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ORIGINAL CONTRIBUTION

Characteristics of undiagnosed children with parent-reported ADHD behaviour

Kathrine Bang Madsen[1] · Mette Holmelin Ravn[1] · Jon Arnfred[1] · Jørn Olsen[2] · Charlotte Ulrikka Rask[3,4] · Carsten Obel[1,5]

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Abstract There is an ongoing public debate on the diagnosis of attention deficit hyperactivity disorder (ADHD) in which critics have claimed that the disorder is over-diagnosed, while the potential under-diagnosis of children with ADHD has received little attention. In this study we estimate the number of children with parent-reported ADHD behaviour at age 7 and absence of recorded ADHD diagnosis through adolescence, and investigate whether socio-demographic characteristics of this group differed from the children diagnosed with ADHD during follow-up. Our study was based on data from the Danish National Birth Cohort, where parents of 51,527 children completed questionnaires, including the Strength and Difficulties Questionnaire (SDQ). ADHD diagnosis was identified through Danish registers and parent-reported ADHD behaviour by the specific SDQ subscale. Socio-demographic predictors of positive parent-reported SDQ ADHD behaviour and absence of recorded ADHD diagnosis in their children were examined using logistic regression analyses. Children with parent-reported ADHD behaviour and no diagnosis (1.3%) were more likely to be girls (OR 1.83; 95% CI 1.45; 2.29), more likely to have mothers with a low socioeconomic status (OR high vs. low 1.49; 95% CI 1.10; 2.02), and to live in certain regions of the country (OR: Capital vs. Southern: 2.04; 95% CI 1.51; 2.73) than children with an ADHD diagnosis. The children showed markedly impairments on all the SDQ subscales. The results demonstrate a considerable number of children with ADHD symptoms who potentially go undetected and underline the influence of socio-demographic factors in the pathway to a diagnosis of ADHD.

Keywords Attention deficit hyperactivity disorder (ADHD) · Strength and Difficulties Questionnaire (SDQ) · Cohort study · Diagnosis · Socio-demographic factors

Introduction

Attention deficit hyperactivity disorder (ADHD) is a developmental disorder with a substantial, lifelong impact on the individual's social, academic and occupational performance depending on ADHD severity, comorbidity and treatment [1]. The consequences of ADHD also bear heavily on the healthcare system and society in general [2, 3]. ADHD is characterised by attention problems and/or impulsivity and hyperactivity, causing impairment in daily life. The disorder is linked to psychosocial, environmental, genetic and biological factors; yet, no specific causality is implied [4]. ADHD affects a substantial part of the population and worldwide its prevalence was recently estimated at 2.6–4.5% [5]. The past two decades have seen a rise in the prevalence of ADHD diagnoses among schoolchildren, making it the most commonly diagnosed childhood disorder in most countries [6, 7]. However, the rise is not homogeneous within countries or between countries, which may

✉ Kathrine Bang Madsen
kathrine.bang@ph.au.dk

[1] Department of Public Health, Aarhus University, Bartholins Allé 2, 8000 Aarhus C, Denmark

[2] Department of Clinical Epidemiology, Aarhus University Hospital, Olof Palmes Allé 43-45, 8200 Aarhus N, Denmark

[3] Child and Adolescent Psychiatric Center, Aarhus University Hospital, Skovagervej 2, 8240 Risskov, Denmark

[4] Department of Clinical Medicine, Aarhus University, Barthsgade 5, 8200 Aarhus N, Denmark

[5] Center for Collaborative Health, Aarhus University, Høegh Guldbergsgade 6, 8000 Aarhus C, Denmark

reflect different thresholds for recognising and referring children as well as different access to diagnostic facilities [8–10].

It is a common conception that ADHD is over-diagnosed probably due to the attention from the public media and the popular press in which concerns about over-medicating children has been raised [11]. However, the current scientific debate about ADHD has been equally concerned with the existence of under-diagnosis of ADHD, especially in girls [12–16].

