



Published in final edited form as:

J Atten Disord. 2015 September ; 19(9): 741–754. doi:10.1177/1087054713513799.

The prevalence of ADHD in a population-based sample

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Abstract

Objective—Few studies of ADHD prevalence have used population-based samples, multiple informants, and DSM-IV criteria. In addition, children who are asymptomatic while receiving ADHD medication often have been misclassified. Therefore, we conducted a population-based study to estimate the prevalence of ADHD in elementary school children using DSM-IV criteria.

Methods—We screened 7587 children for ADHD. Teachers of 81% of the children completed a DSM-IV checklist. We then interviewed parents using a structured interview (DISC). Of these, 72% participated. Parent and teacher ratings were combined to determine ADHD status. We also estimated the proportion of cases attributable to other conditions.

Results—Overall, 15.5% of our sample (95% confidence interval (C.I.) 14.6%-16.4%) met DSM-IV-TR criteria for ADHD. Over 40% of cases reported no previous diagnosis. With additional information, other conditions explained about 9% of cases.

Conclusions—The prevalence of ADHD in this population-based sample was higher than the 3-7% commonly reported. To compare study results, the methods used to implement the DSM criteria need to be standardized.

Keywords

attention-deficit disorder with hyperactivity; ADHD; prevalence; epidemiology; comorbidity

Introduction

Most of what is known about Attention-Deficit/ Hyperactivity Disorder (ADHD) is based on clinical studies. This clinical research has made ADHD one of the most studied childhood disorders and has yielded a nuanced understanding of the relationship between ADHD-like symptoms and neuropsychological function, and between medication treatment and short-term outcomes (National Institutes of Health, 2000). Follow-up studies of the long-term course of symptoms and impairment largely have been based on clinical samples of children who received medication treatment (Klein & Mannuzza, 1991). However, clinical samples provide limited evidence about prevalence because they are strongly influenced by referral patterns and therefore cannot be used to make inferences about an underlying base population (Goodman et al., 1997). Because the ADHD literature has relied heavily on

clinical, rather than representative population-based samples, and because the few published population-based studies either used DSM-III-R or did not follow DSM-IV guidelines for identifying cases, there are crucial gaps in the epidemiology of ADHD. The goal of the current study is to begin to address these gaps using a population-based sample.

Our aim was to identify the entire distribution of public elementary school children in one county who met symptom criteria for ADHD, not just the most severely affected children. Developing a screening method for ADHD is challenging because the DSM-IV criteria are vague about how to combine symptoms from different informants and about how to measure functional impairment even though these are crucial parts of the criteria (Rowland, Lesesne, & Abramowitz, 2002; Scahill & Schwab-Stone, 2000). For example, informant reports about a child's behavior often disagree (Offord et al., 1996), and the methods used to combine those reports can have a large impact on prevalence, (Cohen, Riccio, & Gonzalez, 1994) impairment, (Mota & Schachar, 2000) and even ADHD subtype (Rowland et al., 2008). Similarly, small changes in how functional impairment is defined can make large differences in which children are included in any sample of ADHD cases (Gathje, Lewandowski, & Gordon, 2008).

Estimating the prevalence of ADHD

The prevalence of ADHD is “3-7% in school age children” according to DSM-IV TR (American Psychiatric Association, 2000) According to the 2007 National Health Interview Survey, U.S. lifetime prevalence of clinically diagnosed ADHD among 4-17 year olds was 9.5% representing about 5.4 million children (2010). This estimate suggests the large impact of ADHD but is problematic because many children with ADHD are never evaluated clinically. In addition, many physicians evaluate and diagnose children with ADHD without using teacher rating scales, following standardized protocols, or using the DSM-IV criteria. In 1999, a national study reported that of over 20,000 pediatric visits to evaluate ADHD, physicians had used behavioral questionnaires or used DSM criteria less than 40% of the time (Wasserman et al., 1999). A 2005 survey of pediatricians found 68% reported using some “formalized criteria” but only 26% said they used DSM criteria when diagnosing ADHD (Wolraich, Bard, Stein, Rushton, & O'Connor, 2010). This lack of standardization makes prevalence estimates from parent-reported diagnosis data difficult to interpret.

Among studies based on clinical samples, prevalence estimates vary widely from 0.9% (3 month prevalence in a population of teenagers) to 46.7% in a population of youth receiving public mental health services (Costello, Mustillo, Erkanli, Keeler, & Angold, 2003; Lewczyk, Garland, Hurlburt, Gearity, & Hough, 2003). Two reviews recently summarized the massive worldwide ADHD prevalence literature (Polanczyk, de Lima, Horta, Biederman, & Rohde, 2007; Skounti, Philalithis, & Galanakis, 2007). Polanczyk et al. presented an overall combined prevalence estimate of 5.3%; Skounti et al. concluded prevalence was between 2% and 18% but declined to present one overall estimate, because there was too much variability.

The wide variability in prevalence estimates makes it difficult to evaluate the public health impact of ADHD. Accurate prevalence data are needed to address whether ADHD is under-recognized and under-treated as some have asserted (Jensen et al, 2000), or over-identified

and over-treated as others have argued (Angold, Erkanli, Egger, & Costello, 2000). Improved estimates are also needed to determine whether the incidence of ADHD is increasing (2010) or merely being detected more effectively (CDC, 2010), and to understand reported regional differences within the United States and internationally (CDC/NCHS, 2007; Swanson et al., 1998). A better understanding of prevalence patterns might also yield clues to the etiology of ADHD.

