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Prevalence of the ADHD phenotype in 7- to 9-year-old children: effects of informant, gender and non-participation

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Abstract

Purpose To estimate the prevalence of the ADHD phenotype based on parent and teacher reports in a general population sample of 7- to 9-year-old Norwegian children and evaluate the effect of parent attrition, gender and informant on the prevalence estimate.

Methods The population consisted of all children (N = 9,430) attending 2nd–4th grade in the City of Bergen, Norway. The 18 symptoms of ADHD corresponding to the SNAP-IV and DSM-IV were included in the Bergen Child Study questionnaire to teachers and parents. Teacher information was available for 9,137 children (97%) and information from both informants was available for the

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A. K. Ullebø (☑) RBUP Vest, Uni Helse, PO Box 7810, 5020 Bergen, Norway e-mail: anne.ullebo@uni.no 6,237 children (66%) whose parents agreed to participate in the study.

Results The prevalence of the ADHD phenotype based on the combination of parent and teacher reports was 5.2% among participants. Teacher ratings of non-participants had a doubled rate of ADHD high scorers with an OR of 2.1 (95% CI, 1.9–2.4). The non-participant ADHD high scorers had more inattentive and fewer hyperactive/impulsive symptoms as compared to participating ADHD high scorers. Teachers reported high scores of hyperactivity/impulsivity and the combined symptom constellation much more frequently in boys than girls, while the difference between genders was less marked according to parent reports.

Conclusions The ADHD phenotype was twice as prevalent among non-participants as among participants. Reported prevalences in population studies are therefore likely to be underestimates, if such attrition bias is not accounted for. Choice of informant, criteria for symptom count, definitions of subtypes and gender differences influence the prevalence estimates of the ADHD phenotype.

Keywords Attention-deficit/hyperactivity disorder · Child psychiatry · Epidemiology · Attrition · Gender

Introduction

In spite of decades of research, the prevalence of attentiondeficit/hyperactivity disorder (ADHD) has been difficult to estimate and it is still a matter of controversy how frequent this phenotype is in a general population setting [6]. Some of the discrepancies may be caused by cultural and social differences, acting on both the prevalence directly and on the reporting style. This may be the reason for the somewhat lower prevalence rates of ADHD found in the Scandinavian



countries [12]. There is also a wide variation as regards measures and sample characteristics [6]. Optimally, the population prevalence should reflect the total population, but in practice it has been difficult to establish a level of study participation that makes the sample representative. Those who participate do not represent a random sample and this differentiated attrition biases the prevalence estimates of child psychiatric disorders such as ADHD. Parents of children rated as deviant by teachers have been found to be less likely to consent to research on child psychiatric disorders compared to parents of children rated within the normal range [16]. In a previous publication from the Bergen Child Study (BCS), the impact of non-responder bias on the prevalence of several different child mental health problems was explored and an important finding was that teachers rated non-responders higher on all symptom scales, except tics, and as more impaired than responders [18]. Teacher high scores (75, 90 and 95th percentiles) on inattention and/or hyperactivity had significantly increased relative risk for parental non-response. Yet we know little about the quantitative effect this would have on the estimation of ADHD prevalence. Another important issue of non-response is whether high scorers in the non-participating group might be qualitatively different from high scorers in the participating group with respect to symptom constellation and/or severity. Such bias could lead to important misinterpretation of results in the further stages of the study where clinical measures are applied and one seeks knowledge about clinical conditions in a representative sample from the general population. Few previous studies have had access to data for non-participants, and if such data have been available, it has included only demographics such as living area, ethnicity, age and gender.

Other important factors that influence the prevalence estimate in ADHD include the definition applied, symptom count, use of impairment, cross-situational criteria and choice of informant. As there is a wide variety of definitions, measures, informants and samples [6], a better understanding of the factors that influence prevalence estimates is important when interpreting differences between studies.

The aims of the present study were (1) to estimate the prevalence of the ADHD phenotype in a general child population, based on parent and teacher reports, and (2) to analyze the effect of parental attrition, informant and gender on ADHD prevalence.

We report the prevalence of the ADHD phenotype based on reported symptoms from questionnaires and making no correction for level of impairment, while acknowledging that a clinical diagnosis cannot be based on questionnaire data only. For clinical purposes, the impairment of the symptoms is crucial, but for epidemiological purposes and comparison with other studies we rely on this readily reproducible method to measure the ADHD phenotype in the community.

