Improvement of Practice Management in the Outpatient Setting*

Dilemas Comunes en el Diagnóstico y tratamiento de TDAH. Opiniones de Expertos para el
Mejoramiento la Práctica en Medicina Ambulatoria

Fogelman Y,* Kahan E.**

* Leumit Health Management Organization and Rappaport Faculty of Medicine, Technion-Israel Institute of Technology, Haifa, Israel. ** Department of Family Medicine, Sackler Faculty of Medicine, Tel Aviv University, Tel Aviv, Israel.

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Correspondencia: Yacov Fogelman MD. E- mail: fogelman@netvision.net.

ABSTRACT

Background: Attention deficit-hyperactivity disorder (ADHD) is one of the most common behavioral disorders of childhood. The large variations in care and the growing prevalence of pharmacologic treatment are a source of public and professional debate worldwide. The aim of the study was to evaluate the opinion of experts about the effectiveness of office-based practices in the management of ADHD. **Methods:** An ad hoc, mostly open, questionnaire was distributed to the 10 members of an international forum of experts on ADHD. **Results:** Nine experts recommended multidisciplinary training of medical practitioners in the screening, diagnosis and treatment of ADHD and regular, standardized monitoring of drug use for effectiveness and safety by the care providers in collaboration with parents and school officials. Most of the experts thought that trained primary care physicians (pediatricians and family physicians) could handle straightforward cases and appropriately refer more complicated ones. The large differences in care among countries was attributed to the lack of strong, specific scientific data on the long-term effectiveness of stimulant medication for ADHD; the nonspecific effect of methylphenidate; the difference between the DSM-IV definition of ADHD and the ICD-10 definition of hyperkinetic disorder; the highly subjective and impressionistic nature of current diagnostic questionnaires; and cultural differences in medical models used to treat behavioral problems. The need for broader data on drug misuse was emphasized. **Conclusions:** To improve the effectiveness of office-based practices for ADHD, an improved international diagnostic system is needed, together with standardized tools for patient evaluation, education of professionals, and public and international research projects.

Key words: ADHD, Attention deficit, Child care.

RESUMEN

Antecedentes: El trastorno por déficit de atención-hiperactividad (TDAH) es una de las enfermedades de la conducta más comunes en los niños. La gran variación en los cuidados de estos pacientes y el aumento en la prevalencia del tratamiento farmacológico son una fuente de debate público y profesional en todo el mundo. El objetivo del presente estudio fue evaluar la opinión de expertos acerca de la eficacia del tratamiento del TDAH en el consultorio. **Métodos:** Un cuestionario abierto diseñado *ad hoc* fue distribuido a 10 miembros de un foro internacional de expertos en TDAH. **Resultados:** Nueve expertos recomendaron que los médicos tuvieran un entrenamiento multidisciplinario y que realizaran regularmente acciones de: tamizaje, diagnóstico y tratamiento en casos de TDAH. Uniformar y monitorizar la eficacia y seguridad de los medicamentos en colaboración con los padres de familia y funcionarios escolares. La mayoría de los expertos opinaron que los médicos de atención primaria debidamente entrenados (pediatras y médicos familiares) podrían manejar los casos sencillos y referir oportunamente los casos complicados. Las enormes diferencias de manejo en los diversos países fueron atribuidas a una falta de información sólida sobre el manejo de estimulantes por largos períodos en casos de TDAH; la inespecificidad de los efectos del metilfenidato; la diferencia entre la definición del TDAH del DSM-IV y la definición de desorden hiperquinético del ICD-10; la alta subjetividad y naturaleza emocional de los cuestionarios diagnósticos actuales y las diferencias culturales entre los modelos médicos utilizados para abordar los problemas de conducta. Se hizo hincapié en ampliar la información acerca del uso erróneo de medicamentos. **Conclusiones:** Para acrecentar la eficacia de la atención en el consultorio en los casos de TDAH es necesario perfeccionar el sistema internacional de diagnóstico, en conjunto con la estandarización de herramientas para la evaluación de los pacientes, la educación de los profesionales y la realización de proyectos internacionales de investigación.

