How Common Is Attention-Deficit/Hyperactivity Disorder?

Incidence in a Population-Based Birth Cohort in Rochester, Minn

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Context: The frequency of occurrence of attention-deficit/hyperactivity disorder (AD/HD) is in dispute. This uncertainty has contributed to the concern that too many children in the United States are being treated with stimulant medication.

Objectives: To determine the cumulative incidence of AD/HD in a population-based birth cohort and to estimate the prevalence of pharmacologic treatment for children who fulfill research criteria for AD/HD.


Setting and Subjects: All children born between 1976 and 1982 in Rochester, Minn, who remained in the community after age 5 years (N=5718).

Main Outcome Measures: Medical and school records were reviewed for clinical diagnoses of AD/HD and supporting documentation (symptoms consistent with Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition criteria and positive results for AD/HD-related questionnaires). Research-identified cases were defined as: (1) “definite” AD/HD (clinical diagnosis and at least one type of supporting documentation); (2) “probable” AD/HD (clinical diagnosis but no supporting documentation or no clinical diagnosis but both types of supporting documentation); (3) “questionable” AD/HD (no clinical diagnosis, but at least one type of supporting documentation); and (4) “not AD/HD” (all other subjects). Information about pharmacologic treatment for AD/HD was abstracted for all subjects.

Results: The highest estimate of the cumulative incidence at age 19 years (with 95% confidence interval) of AD/HD (definite plus probable plus questionable AD/HD) was 16.0% (14.7-17.3). The lowest estimate (definite AD/HD only) was 7.4% (6.5-8.4). Prevalence of treatment with stimulant medication was 86.5% for definite AD/HD, 40.0% for probable AD/HD, 6.6% for questionable AD/HD, and 0.2% for not AD/HD.

Conclusions: These results provide insight into the apparent discrepancies in estimates of the occurrence of AD/HD, with less stringent criteria resulting in higher cumulative incidence. Children who met the most stringent criteria for AD/HD were most likely to receive pharmacologic treatment.

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The frequency of occurrence of attention-deficit/hyperactivity disorder (AD/HD) is in dispute, with reported prevalence varying from 1% to 20% among school-aged children.1,2 Potential overdiagnosis of the disorder and overuse of stimulant medications make it imperative to obtain accurate information about the occurrence of AD/HD.3-5 The American Academy of Pediatrics has attempted to address this issue by developing and publishing a clinical practice guideline for the evaluation of children with AD/HD.6 A recently convened National Institutes of Health consensus conference also addressed concerns about the potential overdiagnosis of AD/HD.7 Previous studies of the occurrence of AD/HD have relied on limited sources of information to establish the diagnosis. Examples include teacher questionnaires and lay-administered diagnostic interviews.8,9 To our knowledge, the AD/HD literature does not include any reports of the incidence of AD/HD in a comprehensively studied, large, population-based birth cohort. A more precise understanding of the occurrence of AD/HD is urgently needed to determine whether appropriate numbers of children are being diagnosed and treated for this disorder. In this article, we report the results of a com-p
SUBJECTS AND METHODS

STUDY SETTING

In 1990, the population of Rochester was 70,745, and 96% of the city was white, of whom 82% of adults were high school graduates and primarily middle class. The capacity for population-based epidemiologic research on AD/HD in Rochester is the result of a unique set of circumstances. Rochester is geographically isolated in southeastern Minnesota, and as a result, more than 95% of medical care is provided locally by the Mayo Clinic, Olmsted Medical Center, and the few private practitioners in the area. Through the Rochester Epidemiology Project, all diagnoses and surgical procedures recorded at these medical facilities, including their affiliated hospitals, are indexed for computerized retrieval (Medical Diagnostic Index). The medical records contain complete and detailed information from providers of care to local residents, including the records of all outpatient, inpatient, primary, and specialty care received. This includes the results of psychometric tests and questionnaires, and psychological and psychiatric assessments obtained during interdisciplinary assessments of children with behavior problems, including AD/HD.

Through a contractual research agreement, permission was obtained to access the records of Rochester public and private schools (Independent School District 535), including the complete school records of all children born in Rochester during the years 1976 through 1982 who were ever registered at any of the district’s public, parochial, or private schools. The school records include medical reports; medication records; private tutoring or evaluation reports; individually and group-administered ability and achievement tests; and notations from teachers, parents, or any other persons related to any type of school problems. Copies of assessments, reports, and meeting minutes related to the provision of special educational services are also maintained in the records.