What accounts for discrepancies in prevalence estimates?

Some variability in prevalence estimates is due to methodological differences between studies. For example, of the prevalence studies using population samples, some have relied on information obtained from parents (Costello, Farmer, Angold, Burns, & Erkanli, 1997), or from teachers (Baumgaertel, Wolraich, & Dietrich, 1995), but few have collected reports from both parents and teachers. Multiple reports are critical because DSM-IV emphasizes that impairment from ADHD symptoms must be present in at least two settings (American Psychiatric Association, 2000). In addition, because parent and teacher ratings on the same child often differ (Offord et al., 1996), clinical guidelines emphasize the importance of using teacher ratings when diagnosing ADHD (American Academy of Pediatrics, 2000). Researchers who have compared parent reports of their children's behavior at school with teacher reports have concluded that collecting information directly from teachers is important (Sayal & Goodman, 2009).

Prevalence estimates also may differ depending on how data from different sources are combined. For example, a study of military families found an ADHD prevalence rate of 11.9% when only parent report was used, but 15.1% when child and parent reports were combined (Jensen et al., 1995). A British study reported the prevalence of ADHD was 70% higher when data from teachers was combined with parent report compared to parent report alone (Ford, Goodman, & Meltzer, 2003). However, in a study where parent and teacher reports were required to strictly agree, prevalence plummeted (Wolraich et al., 2004).

Two other methodological issues, connected to age at onset and medication use, may influence prevalence estimates. The DSM-IV requires that some hyperactive-impulsive or inattentive symptoms that caused impairment were present before age 7. This requirement is controversial because it eliminated many children who otherwise met ADHD criteria in the DSM-IV field trials (Applegate et al., 1997). Two leading ADHD researchers advocate not using the age of onset criterion because it excludes children who clearly have ADHD, especially children with the inattentive subtype (Barkley & Biederman, 1997).

Children taking stimulant medication present a particular challenge for epidemiologic research because they can appear asymptomatic when medication treatment is working well. Most prevalence studies have ignored this problem; consequently, many children with ADHD who were receiving medication treatment were not counted as cases. As medication treatment rates for youth with ADHD have increased, the magnitude of this potential bias on prevalence estimates has grown. Other fields handle this problem differently. For example, in cardiovascular epidemiology, people receiving medication to treat hypertension who are asymptomatic are still treated as cases (Mujahid, Diez Roux, Cooper, Shea, & Williams, 2010).

Some differences in prevalence estimates reflect demographic differences between study samples. For example, because hyperactive/impulsive symptoms tend to abate as children grow older (but impairment often persists) and the DSM-IV criteria for ADHD are not different for a 5 year old or a 15 year old, prevalence rates tend to be lower in populations with older children. Comparing estimates across studies is therefore difficult if the age distributions are not similar.

The current study

In this study, we adapted the DSM-IV criteria to create an epidemiologic case definition of ADHD that combined teacher and parent reports. We used this case definition to screen all public elementary school children in grades 1-5 in a central North Carolina County except for a small number of children in self-contained special education classrooms (see below). We also examined how prevalence changed when we made different decisions about how to combine symptom reports, account for age of onset, and handle medication treatment. Below we present prevalence estimates for ADHD in this population-based sample.

Methods

Participants

In 1998 and 1999, we screened all children enrolled in 17 public elementary schools in Johnston County, North Carolina for ADHD using procedures we piloted the year before (Rowland et al., 2001). At that time, Johnston County had 7,847 children enrolled in grades 1-5.

Instruments

The NIEHS Teacher Rating Scale (NTRS) is a DSM-IV behavior rating scale, which includes the 18 DSM-IV symptom questions for ADHD with response categories of “Never, Hardly Ever, Some of the Time, and Often” instead of “Never, Some of the Time, Often and Very Often.” We modified the response categories to combine responses with the DISC, the instrument we used to interview parents. The DISC includes probes for each ADHD symptom and, reflecting the language of DSM-IV, whether it occurred “Often”. Only symptoms rated “Often”, the highest point on the rating scale, were counted. The scale also includes questions about academic or behavioral impairment at school.

In psychometric testing, the NTRS had good internal consistency, reliability and strong construct validity (Rowland, Umbach, Bohlig, Stallone, & Sandler, 2007). The Cronbach's alpha was 0.97. The test-retest reliability when re-administered two weeks later was 0.94 for inattentive items and 0.90 for the hyperactive/impulsive items. The correlation between the Conners' ADHD index and the combined inattentive and hyperactive scales was 0.91.

Diagnostic Interview Schedule for Children (DISC, version 4)—The parent telephone interview included the ADHD module of the DISC (Shaffer, Fisher, Lucas, Dulcan, & Schwab-Stone, 2000), which we adapted by omitting questions about the child's symptoms and impairment at school because we collected this information directly from the teachers themselves. Collecting information directly from teachers usually provides more

accurate information about a child's behavior at school than asking parents (Mitsis, McKay, Schulz, Newcorn, & Halperin, 2000).