Palabras clave: TDAH, Déficit de atención, Cuidados de los niños.

Introduction

Attention deficit-hyperactivity disorder (ADHD) is one of the most common behavioral disorders of childhood, with effects lasting into adult life. The growing use of stimulants for the treatment of ADHD,¹ even in preschool children,²⁻⁴ has generated worldwide debates in the public media and the medical community. Furthermore, studies have shown that potentially effective treatments for ADHD and/or conduct disorder are not optimally applied⁵. For example, most pediatricians use twice-daily dosing when thrice-daily dosing or long-acting agents that provide full-day coverage are generally more desirable⁵.

A major problem is the lack of relevant knowledge, skills and tools among healthcare providers. There are also substantial differences in the availability of specialists and health professionals trained in psychosocial medicine⁶; in the diagnostic classification systems used; in health policies on referrals; in the types of specialists to which affected children are referred; and in the availability and licensing of particular psychopharmacological preparations. To facilitate the exchange of ideas in the care of ADHD, we created an international forum of experts who have published selected reports in the field. The present study describes our analysis of an open questionnaire completed by the panel on controversial issues in ADHD.

Methods

We conducted a Medline search from 1995 to 2005 using the key words "ADHD diagnosis", "ADHD treatment", and "ADHD pharmacology". We identified 26 authors of more than one paper on the subject and invited them by e-mail to participate in an international discussion group. To the 10 experts who agreed, we distributed an ad hoc, mostly open, questionnaire consisting of the following items:

Do you believe the prescription of methylphenidate for ADHD in the community should be restricted to a specific medical specialist? Please explain.

If yes, please specify which of the following specialists (pediatrician, family physician, child neurologist, psychiatrist and/or other) and explain why.

In your opinion, what are the main reasons for the large differences within and among countries in the proportion of children medicated with methylphenidate?

In your opinion, what are the main reasons for the large differences (up to 28-fold) in the proportion of children medicated with methylphenidate by type of residential area?

Do you believe that in some areas there is abuse and/or overtreatment with methylphenidate?

Do you have any proposal for methods to improve the diagnosis and treatment of ADHD and their practical implementation?

Do you have any proposal for methods of monitoring the quality of treatment of children affected by ADHD?

Results

All 10 experts completed the questionnaire.

- Regarding methylphenidate prescription in the community, 9 experts suggested that the medical training of medical practitioners in the diagnosis, screening and treatment of ADHD should be multidisciplinary and comprehensive and that methylphenidate should be prescribed only by properly trained physicians after the proper assessments are performed.

They also recommended that regardless of the specialty of the prescribing physician, the children should be regularly and uniformly monitored for safety and effectiveness by regular care providers in collaboration with parents and school officials.

- Most of the experts agreed that primary care physicians, pediatricians, and family physicians can all handle straightforward cases of ADHD and appropriately refer more complicated ones.

By specialty, the experts believed that child neurologists may be the only specialists capable of managing patients with more complex medical disorders, such as co-morbid tic disorder, but not children with difficult social and psychiatric problems, who should be referred to child psychiatrists. This is clinically important, because extreme ADHD can later evolve into bipolar disorder, generalized anxiety or depression with ADHD, and conduct disorder. Developmental and behavioral pediatricians concentrate on behavioral/psychiatric or neurodevelopmental issues and are trained to handle simple to complex cases that warrant treatment with stimulants.

- The large differences within and among countries in the proportion of children medicated with methylphenidate were attributed to several factors:

1. Despite the wealth of short-term efficacy data, strong evidence on the long-term effectiveness of stimulant medication for ADHD is still lacking. Furthermore, many professionals do not realize that stimulants are nonspecific and may help most normal children as well.

2. The definition of ADHD in the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV) ⁷ differs from the definition of hyperkinetic disorder, which is much less common than ADHD, in the International Classification of Diseases, Tenth Edition (ICD-10) ⁸. Countries using the ICD-10 may therefore report a lower prevalence of ADHD requiring treatment. Furthermore, poor guidance from professional organizations, such as the American Psychiatric Association and the American Academy of Pediatrics, may contribute to inadequate diagnostic criteria and management.