Materials and methods

The Bergen Child Study

All data came from the first (screening) stage of the first wave of the Bergen Child Study (BCS) [13]. The target population comprised all 9,430 children in the 2nd-4th grade of all schools in the City of Bergen, Norway, in October 2002. An informed consent form and a detailed four-page questionnaire were sent to parents through the schools, and similar questionnaires were distributed to teachers. Teachers were asked to complete the questionnaire for every child in every class. If the parent consent form was returned to the school, teachers identified the corresponding teacher questionnaire through the identification code (ID number) provided on the parent consent form. If no parent consent was provided, the completed teacher questionnaire was returned without any personal identification, other than child's gender and grade. No information about school or teacher was given, making the children untraceable. For 9,137 children (96.9%), full teacher information on ADHD symptoms was obtained. For 6,237 children (66.1%), we had full information from teachers and parents (Fig. 1). The study was approved by the Western Norway Regional Committee for Medical and Health Research Ethics and the Norwegian Data Inspectorate.

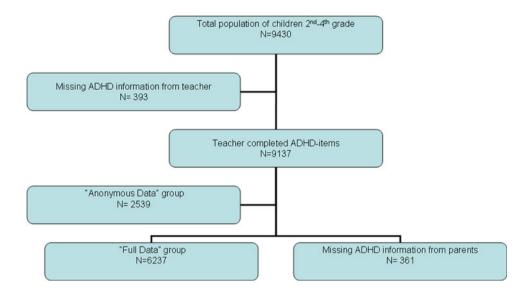
In the present paper, the "Full Data group" refers to participants, i.e., children with parent consent for whom both parent and teacher information on ADHD symptoms was available. The "Anonymous Data group" refers to non-participants, i.e., children for whom only anonymous teacher information was available. Lacking a teacher questionnaire was mainly due to long term sick-leave of the teacher or missing data on ADHD items (N = 3.1%). The children lacking teacher questionnaires were excluded from further analyses. Thus, the non-participants referred to in this paper are defined as the children in the Anonymous Data group. Also, among the participants there was a group of children with missing parent information on the ADHD items (N = 361), thus not contributing to the Full Data group (Fig. 1).

The questionnaire

The BCS screening questionnaire included several measures of child mental health [13]. The present data analyses were based on the 18 ADHD symptoms specified in the DSM-IV criteria for ADHD [3]. The wording of the items was consistent with the SNAP-IV [19], but each item was



Fig. 1 Flowchart of the sample



in contrast to the original version of SNAP-IV scored by parents and teachers on a 3-point Likert scale: 0 for "Not true", 1 for "Somewhat true" and 2 for "Certainly true". A score of 1 or 2 was defined as the presence of a symptom. In agreement with the symptom count according to DSM-IV, the threshold for the definition of ADHD high scorers was set at 6/9 symptoms ("somewhat true" or "certainly true") on at least one subscale. According to our definition, the ADHD combined high scorers had ≥6 symptoms on each of the two subscales. The inattention ADHD high scorers had >6 symptoms on the inattention subscale only, and the ADHD hyperactivity/impulsivity high scorers had six or more symptoms on the hyperactivity/impulsivity subscale only. The ADHD phenotype was defined as being a high scorer according to both informants. High scorers on inattention according to both informants were defined as having the inattentive subtype (ADHD-I). High scorers on hyperactivity/impulsivity according to both informants were defined as having the hyperactive-impulsive subtype (ADHD-H). Children defined as having ADHD combined subtype (ADHD-Co) were either high scorers on each of the two subscales according to both informants, or high scorers on different subscales according to the two informants. Thus, it was possible to fulfill our criteria for the combined phenotype with, i.e., 6/9 (or more) symptoms on the inattention subscale on parent report and 6/9 symptoms on the hyperactivity/impulsivity subscale on teacher report. We found this definition of ADHD-Co to be appropriate given that these children were high scorers according to both informants and they had a symptom count above the threshold within each of the domains.

For the comparison of participant teacher ADHD high scorers and non-participant teacher ADHD high scorers, we also applied the impact supplement part of the SDQ (http://www.SDQinfo.org), which was included in the BCS

questionnaire [13]. The impact score applied here was based on three teacher report items relating to distress, impairment and burden with scores ranging from 0 to 6.

Statistics

To estimate the full population prevalence, we assumed the same ratio between teacher and parent high scorers in the Anonymous group as in the Full Data group. We then multiplied the ADHD prevalence from the Full Data group with the ratio ADHD high scorers teacher non-participants/ ADHD high scorers teacher participants. The confidence interval (CI) of the prevalence estimate was calculated according to the formula for the 95% CI for a proportion p (95% CI, $p \pm 1.96 \times \text{SE}(p)$ where $\text{SE}(p) = p \times (1-p)/\sqrt{n}$).