The DISC is a structured psychiatric interview designed for administration by lay interviews. Lay interviewers administering the DISC have demonstrated reliability equivalent or better than clinicians conducting clinical interviews. (Jewell, Handwerk, Almquist, & Lucas, 2004; Piacentini et al., 1993; Shaffer et al., 1993) The DISC has been used in many epidemiologic studies of psychiatric disorders in children including the DSM-IV field trials of ADHD and the MECA study (Angold et al., 2012; Bauermeister et al., 2011; Lahey et al., 1994; Lahey et al., 1996). Parent interviews of the ADHD module of the DISC had a test-retest reliability of .79 (Kappa statistic) in a clinical sample and .60 in a community sample (Shaffer et al., 2000). The ADHD module had a scale reliability of .84 (intraclass correlation coefficients) for symptoms counts and .77 for criterion counts. The DISC has also been administered as a telephone interview by the National Center for Health Statistics as well as many other epidemiologic studies.(Chilcoat, Breslau, & Anthony, 1996; Merikangas et al., 2010; Richardson, Russo, Lozano, McCauley, & Katon, 2008; Wolraich et al., 2012) To our knowledge, no one has yet reported psychometric data on the reliability or validity of administering the ADHD module of the DISC by telephone. However, other studies have generally concluded that the telephone versions of structured interviews like the DISC are valid substitutes for in-person administration and represent a less expensive way to capture data from participants that might be lost otherwise.(Lyneham & Rapee, 2005; Pearsall-Jones, Piek, Rigoli, Martin, & Levy, 2009; Wells, Burnam, Leake, & Robins, 1988)

Training of interviewers and validation

Two of our lead interviewers received 3 days of training on the DISC at the Columbia Department of Psychiatry and they in turn, trained our other interviewers. Ten percent of the interviews were validated by checking with respondents that the calls had been made. Supervisors monitored over 6% of the calls to check the quality of the interviews, that answers were probed correctly and directions and skip patterns were followed.

Combining informant data

We required cases to have at least 3 symptoms of hyperactivity/impulsivity or inattention at school, at least 3 symptoms of hyperactivity/impulsivity or inattention at home, and when combined, at least 6 of 9 unduplicated hyperactive/impulsive symptoms or 6 of 9 unduplicated inattentive symptoms. We counted a symptom if endorsed by either a parent or a teacher. A symptom reported by both informants was counted only once. This process of adding symptoms from informants but not counting a symptom more than once - the OR rule - was used in the DSM-IV field trials for ADHD (Lahey et al., 1994). The DISC requires at least three symptoms at home to trigger the impairment questions so essentially uses the same three-symptom cutoff that we used.

Impairment

DSM-IV requires that children with ADHD show evidence of impairment from symptoms in at least two settings as well as "clinically significant impairment" in social or academic

functioning. Therefore we required evidence of at least moderate impairment in both the school and home settings and “severe impairment” in at least one setting.

Children were considered severely impaired at school if their teacher rated them “below grade level” in at least one academic subject (Reading, Writing, Spelling or Arithmetic), which at that time in Johnston County Schools meant they were one year or more below grade level. We also considered the child moderately impaired if they had a “moderate problem” in their relationships with other children, teachers or other adults, or with assignment completion, organizational skills, or self-esteem; and severely impaired if they had a “severe problem” in one of these areas. When pretesting the questionnaire, we asked teachers whether they could identify whether the child's impairment was due specifically to his or her inattentive or hyperactive/impulsive symptoms. Because teachers generally indicated that they could not reliably make this distinction, we did not require it.

Impairment at home was assessed using the questions from the DISC and scored according to DISC guidelines. Moderate impairment at home was defined as having a problem that disrupted family activities “some of the time” or that made the child feel “bad”. Severe impairment at home was defined as having a problem that disrupted family activities or the child's daily activities “a lot of the time” or that made the child feel “very bad.”

ADHD Medication Treatment

We classified children taking ADHD medication as cases if they met full symptom criteria while taking medication. If a child did not meet case criteria while taking medication they were classified as cases if they had at least 6 hyperactive/impulsive symptoms or at least 6 inattentive symptoms and severe impairment at home the year before they began treatment. We did not have teacher ratings for the year before treatment so we used parent report. This approach seemed preferable to assuming that all children who were asymptomatic on medication did not have ADHD, or conversely, that all children taking ADHD medication had ADHD.

Age at onset

We report our results without the age-7 age of onset criterion and then again, using the criterion.

Sampling and Screening Procedure

The IRB of the National Institute of Environmental Health Sciences, NIH, approved the study protocol. Our overall sampling goal was a) to screen children for ADHD, first by identifying potential cases using teacher ratings and later by parent telephone interview, and b) to identify a random sample of controls for case-control analyses of risk factors.

One of the obstacles for school-based prevalence studies of ADHD is that systematically screening the school population may increase the number of children with ADHD who the schools would be responsible to accommodate. To address this concern, we partnered with the Johnston County Schools to obtain private foundation funding (K.B. Reynolds Foundation) for a project that provided information and training about ADHD for teachers

and parents. We also set up a weekly mobile ADHD clinic staffed by physicians from the Department of Psychiatry at the University of North Carolina Chapel Hill to evaluate and treat students who had been diagnosed.

To increase participation, we included a strong letter of support from the superintendent of schools with the parent invitations. We met with teachers and principals to explain the purpose of the study and encourage their participation. We hired a school social worker after hours to help us locate parents who did not respond or did not have a phone.

Teachers completed a behavioral checklist (Rowland et al., 2007) on children with written consent. If children were in the random sample of controls or were designated as potential cases, we interviewed their parents by telephone. We then combined parent and teacher ratings to determine case status.