Ideally, children fulfilling the diagnostic criteria should be diagnosed, but social factors may affect detection and diagnosing of ADHD resulting in under-detection and under-diagnosis. It has been suggested that individual factors like the child's gender, the family status, parental mental health, where the child lives and the parents' socioeconomic status (SES) influence the child's probability of getting an ADHD diagnosis [10–12, 16–20]. In a population sample of 10,367 US children Cuffe et al. (2005) found that 1.59% of boys and 0.81% of girls were positive for significant parent-reported ADHD symptoms measured with the Strengths and Difficulties Questionnaire (SDQ), but did not have a clinical diagnosis of ADHD. Furthermore, these children had substantially higher proportions of elevated scores on other SDQ subscales compared to the overall population [21]. Froehlich et al. found that less than half of the children in a sample survey of 3907 US children who met the ADHD criteria from the Diagnostic and Statistical Manual of Mental Disorders 4th edition (DSM-IV) had received the diagnosis [12]. Furthermore, the results suggested that poor children were more likely to meet criteria for ADHD yet were least likely to receive treatment [12]. Under-treatment and low rates of clinical referral to child mental health services of children who were impaired by their ADHD symptoms was also one of the main findings in a Dutch community sample of 283 9-year-old children [22]. Research on gender differences suggests that girls may be consistently under-identified [12–16]. Girls with ADHD tend to exhibit lower levels of disruptive behaviour and higher levels of inattentiveness, and internalizing symptoms than do boys, which make them less likely to disrupt the classroom and may be more readily overlooked [11, 23]. Furthermore, it has been suggested that as ADHD is more frequent in males, a boy might be seen as a more prototypical child with ADHD and might therefore receive an ADHD diagnosis more readily than a girl would [24]. Using case vignettes in a sample of therapists, Bruchmüller found that the therapists diagnosed ADHD twice as much in boys than in girls even though the only difference in the vignettes was the gender [24].

Early identification and interventions are important in relation to child psychiatric disorders like ADHD and a delay in initiation of appropriate treatment may lead to a poor outcome [25, 26]. Several therapeutic interventions have been developed and some, including medical interventions, have been shown to be effective in improving the daily function of and long-term outcomes for children and adolescents with ADHD [25, 27–29].

Until now, only few studies have addressed the potential problem with under-diagnosis of ADHD and related issues in a large population-based sample and in a European context.

In the current study our aim was twofold; first to estimate the number of children with positive parent-reported SDQ ADHD behaviour at age 7 and absence of recorded ADHD diagnosis up till adolescence, and second to investigate whether socio-demographic and other SDQ characteristics of this group differed from the children diagnosed with ADHD during follow-up.

Method

Procedure and sample

The present cohort study was part of the Danish National Birth Cohort (DNBC), which is a nationwide cohort including more than 90,000 Danish women [30, 31]. The recruitment of participants took place at the first antenatal visit to the general practitioners throughout 1996–2003. In the present study, we used information from the follow-up questionnaire, which was completed by the primary caregivers, either through the internet or on paper, in the child's seventh year. The questionnaire addressed the child's health and development and included a parent-version of the Strength and Difficulties Questionnaire (SDQ-Den) (http://www.sdq.info.com). A total of 57,282 parents participated in the 7-year follow-up. We included only singletons with complete SDQ data and excluded younger siblings ($n = 51{,}527$). We linked the information obtained in the DNBC study to the Danish National Patient Register [32], the Danish Psychiatric Central Research Register [33] and the Danish National Prescription Registry [34] to identify children with diagnosed and treated ADHD or other psychiatric diagnoses.

Psychiatric diagnoses

ADHD diagnosed children were identified through two different approaches. First, we used the Danish patient registries [32, 33] where diagnoses are classified according to the International Classification of Diseases, 10th Revision (ICD-10) [35]. These registers hold information on all inpatient hospital admissions and outpatient hospital visits. We defined that ADHD was diagnosed when ICD-10 diagnoses F90.0–F90.9 (Hyperkinetic disorders) or F.98.8 (Other specified behavioural and emotional disorders with onset

usually occurring in childhood and adolescence) were registered either as the main diagnosis or an additional diagnosis after the age of 5. Second, we used the Danish National Prescription Registry, which registers information about prescribed ADHD medication in Denmark [34]. This was done to include ADHD patients diagnosed in private psychiatric practises in Denmark, which are not obliged to report the diagnoses to the national patient registers. Children were categorised as ADHD cases when they had redeemed one or more prescriptions of methylphenidate (N06BA04) or atomoxetine (N06BA09) after the age of 5 years. The registers were updated until March 2013; hence the children were followed until the age of 10–17 years. All children were followed until a diagnosis of ADHD, an ADHD medication prescription, death, emigration or end of registry follow-up, whichever came first. Information on death and emigration was obtained from the Civil Registration System. Henceforth, children who had either an ADHD diagnosis or had redeemed ADHD medication are referred to as ADHD cases or ADHD diagnosed children.