High scorer prevalence in the Full Data group versus the Anonymous Data group was assessed with odds ratio (OR) estimate with 95% confidence interval (95% CI). Gender difference in high scorer prevalence according to each informant was evaluated comparing the ORs. Mean group differences were assessed with two-tailed t tests and differences in proportions of ADHD symptom subtypes with Chi-square (χ^2) analyses. Agreement across informants was evaluated using Cohen's kappa (κ). The level of statistical significance was set at 0.05. We used the software package SPSS 15 [17].

Results

Prevalence of the ADHD phenotype

In the Full Data group, the prevalence of the ADHD phenotype was 5.2% (95% CI, 5.1–5.3%). For all subtypes,



Table 1 Prevalence of the ADHD phenotype according to subtype and informant

	ADHD-Co (%)	ADHD-I (%)	ADHD-H (%)	Any ADHD (%)
Parents	4.1	6.5	2.8	13.4
Teachers	3.1*	5.4*	1.9*	10.4*
Both	1.2	1.6	0.3	5.2

^{*} p < 0.001, for difference in prevalence between parent and teacher reports

parents reported significantly more children as ADHD high scorers than did teachers (Table 1). Note that the ADHD-Co phenotype comprises not only the 1.2% high scorers shown in Table 1 having the full combined symptom constellation from both informants, but also the 2.1% of children rated as high scorers in different symptom domains by parents and teachers (e.g., as inattentive by one informant and hyperactive by the other).

Informant agreement

Agreement between parents and teachers was $\kappa = 0.32$ for ADHD combined high scorers, $\kappa = 0.22$ for the ADHD inattention only high scorers, and $\kappa = 0.13$ for ADHD hyperactivity/impulsivity only high scorers. Agreement on ADHD high scorers for any subscale was $\kappa = 0.37$.

Effects of attrition

The frequency of teacher ADHD high scorers in the Anonymous Data group was 19.9% compared to 10.4% in the Full Data group alone. Combining the Anonymous Data group and the Full Data group (N = 9 137), 13.1% were teacher high scorers. Assuming the ratio between teacher reported ADHD high scorers and the ADHD phenotype (which is defined based on high scores from both informants) in the whole sample to be the same as in the Full Data group (5.2:10.4%), the estimate for the ADHD phenotype in the total population would be 6.6% (95% CI, 6.0–7.2%).

Table 2 Mean teacher scores and frequency of the teacher ADHD high scorer (6/9) subtypes in the Full Data group (N = 6,237) and the Anonymous Data group (N = 2,539)

Full Data Difference (95% CI) Anonymous ADHD symptoms 2.7 4.2 1.5 (1.25-1.75)* Mean sum score 1.0 (0.85-1.15)* Mean inattention subscale 1.6 2.6 Mean hyperactivity subscale 1.1 1.6 0.5 (0.37-0.62)* High scorers χ^2 values (p value) 32.5* Combined 3.1% 5.7% 111.4* Inattention only 5.4% 11.9% Hyperactive/impulsive only 1.9% 2.3% 1.70 (p = 0.192)

^{*} p < 0.001 for difference



The Anonymous Data group had both higher mean symptom scores and a higher frequency of high scorers compared to the Full Data group (Table 2).

When analyses reported in Table 2 were repeated for boys only and girls only, respectively, the pattern of differences between the two groups remained the same, except the difference in frequency of combined high scorers between the participants and non-participants, which was no longer significant for girls ($\chi^2 = 4.37$, p = 0.37).

There were no significant differences in the proportion of girls relative to boys among the participant ADHD high scorers compared to the non-participant high scorers ($\chi^2 = 1.7$, p = 0.19) or any age differences ($\chi^2 = 0.91$, p = 0.32). The non-participant ADHD high scorers showed more inattention symptoms and less hyperactivity/inattention symptoms, both as sum scores and as symptom counts, than the participants. There was no significant difference between the two groups on the sum score of the impact measure (Table 3).

Gender by informant effects

Boys had significantly higher mean scores than girls on all subscales (p < 0.001 for all comparisons) (Table 4).

The gender (boy:girl) OR (95% CI) for ADHD high scorers according to each informant and ADHD symptom domain are summarized in Table 5. The ORs show increased risk for boys among high scorers for all ADHD symptom domains and according to each informant. For ADHD combined high scorers and ADHD hyperactivity/impulsivity high scorers, teacher reports yielded higher gender (boy:girl) ORs than parent reports (CIs not overlapping).