We identified controls by taking a random sample of all children with completed teacher-rating scales and then excluding any child who became a case following the parent interview. Our rationale was that controls should reflect a random sample of the school population, including those with some symptoms of ADHD, but not include those who met full case status.

There were 7,847 children enrolled in grades 1-5. We excluded children with developmental disabilities in self-contained classrooms (N=146) and children with special education designations for autism, mental handicap (IQ<70) or severe health problems (N=114). Our rationale for the exclusion was that we did not think we could reliably identify ADHD in these special populations with our instruments. All children with learning disabilities or behavioral problems were included. After exclusions, 7,587 children were eligible (Figure 1).

Parents or guardians of 6,139 (81%) of the children gave written permission for the teacher survey. Of 355 teachers, 98% participated. Teachers completed forms on 6,072 children (80% of the eligible sample). After the teacher screening, 411 children were excluded because they had a severe medical disability (N=111), were in the classroom less than 9 weeks (N=10), or had parents with low English proficiency (N=290).

We used two procedures to select children for the parent telephone interview. To select controls (*left side of* Figure 1), we chose a 12.5% random sample of the 5,661 eligible children which was our best estimate of the proportion needed to identify similar numbers of cases and controls after screening. Of these 706 randomly selected children, 169 were classified as “*potential cases*” because they were taking medication to treat ADHD, or because they often exhibited at least 3 of 9 DSM-IV hyperactive/impulsive behaviors or at least 3 of 9 inattentive behaviors, as well as evidence of impairment at school during the teacher screening. In addition to those selected as part of the random sample, the teacher screening identified another 1,245 potential cases (*right side of* Figure 1). Because of budget constraints, we randomly excluded 332 of these potential cases from the parent interview. After the teacher screening, we completed 1,160 telephone interviews (71.6%) with parents of the total 1,619 children who were eligible.

After the parent interview, we combined parent and teacher reports as described above to determine final case status using DSM-IV criteria. Three groups were identified: 475 cases, 442 controls (all the children from the random sample who did not meet DSM-IV criteria) and 243 children in the subthreshold group. The subthreshold group consisted of potential cases who did not meet DSM-IV criteria when the parent and teacher information was combined. We identified the controls and the subthreshold group primarily for future etiologic and outcome analyses, but their numbers (weights) are included in the statistical analysis below.

Statistical Analysis

Because of the complex sampling design, prevalence cannot be calculated as a simple proportion (Heeringa, West, & Berglund, 2010). The probabilities for inclusion in the study differed between the random sample portion of the design and the case selection portion of the design. To account for these sampling differences, we calculated sampling weights as the inverse of the sampling fraction for each of 5 strata in each of two years (10 sampling weights in all). The strata were defined as: potential cases in the random sample taking ADHD medication; potential cases in the random sample not taking ADHD medication; potential cases who were not in the random sample and were taking ADHD medication; potential cases who were not in the random sample and were not taking ADHD medication; and non-potential cases. We used SAS[®] version 9.1 to calculate weighted prevalence estimates and 95% confidence limits. Similar procedures were used to calculate prevalence in the National Comorbidity Study (Little, Lewitzky, Heeringa, Lepkowski, & Kessler, 1997) and in previous studies of ADHD (Bird et al., 2006).

Clinical Validation Sample

To address the DSM-IV Criterion E, which stipulates that symptoms and impairment are not better explained by another disorder, 34 children who met study criteria for ADHD and their parents were interviewed by a clinician using the semi-structured KIDDIE SADS-PL (Kaufman et al., 1997). We focused on assessing the rate of false positives because few studies have assessed Criterion E, and to estimate the false negative rate also would have required a much larger study.

Clinicians had access to all the epidemiologic data we collected including a teacher behavioral rating scale, the ADHD module of the DISC, the Child Behavior Check List, and the Columbia Impairment scale, as well as additional DSM-4 teacher rating scales, school records, parent child behavior checklists, two youth-completed forms, the Children's Depression Inventory (Kovacs, 1985) and the SCARED (Birmaher et al., 1997), a measure of anxiety disorders. For nine children, school records were not sufficient to assess learning disability or mild mental handicap, so a psychologist administered two subtests of the WISC (block design and vocabulary) and several portions of the Woodcock-Johnson Achievement test battery (word identification, word attack and comprehension), depending on what was needed to make an assessment.

The final step was for each clinician to present his or her findings to a consensus panel chaired by a senior clinician (AJN) and modeled on established procedures (Leckman,

Sholomskas, Thompson, Belanger, & Weissman, 1982; Young, O'Brien, Gutterman, & Cohen, 1987). The goal was to determine how many cases of ADHD were better explained by another disorder when clinical experts were given additional information and were able to interview both the parent and the child. The specific question we asked was “*what proportion of ADHD cases in our sample would be given a different diagnosis if they had been interviewed by a skilled clinician given all available school, medical, psychiatric, and psychological testing information?*”

Results

The telephone sample included children age 6-12. Two-thirds were male because potential cases were more often boys. The mean age was 8.7 years (S.D. =1.5). About 25% of the sample was non-white (predominately African-American). Twenty-four percent had household incomes below \$20,000 a year and 30% had household incomes greater than \$50,000 a year. These proportions were similar to the U.S. Census figures for Johnston County (Table 1). Children whose families participated in the telephone interview (N=1160) did not differ from those who did not respond (N=459) on either gender or age. More participating families had a child previously diagnosed with ADHD (26% vs. 19%) and fewer were African American (23% vs. 32%).