3. The diagnostic questionnaires now in use are highly subjective and impressionistic. Items such as “often talks excessively” assess the perceptions of the caregiver, not the discomfort of the child.

4. The American pharmaceutical industry is powerful and its marketing practices work, even if that means that drugs are sometimes prescribed without adequate evaluation and follow-up (“seductive advertising”). Other countries might have better checks on the power of the pharmaceutical industry to influence prescribing practices of physicians. Legislation regarding drug availability differs as well.

5. There are important differences in the medical models used to explain and treat behavioral problems in children. Factors that play a role include social class, income, education, race/ethnicity, and religion. These, in turn, affect attitudes to child behavior, expectations of children, and recognition of the full range of normal behavioral variations, including temperament differences, in addition to treatment availability, legislation, and insurance policies.

6. Differences in medical training and approach can lead to variations in the conceptualization of certain behavioral problems such as conduct disorder vs. impulsivity/hyperactivity. Furthermore, ADHD is often complicated by comorbidities, such as learning disabilities, conduct disorders, and anxiety disorder whose symptoms may mimic ADHD itself.

7. Accordingly, stimulant medication is often prescribed with inadequate evaluation, dose titration, or follow-up. This is irresponsible and inappropriate for a drug that is often given to children over many years.

- The main reasons for the large differences (up to 28-fold) in the proportion of children receiving methylphenidate by type of residence was explained by differences in access to mental health or medical specialties and to tertiary care facilities, and differences in the training of prescribing physicians.

The experts suggested that geographic variations were also related to differences in race/ethnicity/culture (attitude to behavioral problems, their evaluation, and their medical treatment, school pressure, etc.), income (cost of treatment), and education (knowledge of behavioral problems and their treatment, likelihood of school authorities to refer children for treatment).

- Regarding drug abuse, the experts noted that misuse or overtreatment is possible for any medication administered for a long-term (chronic) condition. They suggested that one of the primary difficulties in overtreatment (i.e., treating children who do not meet the DSM criteria for ADHD) and undertreatment (i.e., not treating children who would benefit from treatment) is the inability of researchers to reach conclusions from current drug utilization data.

Other problems include nonstandardized and relatively poor diagnostic evaluations, inadequate medical training, and time and cost limitations. History has shown this to be the case with amphetamines for the treatment of weight loss and with anxiolytics (e.g., meprobamate). Methylphenidate also has effects that may result in patient abuse, e.g., increased attention and performance. Although the US data on this issue are restricted and based only on school surveys, so far, strong misuse patterns have not been detected, probably because the Food and Drug Administration monitors access by means of C-II classification. Community-based cohort studies are needed to establish the appropriateness of treatment.

- There were several proposals for methods of improving the diagnosis and treatment of ADHD and their practical implementation.

1. The critical first step is collaboration among medical and developmental specialists (e.g., pediatricians, psychiatrists, psychologists, and school specialists) to ensure the use of an identification, treatment and evaluation model that is capable of demonstrating benefits and assessing risks.

2. The diagnosis of ADHD should be standardized worldwide. ADHD and disruptive behavior disorders are classified differently in the DSM-IV and ICD-10. For a diagnosis of ADHD, children must have 6 or more of the 9 inattention symptoms of the DSM-IV or 6 or more of the 9 hyperactivity/impulsivity symptoms of ICD-10 "for at least six months to a degree that is maladaptive and inconsistent with developmental level." Some of the symptoms must have been present before age 7, and some impairment must be present in 2 or more settings (social, academic, occupational). Furthermore, the DSM fails to acknowledge the role of temperament, which could lead to overdiagnosis.

3. Adherence to official guidelines should be encouraged. Whether or not one approves of the ADHD criteria, there is strong evidence that at the practical level, they are not being faithfully applied.