Consent was also obtained to review the records of birth cohort subjects who had been treated at the only private community psychiatric practice, the records of which are not included in the Rochester Epidemiology Project.

RESULTS

The combined cumulative incidence of definite AD/HD, probable AD/HD, and questionable AD/HD among subjects in the 1976-1982 birth cohort by age 19 years was 16.0% (95% CI, 14.7-17.3) (Table 5 and Figure 2). The combined cumulative incidence figure of 16.0% represents the highest estimate of the occurrence of AD/HD in the birth cohort.

The combined cumulative incidence of definite AD/HD and probable AD/HD was 9.4% by age 19 years (95% CI, 8.3-10.4) (Table 5 and Figure 2). This figure represents an intermediate estimate of the occurrence of AD/HD in the birth cohort.

The cumulative incidence of definite AD/HD in the birth cohort was 7.5% by age 19 years (95% CI 6.5-8.4), which represents the lowest estimate of the occurrence of AD/HD in the birth cohort (Table 5 and Figure 2).

Table 4 provides details about the numbers of subjects who fulfilled the criteria for the 3 research-identified categories of AD/HD. Of the 305 subjects with definite AD/HD, 151 had a clinical diagnosis plus both types of supporting documentation (subject fulfilled DSM-IV criteria and had positive AD/HD-specific rating scales). Furthermore, 30 of 70 subjects with probable AD/HD had a cli-

IDENTIFICATION OF THE 1976-1982 ROCHESTER BIRTH COHORT

The birth cohort included all children born between January 1, 1976, and December 31, 1982, to mothers residing in the 5 Olmsted County, Minnesota, townships composing Minnesota Independent School District 535 (N=8548). Subjects were identified through the computerized birth certificate information from the Minnesota Department of Health, Division of Vital Statistics. Vital status for each member of the birth cohort during the 1995-1996 school year were established using resources from the Rochester Epidemiology Project, Independent School District 535, and the Minnesota Department of Health. Children who still lived in Rochester until at least age 5 years were included in the study (N=5718, Figure 1). This age cutoff was used because it represents the typical age of school entry. A careful analysis comparing birth certificate data of subjects who moved away vs data of those who remained in the community was published previously. Only slight differences were found, and these were unlikely to compromise the identification of AD/HD incident cases or other related research findings. Authorization to review the medical records of birth cohort subjects was obtained in accordance with Minnesota statutes and approved by the Mayo Clinic institutional review board.

IDENTIFICATION OF AD/HD CANDIDATES (POSSIBLE INCIDENT CASES) IN THE 1976-1982 BIRTH COHORT

The complete school records for all 5718 children in the birth cohort were reviewed page by page. The records of 1951 subjects were found to have some indication of concern about school performance, including the presence of an Individual Education Program, medical reports, medication records, any referral for assessment of a school problem, or any remarks related to a school problem (Figure 1). For each of these 1951 subjects, information related to AD/HD was then abstracted from both medical and school records. This information included:

- Clinical diagnoses. Diagnostic terms for clinical diagnoses of AD/HD changed several times during the years relevant to this study. Therefore, diagnoses were abstracted and then recategorized into 1 of the 3 Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV) AD/HD categories (Table 1).
• AD/HD symptoms. An extensive glossary of words and terms consistent with AD/HD symptoms as specified in the DSM-IV was developed. The date, setting (home, school), and observer (teacher, parent, psychologist, etc) for each AD/HD symptom for each subject was recorded by abstractors under the supervision of a developmental and behavioral pediatrician and child psychologist (W.J.B. and R.C.C.). Even single notations of “hyperactivity,” “impulsivity,” or “inattention” found in the medical or school records were abstracted.

• AD/HD-related questionnaires and laboratory tests. The results of AD/HD-related questionnaires and laboratory-based psychometric tests contained in the school and medical records were recorded (Table 2).

• Medications. Documentation of treatment with medications commonly prescribed for children with AD/HD, including psychostimulants, centrally acting α-adrenergic agonists, and tricyclic antidepressants, was abstracted.

From this process, 1171 subjects (AD/HD candidates) were found to have 1 or more of the previously mentioned 4 types of information in their medical and/or school records (Figure 1).

For the remaining 3767 subjects whose school records did not include any suggestion of school problems, the computerized Medical Diagnostic Index was used to identify that medical records for all children with any diagnosis related to or including AD/HD (Table 3). The records of birth cohort subjects who had received care at the only private community provider of psychiatric care whose records are not included in the Rochester Epidemiology Project were also reviewed.