At the time of the study, Johnston County was similar to the rest of North Carolina and the U.S. on a range of demographic characteristics including age, income, and poverty status (Table 1). Johnston County was more rural, had slightly fewer minorities, and fewer college graduates than the rest of North Carolina and the United States.

Prevalence estimate

Overall, applying the DSM-IV-TR diagnostic criteria and sampling weights as described above, we estimated that 15.5 % of our population had ADHD (95% C.I. 14.6-16.4) (Table 2). If we had ignored stimulant medication use as in other studies, our prevalence estimate would have been 14.0%. If we had used the DSM-IV age-of-onset criteria and eliminated those who first exhibited symptoms at age 7 or older, prevalence would have dropped to 12.6%. If instead of using the 3-3-6 algorithm for case definition (three symptoms at school, three at home and six symptoms after combining the data), we had used a more stringent 6-4-6 (six symptoms in one setting, four symptoms in the other and six combined symptoms) algorithm, as some researchers have proposed (Mota & Schachar, 2000), our prevalence estimate would have been 13.0%. If we had used a 6-4-6 algorithm, ignored medication status, and included the age-of-onset criteria, the estimated prevalence would fall to 9.3%. When we made the impairment criteria stricter by requiring “severe” impairment on the DISC, we had a similar result. Even using this strictest combination of criteria, the estimated prevalence rate was still substantially higher than the estimate in the DSM.

Characteristics associated with ADHD cases

Using the same criteria that gave 15.5% overall prevalence, 63.4% of the ADHD cases (N=301) were the combined subtype (ADHD-C), 25.3% were the predominately inattentive subtype (ADHD-I) (N=120), 3.6% were the predominantly hyperactive subtype (ADHD-

PH) (N=17) and 7.8% were not otherwise specified (ADHD-NOS) (N=37). The ADHD-NOS youth were cases receiving medication treatment who displayed only a few ADHD symptoms who could not be further subtyped.

Previous identification

Of the 475 children identified as ADHD cases, 58% had been previously diagnosed but over 40% had not. About 42% of cases were taking medication to treat ADHD (73% of those who reported a previous diagnosis). Of those taking ADHD medication, 89% were taking a stimulant.

Clinical Validation Study

Results of the validation yielded an agreement rate for study-defined cases of 91% (31/34). That is, the clinicians concluded that the child's symptoms were better explained by a psychiatric disorder other than ADHD in 3 of 34 cases (9%). Each of the three children whose symptoms the experts attributed to other disorders had a complex clinical picture that included family problems like substance use, custody disputes, traumatic events and conflicts with parents or step-parents as well as the child's own conditions. Although the validation sample was small, if we adjusted our over-all prevalence estimate of ADHD for this misclassification, it would be about 14.1%. We did not generate an estimate of the false negatives; if we had been able to correct for these, the overall prevalence estimate could have been higher.

Children in the validation sample also had a high rate of comorbid conditions (Table 3). Among 34 children with ADHD, almost 60% had a comorbid condition (if one counts learning disabilities). Over 20% had two or more comorbid conditions. If learning disabilities were not included, over 40% had two or more conditions besides their ADHD.

Discussion

Our estimate of the prevalence of ADHD among children in grades 1-5 in this diverse North Carolina County was 15.5% (95% C.I. 14.6%-16.4%). Using similar methods, we previously estimated the prevalence at 16.1% (95% C.I. 12%-20%) in a pilot study in a different sample of Johnston County children (Rowland et al., 2001). However, both estimates are well outside the DSM-IV TR prevalence of ADHD (3-7%). How do we account for the discrepancy?

We think the prevalence of ADHD has been underestimated for six reasons: 1) Studies that have relied on clinical diagnosis in the community miss many children who are not evaluated or are evaluated incompletely. Children with poor access to care or with less severe impairment are most likely to be missed. 2) Because of resource limitations, school systems typically do not systematically screen all their children for ADHD (as we did in this study). Consequently school statistics likely undercount the number of children with ADHD. Because school referrals are an important determinant of which children get identified, the lack of systematic screening limits accurate knowledge of prevalence. 3) Many epidemiologic studies have ignored children's medication status when estimating the prevalence of ADHD. Excluding children with ADHD who do not meet symptom criteria

because of a positive medication response misclassifies many children with ADHD. 4) The age-of-onset criterion artificially eliminates many children with ADHD whose symptoms first appeared after age 7. This is problematic for children with attention problems which tend to emerge later than hyperactive/impulsive symptoms (Barkley & Biederman, 1997). 5) Many epidemiologic studies have not included younger children, which is when prevalence of ADHD peaks (Skounti et al., 2007). 6) Many epidemiologic studies have only used parents as informants; not including information from teachers misses a key source of data and probably limits the number of endorsed ADHD symptoms.

In addition, some studies have used a dimensional approach to define abnormalities in attention or behavior (Elberling, Linneberg, Olsen, Goodman, & Skovgaard, 2010). In these studies, abnormality might arbitrarily be defined as the upper 2%-5% of symptoms in the population. If abnormal impairment or symptoms are defined this way, prevalence estimates would be artificially capped. In addition, the designation of the upper 2% or 5% of the distribution of behaviors as the “clinical range” on many instruments subtly creates an expectation that prevalence estimates above 5% must be over-identifying cases, regardless of the number of children whose symptoms and impairment meet DSM-IV criteria.