4. Clinicians should consider the full differential diagnosis from the beginning, and not just after they cannot fit the symptoms to the highly flexible criteria of ADHD. School problems require comprehensive examinations including psycho-educational testing and evaluation of the child's temperament and adjustment. Assessments must be detailed, broad, and multidimensional, and should include the children's strengths as well.

5. Medication often needs to be combined with behavioral therapies to achieve optimal results. Treatment should be designed to fit the child's specific strengths and problems, with greater reliance on psychosocial and educational interventions. Behavioral controls can be learned. An aversive temperament, however, cannot be managed by behavior modification, but can be successfully accommodated by alternative management.

6. Physicians and mental health providers should work closely with the patients, their families, and their schools to improve school functioning and parent-teen interactions. In addition, the responsibility to make meaningful decisions within the context of a supportive family and professional environment can enhance the self-esteem and self-efficacy of these children.
7. Close clinical monitoring of symptoms is important to minimize impaired functioning, side effects, parental dissatisfaction and noncompliance with treatment.
8. Better education of professionals and the public is needed, including the provision of more background information on the broad range of normal behavioral variations and the nonspecificity of stimulants. Many practitioners fail to recognize the existence and importance of variations in temperament. Furthermore, caregivers today often have unrealistic expectations of high performance and conformity, and they may exert pressure on physicians to prescribe drugs. School officials should be targeted for educational sessions because they are often the first to detect children with suspected ADHD and can play an essential role in monitoring the effectiveness of treatment.
9. Better research is mandatory. Despite the confidence of ADHD spokespersons, expressed in the 2002 statement of the self-appointed International Consensus Committee on ADHD, much is uncertain.
10. Other suggestions included better monitoring of the aggressive advertising by drug companies, with elimination of all physician conflicts of interest; a better insurance system to compensate physicians who need more time for adequate evaluations; and better training of family and primary care providers to diagnose and initiate treatment of ADHD themselves or at least do the follow-up (assuming this does not contravene national/regional medical policy), which would balance the insufficient number of specialists in many countries, decrease the length of first referral times, and ensure that only patients with complicated or refractory disease are referred for secondary care.

Discussion

According to the DSM-IV, the prevalence of ADHD in the school-age population is 3% to 5%⁷. Besides its impact on the social and scholastic adjustment and self-image of patients, ADHD takes a high toll in family cohesion and places a financial burden on the health system⁹. Health care costs for a child with ADHD may be more than twice as high as those for children without ADHD¹⁰, and are comparable to the health care costs of children with asthma¹. Several studies indicate that children with ADHD are also at an increased risk of unintentional injury¹¹ and hospitalization¹².

The epidemiological characteristics of ADHD and the use of methylphenidate have been investigated in large-scale studies in North America and Europe¹³⁻¹⁸. Safer and Krager¹³ examined trends in the use of methylphenidate over a 25-year period in Baltimore County, Maryland, using data from biannual registries of school nurses who listed the students receiving medication for "hyperactivity". They found that the use of methylphenidate had increased steadily over time at all grade levels, and by 1987, it was being prescribed for 5.96% of all public elementary school children. On the whole, in the United States, the average consumption of methylphenidate increased 2.5-fold from 1981 to 1992¹⁴. Although stimulant prescriptions may have temporarily decreased to 3% around 1990¹⁵, a subsequent study documented a continuing increase of more than 4-fold from 1992 to 1998¹⁶. In the United Kingdom, prescriptions rose from 183,000 in 1991 to 1.58 million in 1995¹⁷. By contrast, in other European countries, reports showed methylphenidate consumption to be very low¹⁸, and restricted by custom¹⁹. In West Germany, only 2580 children used the drug regularly during 1991, for a prescription rate 100- to 300-fold lower than in the USA²⁰. This difference may be due in part to major differences in the methods used for the diagnosis of hyperkinetic disorder and ADHD and to whether coexisting conditions such as conduct, learning, or aggressive disorders are considered the primary diagnosis or secondary to attention deficit and overactivity.