The Strengths and Difficulties Questionnaire (SDQ)

The SDQ is a brief screening tool for emotional and behavioural problems [36]. The SDQ consists of 25 questions scored 0–1–2 on a Likert scale ('not true'–'somewhat true'–'certainly true'). The questions cover five subscales: hyperactivity/inattention, conduct problems, emotional symptoms, peer relationship problems and prosocial behaviour, each rated as the sum score of five items. In addition, an impact supplement is provided to the informants, inquiring about the child's impairment interfering with home life, friendship, classroom learning, and leisure activities. The instrument is a multi-informant questionnaire available as a parent and teacher version of 5–16 years old and as a self-report version for 11–17-year-olds [37]. A computerised algorithm has been developed that combines teacher, parent and child reports to predict child hyperactivity-inattention disorders (SDQ ADHD). The SDQ ADHD algorithm generates "unlikely", "possible" or "probable" ratings for hyperactivity disorders [38, 39]. A program for scoring the algorithm is available at the SDQ website http://www.sdqinfo.com. The psychometric properties of the SDQ have been found to be satisfactory [40, 41].

Goodman described the psychometric properties in a study of about 10,000 British 5–15-year-olds. For the specific hyperactivity/inattention subscale he found a specificity of 92% and a sensitivity of 74% in predicting ADHD when reported only by the parent [42]. In a general population study of 2315 Danish children, the instrument identified children with highly increased risk of later ADHD diagnosed in school age (hazard ratio of 20.65 and a sensitivity of 45% and a specificity of 99.6%). The predictive algorithm for hyperactivity-inattention disorders (SDQ ADHD) was calculated with SDQ reports from both parents and teachers [43]. In another population study of 6233 Norwegian children, the SDQ predictive algorithm using both parent and teacher reports identified 74% of children with ADHD of the combined type; the study found a sensitivity of 52% and specificity of 98% [44].

In our study, we used the hyperactivity/inattention (H/I) scale with the prediction algorithm (SDQ ADHD) with only one informant (the parent). The mothers completed 99.1% of the reported SDQ questionnaires, while the rest were completed by fathers or other primary caregivers.

The children positive for SDQ ADHD and absence of registered ADHD diagnosis

We identified the children who exhibited ADHD behaviour using the SDQ ADHD algorithm for probable ADHD. Ideally, the SDQ ADHD prediction should include information from both a parent and a teacher. However, with only one informant (parent) available, we based the analyses on the most strict prediction algorithm to reduce false positives; H/I score $\geq$7 and impact score $\geq$2. In addition, children were excluded if the impact score did not apply to more than one setting. Children diagnosed with F.84 (pervasive developmental disorders) were excluded as difficulties corresponding to ADHD may have been recognised without a corresponding diagnosis being registered, respecting the exclusion rule in the ICD-10. Children with positive SDQ ADHD behaviour who were not registered with an ADHD diagnosis were followed in the registers for other psychiatric diagnoses.

Independent variables; socio-demographic factors

Socioeconomic information was derived from national registers at Statistics Denmark and based on the current or most recent job within 6 months or the type of education. The category 'high' included working in management or in jobs requiring higher education. Office workers, service workers, skilled manual workers and working in the military constituted the 'middle' category, while unskilled workers and the unemployed were classified into the 'low' category. Women who could not be classified in this way (4.1%) were categorised according to their husband's SES, defined as above [45]. Information on the family status was obtained from the 7-year follow-up questionnaire and based on the question whether the parents had been living together since the birth of their child.

We included maternal depression in the analysis because maternal levels of depression have been suggested to be associated with an over-report of the child's behaviour problems [46]. Maternal depression was self-reported and collected at 7-year follow-up referring to the time from

childbirth to child age 7 years. Maternal depression was positive when the mother reported (1) to have had a psychiatric illness, and (2) to have been in contact with a physician or a psychologist because of this, and (3) that the psychiatric illness was depression.

Place of residence was obtained from the Civil Registration System and each ADHD case was assigned to the region in which they were diagnosed or had redeemed medication. Children without an ADHD diagnosis were assigned to the region in which they were born.

Statistical analysis

First descriptive characteristics are presented for the overall sample, the ADHD diagnosed children and the SDQ ADHD positives in the absence of an ADHD diagnosis. Second other mental and behavioural diagnoses are presented for the latter children.

To determine the possibility of gender, family status, maternal depression, place of residence and SES status being associated with the SDQ ADHD positives and no ADHD diagnosis, we conducted a logistic regression model comparing these children with the ADHD diagnosed children. First, gender, family status, maternal depression, place of residence and SES were analysed separately. Next, all the independent variables were included in the model. Multiple logistic regression results are presented with odds ratios (OR) and 95% confidence intervals (CI) for each variable. *t* test analyses were used to compare the SDQ subscale scores between the SDQ ADHD positives in the absence of an ADHD diagnosis and the ADHD cases.

The statistical analyses were conducted using STATA 11.1. A two-sided significance level of 0.05 was used in all analyses.