Some observers believe the prevalence of ADHD is too high and it should be capped at about the top 5% of the distribution because it is expensive to extend services to youth with ADHD and because too many children may be inappropriately treated with medication. Using a stricter definition such as requiring that parents and teachers both rate a child as having 6 or more ADHD symptoms would also lower the prevalence rate. However, both approaches would leave many children with ADHD symptoms below these arbitrary cutoffs without access to treatment or preventive services for the comorbid conditions that are associated with ADHD (Angold, Costello, Farmer, Burns, & Erkanli, 1999).

The generalizability of our prevalence estimates beyond Johnston County is unclear. Other data on parent report of ADHD diagnosis suggests prevalence is highest in the South, and lowest in the West (CDC, 2010). The CDC also recently reported that between 2003 and 2007 the prevalence of parent-reported ADHD in North Carolina increased from 9.6% to 15.6%, a 62% increase. The reasons for the increase are not known. Although the 2007 figure is remarkably similar to our prevalence estimate, the CDC measured a different outcome in a different time period. The first 2003 estimate (9.6%) was collected closer in time to when we collected our data, which makes it more comparable. However, our data included both diagnosed and undiagnosed ADHD using parent and teacher reports and a structured interview, but the CDC data is based on parent-reported history of ADHD diagnosis. Parent report of clinical diagnosis is valuable as a measure of how clinical diagnostic patterns are changing but is a poor measure of prevalence because so many youth with ADHD remain unidentified and undiagnosed.

We presented data on the impact of different components of our case criteria on prevalence estimates. For example, implementing the age-of-onset criteria (symptoms causing impairment present before age 7) would have dropped our prevalence estimate about 18 % (from 15.5% to 12.7%). Our study used a 3-3-6 algorithm for estimating prevalence (at least three symptoms at school, at least three symptoms at home, and six combined unduplicated

symptoms). Use of a stricter 6-4-6 symptom definition lowered the prevalence estimate but not as much as one might expect (about a 17 percent drop-from 15.5% to 12.9%). This observation suggests that other components of the case definition of ADHD are as important as symptom cutoffs since our highest estimate (15.5%) was 40% higher than the lowest (9.3%). The proposed American Psychiatric Association DSM-V criteria for ADHD will include changes to how the subtypes are conceptualized and will extend the age of onset to age 12 but do not include specific recommendations about how to combine symptoms from different informants or how impairment is defined. Yet, these details are critical for any attempt to standardize how the prevalence of ADHD is measured or to compare prevalence across studies.

Many ADHD teacher-rating scales include “often” and “very often” choices on their response scales and use either choice as a positive symptom. Our scale used only “often” as the highest response category (which is how the DSM defines a positive symptom) and is also what our structured interview (DISC) used. “Often” is also the descriptor for a positive ADHD symptom in DSM-IV. In psychometric testing, we compared the impact of using “often” as the response anchor. At a symptom cutoff of 6 symptoms, 6.0% met criteria when “often” was used and 9.8% met criteria when either “often” or “very often” responses were counted.(Rowland et al., 2007). This finding suggests that our prevalence estimate would have been higher if we had counted “often” and “very often” as a positive symptom (as many other studies have done).

Two recent epidemiologic studies of ADHD in population-samples represent important milestones in understanding the prevalence of ADHD in the U.S. Merikangas et al interviewed a national representative sample of the parents of over 3000 children age 8 to age 15 as part of the NHANES study using the DISC. They reported an ADHD prevalence rate of 8.6% (95% C.I. 7.2-10.00) (Merikangas et al., 2010). Wolraich et al studied the prevalence of ADHD in four school districts in Oklahoma and South Carolina (Wolraich et al., 2012). They screened over 10,000 children and reported prevalence rates of 8.7% (95% C.I. 7.2 -10.5) in South Carolina and 10.6% (95% C.I. 7.5-14.9) in Oklahoma. All three prevalence estimates are outside the 3-7% range described in DSM-IV TR but lower than ours. It is important to realize that these studies would have generated higher prevalence estimates if they had made only small methodologic changes. The Merikangas et al. study did not include children younger than 8 and used one informant (parents). The Wolraich study used parent and teacher informants but used a 6-4-6 algorithm which meant that if a parent did not endorse 6 ADHD symptoms of hyperactivity or impulsivity, the child was classified as not having ADHD. In our study we combined symptoms from different informants to reach diagnostic thresholds. Wolraich also excluded children taking ADHD medication as cases if they did not meet ADHD criteria on medication and used the age at onset criteria which we did not. Using the criteria used by Wolraich et al, we estimated the prevalence of ADHD in Johnston County as 9.3% (95% C.I. 8.4-10.2) (Table 2, line H). This suggests that the prevalence of ADHD in Johnston County is in between the prevalence of ADHD in Oklahoma and South Carolina and that our methods for estimating prevalence yield similar results when we make similar assumptions. Going forward, it will be important for researchers to be explicit about the methods they used to classify cases so that a more standardized approach emerges.

A substantial proportion (42%) of children in our study who met criteria for ADHD had never been previously diagnosed and only 42% of ADHD cases were receiving medication treatment. In our pilot study, we reported similar results; 39% of children with ADHD had not been previously diagnosed and only 45% of cases were receiving medication treatment (Rowland et al., 2001). These proportions suggest both under-identification and under-treatment of ADHD children but need further replication in other samples.