Large differences (up to 28-fold) have also been noted in the proportion of medicated children by type of residential conditions²¹. In a study in Michigan, a 10-fold difference was reported among communities, which the authors attributed to the wide range of prescription practices among physicians¹⁴. This finding was supported by a national survey in the United States on the knowledge and attitudes of pediatricians regarding the diagnosis and treatment of ADHD²² and by other studies as well²³.

Adequate treatment of ADHD is needed to avoid academic impairments, social dysfunction, and poor self-esteem. Stimulants such as methylphenidate are currently the treatment of choice because of their efficacy, ease of administration, high tolerability, and relative freedom from potential abuse²⁴. They increase the ability of affected children to concentrate and to control impulsive behavior. However, findings on the long-term effects in children are still controversial²⁵.

Several studies and editorial and review articles published in academic journals²⁶⁻³⁰, and lay publications³¹⁻³⁶ have outlined several concerns about pharmacotherapy in very young children. These may be divided into 3 major domains: the short- and long-term safety of these agents for very young children, particularly their possible effects on the developing brain; the lack of efficacy data demonstrating that these medications attenuate the behavioral and emotional symptoms targeted in these young children; and the unclear context in which these medications are prescribed (e.g., characteristics of the children, their families, and the prescribing clinician; accompanying medical and psychosocial services). Therefore, besides stimulant medication, experts today are encouraging the consideration of nonstimulant medication as well as alternative therapies, based on a comprehensive clinical assessment including a detailed patient history, clinical interview and observation, and a thorough physical examination³⁷.

The diagnosis of ADHD, however, remains subjective. There are no simple diagnostic or laboratory tests that reliably predict or diagnose ADHD. Neuroimaging techniques, although helpful in research settings to document the neurobiologic basis of the disorder, are not diagnostic for an individual patient. Neuropsychological testing is a useful tool in assessing learning disabilities but is not necessary for formulating a diagnosis of ADHD³⁸⁻⁴⁰. These difficulties have translated into difficulties developing an adequate case definition for epidemiological studies, as diagnosis depends heavily on parent and teacher reports, and prevalence estimates of ADHD are sensitive to who is asked what and how information is combined⁴¹. As the National Institutes of Health panel advised, improved diagnostic criteria are urgently needed. Distinctions must be made between “hyperkinetic” children, who are truly pervasively overactive or inattentive, and those who have primarily other problems. The current ADHD formulation is based on the presence of a certain number of troublesome behaviors (and other criteria), and overlooks the fact that these behaviors may also represent a normal but aversive temperament that leads to dysfunction because it generates dissonant interactions between the child and his or her environment. This use of cut points has not been validated.

Therefore, the overly simple and broad diagnostic process for ADHD should be phased out and replaced by more comprehensive individual assessments of children with behavioral and scholastic problems. Instead of trying to fit the patient to the convenient DSM-IV ADHD categories, we should be performing functional evaluations of physical and neurological status, developmental and cognitive status, temperament, and behavioral adjustment. They should inquire about early behavior and academic functioning through grade school, middle school, and high school, and determine whether the impairment affects home, school, and leisure time activities. Strengths should be noted as well as weaknesses. The quality of significant elements of the environment and the child's interactions with them must be included⁴². Only in this way can the uniqueness of the individual child be appreciated and the treatment or management matched with his or her special needs. This issue was highlighted in two recent comprehensive studies, one including more than 400 physicians throughout the USA⁴³ and one based in North Carolina⁴⁴, reported that in more than half the cases of ADHD, the diagnosis and the start of stimulant medication were not based on accepted criteria and thorough assessment. Thus, to be effective, these changes must go hand-in-hand with changes in legislation and health management and insurance policies⁴⁵.

Conclusion

A large number of controversial issues dealing with the diagnosis and care of ADHD have been described and analyzed. Our group of experts suggest that primary care physicians can handle straightforward cases. They have found large variations in the diagnosis and treatment of ADHD, and mostly owing to differences in cultural/religious/philosophical perceptions, medical training, and diagnostic tools. They recommend the formulation of more accurate well-established clinical practice guidelines for ADHD management in the outpatient setting, in addition to a better international diagnostic system, better patient evaluation, better education of professionals and public and international research projects.

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