Children with moderate-to-severe mental retardation (full-scale IQ ≤ 50) were excluded from further consideration (n = 17).

A total of 1344 subjects (AD/HD candidates) were identified as possible cases of AD/HD at the conclusion of the steps outlined above (Figure 1). Data collection was completed in 1999.

IDENTIFICATION OF AD/HD INCIDENT CASES USING RESEARCH CRITERIA

Explicit research criteria were developed to identify AD/HD incident cases among the AD/HD candidates. Subjects were identified as “definite” AD/HD incident cases if their records included a clinical diagnosis and at least one form of supporting documentation (subject fulfilled DSM-IV criteria for AD/HD, and/or had a positive parent and/or teacher AD/HD questionnaire result) (Table 4). To fulfill DSM-IV criteria for “inattention” or “hyperactivity-impulsivity,” subjects had to have 6 or more separate entries in the medical or school records that were consistent with DSM-IV criteria. Symptoms also had to be noted by 2 or more different observers. Subjects were identified as “probable” AD/HD incident cases if their records included a clinical diagnosis without any supporting documentation or no clinical diagnosis with both forms of supporting documentation (ie, fulfills DSM-IV criteria and has a positive questionnaire result, Table 4). The exclusion criteria specified in the DSM-IV were followed (ie, no subject could be identified as an AD/HD case if they had a diagnosis of pervasive developmental disorder, severe mental retardation, schizophrenia, or a psychotic disorder). Subjects whose records included information consistent with AD/HD symptoms as specified in the DSM-IV or who had positive questionnaire results, but who did not fulfill research criteria for either definite AD/HD or probable AD/HD, were designated “questionable” AD/HD. Subjects who did not fulfill criteria for definite, probable, or questionable AD/HD were designated “not AD/HD.”

STATISTICAL ANALYSIS

To estimate the probability that an individual would meet the research criteria for AD/HD at some time between 5 and 19 years of age, cumulative incidence was estimated according to the method of Kaplan and Meier. Children in the birth cohort without AD/HD who had not moved or died were censored. Emigration was ascertained by a detailed review of the school and medical facilities to determine the actual move-out date. Cumulative incidence was estimated for the entire birth cohort and separately for males and females. Ninety-five percent confidence intervals (95% CI) for the cumulative incidence were calculated using the Greenwood formula. Hazard ratios (males vs females) for AD/HD, and corresponding 95% CI, were estimated with Cox proportional hazard regression models.

A χ² test for a contingency table, using ridit scores for evaluating trends in binomial proportions, was used to evaluate whether the prevalence of medical treatment increased across the 4 research-identified AD/HD groups (not AD/HD, questionable AD/HD, probable AD/HD, definite AD/HD).
This study provides information about the occurrence of AD/HD and helps to explain the wide variation in reported rates of occurrence of this disorder. We believe that this study represents the first report of the occurrence of AD/HD in a large, population-based birth cohort. The AD/HD incident cases in the current study were identified on the basis of rigorous research criteria, including a clinical diagnosis and extensive supporting documentation. We were also able to obtain comprehensive information about birth cohort subjects from both medical and school records.

The available literature includes estimates of AD/HD occurrence based on a wide range of sample sizes, often with convenience samples that may not be representative of the communities from which the subjects were selected. Existing studies frequently employed limited sources and types of information, often relying on a single rating scale to identify AD/HD cases. Finally, since it has been shown that parents and teachers often give conflicting reports of AD/HD symptoms, it is important to include information from all observers to identify children with AD/HD.

The cumulative incidence results from this study help to explain the variation in reported occurrence of AD/HD.
Incidence studies are an important epidemiological tool primarily used to estimate the risk to an individual of acquiring a particular condition. The use of a birth cohort provides an opportunity to study the natural selection of subjects by placing them into different categories of risk for AD/HD, minimizing many of the biases inherent in studies based on prevalence cases (eg, net migration due to children with AD/HD moving into or out of the community). Prevalence studies are used primarily as a measure of the burden of a condition on the community and are less desirable for etiological studies.