Discussion

We found twice as many children with the ADHD phenotype among children in the Anonymous Data group versus the Full Data group, which demonstrated that

Table 3 Mean sum scores and number of symptoms on teacher reports for ADHD high scorers in the Full Data group (N = 648) and the Anonymous Data group (N = 504)

	Impact sum score ^a	Hyperactivity sum score	Inattention sum score	Hyperactivity symptoms	Inattention symptoms
Full Data	1.45	6.12	8.46	4.63	6.53
Anonymous Data	$1.54 \ (p = 0.450)$	$5.50 \ (p = 0.028)$	$8.98 \ (p = 0.020)$	4.14 (p = 0.007)	$6.90 \ (p = 0.002)$

^a For eight children in each group impact score was missing

Table 4 Mean ADHD symptom sum scores for each gender and informant

	Inattentive	Inattentive		Hyperactive/impulsive	
	Parents	Teachers	Parents	Teachers	
Boys	2.75	2.34	2.03	1.70	
Girls	1.66*	0.88*	1.26*	0.45*	

N = 6,237 (boys, 3,107; girls, 3,130)

Table 5 Gender (boy:girl) ORs (95% CI) for the ADHD high scorer subtypes for each informant

	Combined	Inattention	Hyperactive/impulsive
Parent	2.9 (2.2–3.9)	2.1 (1.7–2.6)	1.7 (1.3–2.4)
Teacher	6.2 (4.2–9.3)	3.1 (2.4–3.9)	5.4 (3.3–8.8)

N = 6,237 (boys, 3,107; girls, 3,130)

attrition in studies with a typical attrition rate underestimated the ADHD phenotype prevalence. We estimated the prevalence of the ADHD phenotype to 5.2% (parent and teacher reports) among children whose parents consented to participate in the study, but 6.6% in the total population. Both parents and teachers reported more ADHD symptoms in boys than in girls, but the gender difference was greater according to teacher reports. The excess proportion of boys with hyperactivity/impulsivity and the combined symptom constellation high score was higher according to teacher reports than parent reports. Informant agreement was low to fair.

The estimated ADHD phenotype prevalence of 5.2% in our study was considerably higher than the DAWBA-based ADHD prevalence of 1.3% from a second study phase in the same population based on the Development and Well-Being Assessment (DAWBA) [13]. This is not unexpected given that a DAWBA diagnosis requires the impairment criteria to be fulfilled and is therefore more comparable to a clinical diagnosis. Interestingly, our prevalence estimate for the ADHD phenotype was in the range of that reported from similar studies, while the DAWBA ADHD

prevalence rate in the BCS was considerably lower than in a comparable British survey in a head-to-head comparison of the two samples with similar age groups and informants [12].

Our prevalence estimate of 5.2% for the ADHD phenotype is comparable to that found in a recent German study [5] reporting a prevalence of 6.4% in the same age group. Our prevalence estimate relied on two informants (which led to a decrease in prevalence), whereas the German study only included parent reports. On the other hand, the study included a 4-point response scale and the two most deviant responses were regarded as indicating the presence of "symptom". This is probably a more conservative symptom definition than ours, given that we had only three response categories and defined the two most deviant as indicating symptom. Observing the behavior in different settings diminishes the likeliness of mixing it up with other behavioral disorders. The German study included no adjustment for non-responders, meaning that their prevalence rate was probably also an underestimate. Given these important methodological differences, it is somewhat surprising that the prevalence estimates are in the same range. This is not to be taken as support for a more solid evidence basis—that at the end of the day the reported prevalence rates were very similar. This may rather reflect that the choices made in a study may be influenced by previously reported results. This also demonstrates the liability of prevalence estimates to definition and the importance of thorough characterization of the methodology applied when referring to any reported prevalence of ADHD.