The validation study results suggest that some children – particularly those who have complex clinical pictures including other comorbid conditions, family problems or recent traumatic experiences -- may look like ADHD cases in epidemiologic studies, even though their symptoms may be better explained by another disorder. This happens relatively infrequently and therefore would result in over-estimating prevalence by only a small amount. The high rate of comorbidity among children with ADHD in the validation sample suggests the extent of difficulties many children with ADHD face, even when they are in elementary school. More research is needed on whether these comorbid conditions are being adequately treated in populations of children with ADHD and how these comorbid conditions impact long-term outcomes.

Strengths

The most important strength of this study was that the sampling was population-based and we were able to screen almost the entire student population in grades 1-5. According to the 2000 Census, less than 4% of the children in Johnston County attended private school. Our study participants resembled the pool of all children with ADHD in the general population, not just those who were most severely affected as in many clinic-based studies. Our study's other strengths were careful operationalization of the DSM criteria, use of parent and teacher informants, use of a structured parent interview (the DISC), use of information about ADHD medication treatment, and inclusion of the validation study to estimate the number of cases better explained by other conditions.

Limitations

This study was conducted in one North Carolina County, which potentially limits its generalizability. However, Johnston County is demographically similar to many counties in North Carolina and the U.S. Not much is known about the factors that might lead to regional variation in prevalence estimates.

The overall response rate for this study was 81% of the teachers and 72% of parents. This participation rate is comparable to or better than many well-done epidemiologic studies. It is possible that the prevalence of ADHD among non-respondents was different from the prevalence of ADHD in participants. In general we would expect non-respondents to be disproportionately young, poor, or minority, (Drivsholm et al., 2006; Littman et al., 2010; Tolonen, Dobson, & Kulathinal, 2005) but the fact that participants were similar to the population of the county as a whole suggests that non-responders were demographically similar to responders and response bias probably did not have a major impact on our results.

One of our inclusion criteria (due to budget limitations) was that at least one parent in the household could speak English well enough to be interviewed by phone. Because many of

the families who were excluded for this reason were Hispanic, our results have limited generalizability to Hispanic populations, in particular.

The DSM-IV field trials used a simple OR rule to combine symptoms from informants which combined all symptoms reported in each setting (Lahey et al., 1994). Because we used a more conservative case definition that required that at least 3 symptoms at home and 3 symptoms at school, we may have underestimated prevalence.

The validation study we report here is, to our knowledge, one of the first attempts to estimate the false positive rate by comparing an epidemiologic case definition of ADHD with a gold standard using an expert clinical consensus approach. Our small validation study was limited by not including a random sample of non-cases. Additional studies that provide estimates of the false negative rates as well as the false positive rate are needed.

Conclusions

These data suggest that many children with ADHD are not identified and, therefore, may not be getting adequate treatment and support services for their disorder. Our data suggest that the prevalence of ADHD may have been under-estimated, and we suggest that if population-based prevalence studies are carefully done, that ADHD prevalence rates higher than 3%-7% will be uncovered in many communities.

To better understand regional variation in prevalence of ADHD, additional population-based studies that operationalize the DSM criteria are needed. To understand whether ADHD is increasing or just being clinically diagnosed more often, studies that survey the same population over time using the same methods will be required. Because comorbidity influences the outcomes of youth with ADHD, future studies should consider collecting data on patterns of comorbidity as part of their prevalence data.

From our perspective, the wide variation in ADHD prevalence estimates is a serious problem. Until progress is made in standardizing criteria, it will be difficult to compare prevalence estimates across studies, to determine whether the prevalence of ADHD is increasing, to understand why prevalence varies across regions, or to fully appreciate the public health impact of the disorder.

Acknowledgments

This research was supported in part by Intramural Research Programs of the NIH, National Institute of Environmental Health Sciences. Data analysis was supported, in part, by the NM NIEHS Center, P30 ES-012072, by a RAC grant from the University of New Mexico Health Sciences Center, and by 5 R01 MH071563-01 from the National Institute of Mental Health.

Donna Baird PhD helped design the questionnaires. Lilian Stallone MPH was the study manager. Lewis P Rowland MD, Kristine Tollestrup PhD, and Kathleen Wayland PhD provided thoughtful comments which improved the manuscript. We want to thank the clinicians who worked on the validation study. Vann Langston and Keith Beamon, of the Johnston County Schools, were both instrumental in making the study possible.