In the absence of birth cohort–based incidence studies of AD/HD, we can cautiously compare the cumulative incidence from our study with the prevalence reported by other investigators. The highest estimate of the incidence of AD/HD in the birth cohort by age 19 years, based on the least restrictive research criteria for case identification, was 16.0% (definite AD/HD plus probable AD/HD plus questionable AD/HD). Wolraich et al and Baumgartel et al recently reported prevalence rates of 11.4% and 17.8%, respectively. In both of these studies, a single teacher rating scale of AD/HD symptoms, based on DSM-IV criteria, was employed. If applied to our birth cohort, this method would likely identify subjects who would fulfill our least restrictive research criteria. Another recent study that employed a teacher survey based on DSM-III-R criteria found a prevalence rate of 8.3% among 11- to 14-year-old boys. This lower figure may reflect the fact that DSM-IV criteria have been found to identify more children with AD/HD than DSM-III-R criteria. Subjects included in our highest estimate of the occurrence of AD/HD may not all represent true cases of the disorder. The questionable AD/HD group had information in the records consistent with DSM-IV criteria or had documentation of a positive parent and/or teacher rating. As specified in the DSM-IV and in the American Academy of Pediatrics practice guidelines for AD/HD, the presence of symptoms consistent with AD/HD is only the first step in the diagnostic process. A more thorough evaluation may offer alternative explanations for the same set of symptoms. This may account, in part,
for the large number of children treated for AD/HD in some communities.3-5

The intermediate estimate of AD/HD occurrence in the birth cohort (9.4% by 19 years of age) was based on the combined research criteria for either definite AD/HD or probable AD/HD. In a previous report, we demonstrated that these 2 groups were similar in their history of health care costs, utilization, and medical comorbidity.22 This intermediate estimate is comparable with prevalence figures from several studies that employed a structured diagnostic interview of selected groups of children. Cohen et al23 studied children from 2 upstate New York counties, and found prevalence rates of 17.1% and 8.5%, respectively, for 10- to 13-year-old boys and girls, comparable with 13.3% of boys and 5.1% of girls in our intermediate estimate of AD/HD occurrence. Recently, Jensen et al3 used a structured diagnostic interview and found an AD/HD prevalence of 9.4% in Atlanta, Ga, and 7.0% in New Haven, Conn.3 Shekim et al16 employed a DSM-III–based diagnostic interview of 114 nine-year-old children living in the United States and found a 12% prevalence rate.16

The lowest and most conservative estimate of AD/HD occurrence in the birth cohort was 7.5% by age 19 years, based on the research criteria for definite AD/HD. These criteria required both a clinical diagnosis of AD/HD and supporting documentation in the medical and school records. It is not surprising that we identified far fewer children with definite AD/HD since it has been demonstrated that direct assessment, combined with parent and teacher ratings, leads to the identification of far fewer children with AD/HD.4 The 7.5% cumulative incidence of definite AD/HD by age 19 years is comparable with the 6.3% overall prevalence among Canadian children as reported by Szatmari et al.24 In that study, structured interviews of parents, teachers, and children were obtained and used to identify AD/HD cases. August et al25 employed a sequential case-identification method of teacher ratings, parent ratings, and a diagnostic interview, and found an AD/HD prevalence rate of 4.3% among children in grades 1 through 4.25 The 7.5% cumulative incidence of definite AD/HD from the current study includes subjects who met the most restrictive criteria and

<table>
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<tr>
<th>Table 5. Cumulative Incidence of AD/HD in the 1976-1982 Birth Cohort*</th>
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<tr>
<td>Cumulative Incidence of AD/HD by Age 19 Years, % (95% CI)</td>
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<tr>
<td>---------------------------------------------------------------</td>
</tr>
<tr>
<td>Definite AD/HD</td>
</tr>
<tr>
<td>Overall</td>
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<tr>
<td>Males</td>
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<tr>
<td>Females</td>
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<tr>
<td>Definite AD/HD plus probable AD/HD</td>
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<tr>
<td>Overall</td>
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<tr>
<td>Males</td>
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<tr>
<td>Definite AD/HD plus probable AD/HD plus questionable AD/HD</td>
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<td>Males</td>
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<td>Females</td>
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*AD/HD indicates attention-deficit/hyperactivity disorder; CI, confidence interval.
The frequency of occurrence of attention-deficit/hyperactivity disorder (AD/HD) is in dispute, with reported prevalence varying from 1% to 20% among school-aged children. Potential overdiagnosis of the disorder and overuse of stimulant medications make it imperative to obtain accurate information about the occurrence of AD/HD. In this study, the authors used a population-based birth cohort and 3 different case-identification criteria for AD/HD. The cumulative incidence of AD/HD varied from 7.5% to 16%, depending on the research definition of AD/HD. Stimulant medications were most likely to have been prescribed for subjects meeting the most stringent research criteria. These results help to explain the wide variation in the reported frequency of occurrence of AD/HD in the existing literature.