The access to anonymous teacher questionnaires for most of the non-participants was a special asset of our study. Comparing participants to non-participants, a much higher level of ADHD symptoms was found in the latter group and this finding is relevant for all population-based epidemiological studies independent of their definition of ADHD. Similar trends have been reported for autistic symptoms in the same cohort [15]. Teacher reports showing a prevalence of 19.9% ADHD high scorers in the Anonymous Data group compared to 10.4% in the Full Data group (an OR of 2.1) clearly illustrate the very important effect of non-participation in population studies of ADHD symptomatology. The non-participant ADHD high scorers did not significantly differ from the participant



^{*} p < 0.001 for difference between boys and girls mean scores

ADHD high scorers in boy:girl ratio, age or on the impact measure. Thus, we did not get any support for the hypothesis that teacher-rated non-participant children with ADHD symptoms would be more impaired than participants. Teachers completed the questionnaires without any knowledge of who would later belong to the non-participant group. However, one could suspect that they might have had a pre-conceived idea of who was going to participate or not. Interestingly, the non-participant ADHD high scorers had higher inattention scores and less hyperactivity/impulsivity than the participant ADHD high scorers. The explanation for this finding is speculative as we lack comparable reports from other studies. The finding underscores the importance of trying to assess nonresponder bias in epidemiology in general and in psychiatric research specifically. Though generally assumed that the non-participants are at higher risk for mental disorders and less privileged socially, few studies have explored the non-participation in sufficient detail to characterize the possible heterogeneity of non-participation. Investigating selective participation in the British Child and Adolescent Mental Health Surveys, Goodman and Gatward reported important heterogeneity in the effect of deprivation on parental non-participation [9]. Thus, it is important to note that the process of non-participation is probably complicated with a heterogeneous set of reasons, which give rise to diverse effects on the non-participating group.

We reported an estimate of the influence of attrition on the ADHD phenotype prevalence estimate by assuming that the hypothetical parent reports of the children in the Anonymous group would have related to teacher reports at the same high scorer ratio as in the Full Data group. More sophisticated methods taking account of the differential parent-teacher agreement across number of symptoms for the high scorers or bootstrap methods might have been used to estimate the effect of attrition on the total population prevalence. However, as discussed above, there are several different uncertainties and limitations attached to the prevalence estimate (such as the differential use of impact, etc.) that in the end we opted for illustrating the non-response effect by this simple method as the interpretation of this estimate is straightforward. We underline the importance of evaluating each aspect of the various methodological influences rather than taking any one prevalence estimate as reflective of the "true" rate.

Our reported boy:girl ratios for ADHD high scorers on DSM-IV symptoms are in the range of earlier studies in community samples [4, 8, 10, 11, 14, 20, 21]. Parents identified more girls than teachers, a finding that has been reported for the hyperactive/impulsive and for the combined subtypes in a previous study [8], but it is not clear whether the higher number of girls identified by parents represent an underidentification by teachers or an

overidentification by parents. Boys with ADHD are reported to engage in more rule breaking and externalizing behavior than girls with ADHD [2], and this has been found to affect teacher ratings of ADHD [1]. Some authors have found support for the hypothesis that the difference in symptom ratings across informants could be due to real situational differences [7]. Although the cause of the difference in parent and teacher reports on ADHD symptoms in girls remains unresolved, it is important to bear this in mind and to explore the issue further in future studies.

The BCS is unique in that teacher questionnaires cover 97% of the total population. The current study focused on symptoms of ADHD as reported on questionnaires. The validity of such reports may be questioned, since informants may misunderstand items, and may also have reasons for over- and underreporting problems in the child. Also, the DSM-IV diagnostic criteria require an early onset of the disorder (before age 7) and pervasive impairment from the symptoms. Thus, the phenotype and subtypes referred to here only indicate symptom constellations as specified in the diagnostic criteria and are not comparable to a clinical diagnosis. However, the symptom count approach may be more readily reproducible than clinical diagnoses in epidemiological research.

The use of only three response categories represented a problem in the current study. It is not clear whether the middle category should be regarded as having the symptom or not. Many DSM-IV ADHD rating scales have used 4-point scales, where the two highest scores have been interpreted as indicating a symptom [4, 8, 21]. However, our prevalence of the ADHD phenotype according to teacher reports is comparable to figures reported in previous studies of teacher-reported DSM-IV ADHD [4, 8, 15, 21]. Similarly, the frequency of parent-reported ADHD symptom subtypes was comparable to that found by other studies using parent information [10]. Our use of strict cross informant criteria compensated for a somewhat less restrictive individual symptom definition in estimating the prevalence based on both informants. A more conservative definition of symptom presence would have been to count only "Certainly true" answers as symptom present. We considered that the somewhat more inclusive symptom criteria were suitable for the epidemiological considerations in this general child population study.

Conclusion

The prevalence of the ADHD phenotype based on teacher and parent-reported symptomatology was clearly influenced by non-participation. The non-participation not only led to an underestimation of the prevalence, but also affected the rates of inattention and hyperactivity/



impulsivity. The definition of the phenotype, gender and choice of informant also influenced the detailed epidemiology of the ADHD phenotype in the present study.

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