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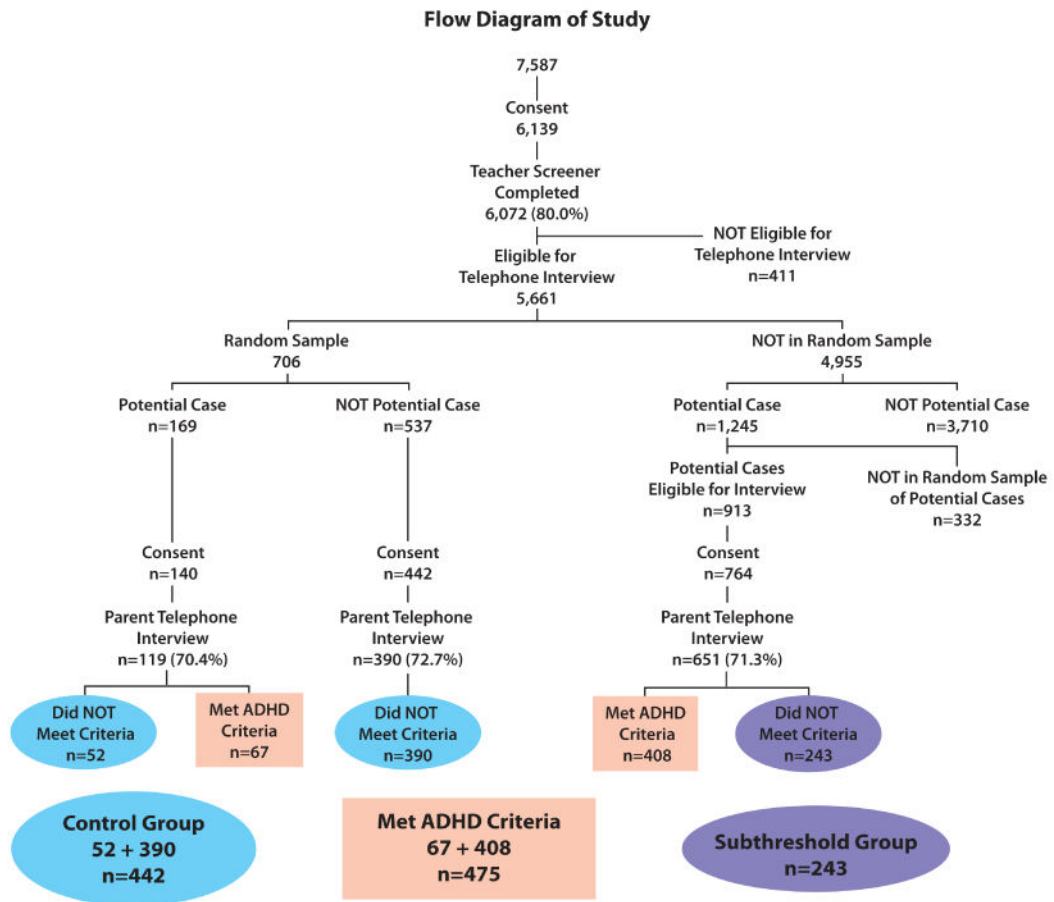


Figure 1. Flow diagram of the recruitment process

Table 1
Demographic Comparison of Johnston County, with the rest of North Carolina, and the U.S., 1999/2000

	Johnston County	North Carolina	United States
Age: median age years 2000	34.2	35.3	35.3
Age: % of Households with individuals under 18, 2000	38.8 %	35.3%	36%
Race: % White,	78.1%	72.1%	75.1%
% African American or Black	15.7%	21.6%	12.3%
% Other non-white	6.2%	6.3%	12.6 %
Income: median income 1999	\$40,872	\$39,184	\$41,994
Income: % living in poverty, 1999	12.8%	12.3%	12.4%
Income: family income < \$25000	30.0%	30.7%	28.7%
Income: family income \$50,000 or higher	39.8%	37.7 %	42.0%
Education: % population 25 and older with high school degree	75.9%	78.1%	80.4%
Education: % population 25 and older with BA or higher	15.9%	22.5%	24.4%
Urban/Rural: 2000 % urban	31.3%	60.2%	79.0%
% rural	68.7 %	39.8%	21.0%

* Source : U.S. Census tables 2000, United States, and North Carolina

Table 2
Impact of Using Different Study Definitions of ADHD on Prevalence Estimates

Case Definition for ADHD	Estimated ADHD Prevalence (95% CI)
A. 3, 3, 6 using year-before data for those on medication, impairment in both settings, and severe impairment in one setting, without using age of onset criterion.	15.5% (14.6%, 16.4%)
B. Same symptom and impairment criteria as A but using current symptom data for those on medication	14.0% (13.0%, 14.9%)
C. Same symptom and impairment criteria as A and using age 7 age-of-onset criterion	12.6% (11.7%, 13.5%)
D. Same symptom and impairment criteria as A without using year-before data for those on medication but using age 7 age-of-onset criterion	11.1% (10.2%, 12.1%)
E) Same symptom and impairment criteria as A but only including children with a rating of severe impairment on DISC (Diagnostic Interview Schedule for Children)	10.5% (9.6%, 11.4%)
F) Same symptom and impairment criteria as A but not using self-esteem as a indicator of school impairment	15.5% (14.6%, 16.4%)
G) 6,4,6 using year-before data for those on medication, impairment in both settings, and severe impairment in one, without using age of onset criteria	13.0 (12.0%, 13.9%)
H). Same symptom and impairment criteria as G but without using year-before data for those on medication and using age 7 age-of-onset criterion	9.3% (8.4%, 10.2%)

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Table 3
Patterns of Comorbidity in the Clinical Validation Study Sample among 34 Youths with ADHD

Comorbid Conditions Among youth with ADHD N=34	N ^a	%
Depression	0	(0)
General anxiety disorder	2	(5.9%)
Separation anxiety disorder	4	(11.8%)
Oppositional Defiant Disorder	8	(23.5%)
Conduct Disorder	2	(5.9%)
Mental Retardation mild	1	(2.9%)
Tourettes/ Tic disorder	4	(11.8%)
With Learning disability	9	(23.5%)
Disability of written expression	4	
Reading disability and disability of written expression	4	
Math disability	1	
Any comorbid condition including learning disability	20/34	(58.8%)
Any comorbid condition excluding learning disability	14/34	(41.2%)
Two or more comorbid conditions (including LD)	9/34	(20.6%)

^a Some of the 34 children exhibited multiple comorbid conditions

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