**Table 6. Medication Usage by AD/HD Status**

<table>
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<tr>
<th>Medical Treatment</th>
<th>AD/HD Status Based on Research Criteria, No. (%)</th>
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<tbody>
<tr>
<td></td>
<td>Definite AD/HD (n = 305)</td>
</tr>
<tr>
<td>STIM only</td>
<td>220 (72.1)</td>
</tr>
<tr>
<td>STIM and CAA or TA</td>
<td>44 (14.4)</td>
</tr>
<tr>
<td>CAA or TA only</td>
<td>3 (1.0)</td>
</tr>
<tr>
<td>None</td>
<td>38 (12.5)</td>
</tr>
</tbody>
</table>

*AD/HD indicates attention-deficit/hyperactivity disorder; STIM, psychostimulants; CAA, centrally acting α-adrenergic agonists; and TA, tricyclic antidepressants.

The frequency of occurrence of AD/HD varied across the research-identified groups. In particular, treatment with stimulants alone (72.1%) or in combination with either tricyclic antidepressants or centrally acting α-adrenergic agonists (14.4%) was most likely for subjects in the definite AD/HD group. There was a significant trend toward decreasing prevalence of treatment across the definite, probable, questionable, and not AD/HD groups. Subjects in the not AD/HD group were unlikely to have ever been treated with stimulants or other medications typically used to treat AD/HD. Thus, treatment decisions made by clinicians evaluating these children correlated with the likelihood that the child would be identified as an AD/HD case using our research criteria. The prevalence rate of treatment with stimulants in the definite AD/HD group is comparable to the 74.2% to 75.4% treatment proportions reported for psychiatrists and pediatricians in a recent study of treatment services for children with AD/HD. Stimulant therapy has also been shown to be the focus of 76.6% of physician visits for 5-to-14-year-old children with AD/HD. Cumulative incidences of AD/HD among males and females in our study are consistent with the widely acknowledged male preponderance for AD/HD. Males were 2 to 3 times more likely to fulfill research criteria for AD/HD. Males were also more likely to have some information in their medical and school records indicating the presence of some characteristics of AD/HD (questionable AD/HD) than females.

The mean age at which subjects could be documented to have fulfilled research criteria was 10 years for definite AD/HD and 11 years for probable AD/HD. To make a diagnosis of AD/HD, the DSM-IV specifies that some symptoms must be present before age 7 years. The mean ages reported in this study reflect the ages at which all required information was documented in the medical and school records, and they should not be interpreted to imply that AD/HD symptoms do not appear until age 10 or 11 years.

There are several potential limitations that should be noted. First, we did not directly assess the subjects, and our results depended on the information documented in the medical and school records. Nevertheless, the well-developed medical record-keeping and retrieval systems of the Rochester Epidemiology Project, the very detailed and complete record-keeping system employed by Independent School District 535, and our careful review of the records of all 5718 subjects make it unlikely that significant numbers of AD/HD cases were not identified. Second, the racial makeup and socioeconomic characteristics of the Rochester population may affect our ability to generalize these findings to other communities or populations. Nevertheless, the results from this study provide much needed baseline information for comparison with populations in other communities.

This article represents what we believe to be the largest population-based birth cohort study of the cumulative incidence of AD/HD to date, and it indicates that this disorder is commonly seen in children between the ages of 5 and 19 years. We believe that the cumulative incidence of 7.5% for definite AD/HD is the most accurate estimate of the occurrence of this disorder. Our criteria for definite AD/HD are similar to those specified in the recent American Academy of Pediatrics practice guidelines for AD/HD. Furthermore, clinicians who evaluated and treated the children in our study were much more likely to have prescribed stimulant medications, either alone or in combination with other psychotropic medications, to children who fulfilled research criteria for definite AD/HD. The intermediate (9.4%) and highest (16.0%) estimates of the cumulative incidence of AD/HD from our study are consistent with prevalence figures reported by authors who employed less stringent criteria to establish AD/HD case status. The use of 3 different case-identification criteria helps to explain the wide variation in the reported frequency of occurrence of AD/HD in the existing literature.

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