Results

Of the 51,527 children 1046 received an ADHD diagnosis and 998 had redeemed ADHD medication prescriptions during follow-up. A total of 1373 children were registered as ADHD cases (2.7% of the cohort) because of an overlap of 671 children between medication and diagnosis. In Table 1, the number of children with and without recognised ADHD was tabulated with the number of children with a 'probable', 'possible' or 'unlikely' SDQ ADHD. Table 1 shows that out of the 1179 children with a positive SDQ ADHD prediction, 680 were not identified with an ADHD diagnosis. Excluding children if the impact did not apply to more than one setting ($n = 14$) and with a diagnosis of F.84 Pervasive development disorder ($n = 13$), we found that the SDQ positives in the absence of an ADHD diagnosis ($n = 653$) represented 57% of the SDQ ADHD 'probables' and 1.3% of the total cohort. Of the 1373 ADHD diagnosed children 727 (53%) were predicted 'unlikely' of SDQ ADHD.

Table 1 Children with and without ADHD diagnosis and the SDQ ADHD prediction categories

ADHD diagnosed	SDQ ADHD prediction			
	Unlikely	Possible	Probable	Total
No	48,794	680	680	50,154
Yes	727	147	499	1373
Total	49,521	827	1179	51,527

In Table 2, the distributions of socio-demographic variables are reported for the whole sample, the ADHD diagnosed children and the children with SDQ ADHD behaviour and no ADHD diagnosis. Compared with the overall sample, ADHD diagnosed children were more likely to be boys (79 vs. 51.2%), less likely to live with both parents (69.4 vs. 83.8%) and more likely to belong to low SES (14.2 vs. 7.8%) (Table 2). In the group of SDQ positives and absent ADHD diagnosis the gender distribution was also in favour of boys, although the difference was smaller than in the group of ADHD cases. The SDQ positives in absence of an ADHD diagnosis were more similar with the ADHD cases than the overall sample on family status, mother's socioeconomic status and maternal depression (Table 2). The mean child age at end of follow-up did not differ between the overall sample, the ADHD cases and the SDQ ADHD positives and absence of ADHD diagnosis.

In the group of children with a positive SDQ ADHD in absence of an ADHD diagnosis, 46 (7%) had other mental and behavioural disorders (see Table 3). The majority had a diagnosis related to disorders of psychological development (35%) or behavioural and emotional disorders (35%).

The results of the logistic regression analyses estimating the association between the predictors and not receiving a diagnosis of ADHD during childhood or adolescence while exhibiting ADHD behaviour at age 7 years compared to children with an ADHD diagnosis are shown in Table 4. The SDQ positives in absence of an ADHD diagnosis were more likely to be girls ($OR_{adjusted}$ 1.83; 95% CI 1.45; 2.29), more likely to have mother's with a low SES ($OR_{adjusted}$ 1.49; 95% CI 1.10; 2.02) and more likely to live either in the Zealand Region ($OR_{adjusted}$ 1.47; 95% CI 1.05; 2.05) or the Southern Region ($OR_{adjusted}$ 2.04; 95% CI 1.51; 2.73) of Denmark with the Capital Region serving as the reference (Table 4).

Associated mental health problems were measured with the SDQ subscales and in Table 5 the differences in mean scores on the subscales are presented. The SDQ positives in absence of ADHD diagnoses had significantly higher scores on all subscales compared to the children who received an ADHD diagnosis during follow-up except for the prosocial scale, which is a positive

Table 2 Distribution of socio-demographic variables for the overall sample, the ADHD diagnosed and the SDQ ADHD positive without an ADHD diagnosis

	Overall sample *N* (%)	ADHD diagnosed[a] *n* (%)	SDQ ADHD positive, no ADHD diagnosis *n* (%)
All	51,527 (100)[b]	1373 (2.7)[b]	653 (1.3)[b]
Child's gender			
Boy	26,371 (51.2)	1085 (79)	440 (67)
Girl	25,144 (48.8)	288 (21)	213 (33)
Missing	12 (<0.1)	0	0
Family status			
Living with both parents	43,156 (83.8)	953 (69.4)	445 (68.1)
Parents divorced	8254 (16)	417 (30.3)	207 (31.7)
Missing	117 (0.2)	3 (0.3)	1 (0.2)
Mother's socioeconomic status			
High	27,243 (52.9)	561 (40.9)	236 (36.2)
Middle	17,938 (34.8)	555 (40.4)	268 (41.0)
Low	4006 (7.8)	199 (14.5)	108 (16.5)
Missing	2340 (4.5)	58 (4.2)	41 (6.3)
Maternal depression			
Yes	3740 (7.3)	227 (16.5)	96 (14.7)
No	47,787 (92.7)	1146 (83.5)	557 (85.3)
Mean child age at end of follow-up (SD)	12.49 (1.36)	12.59 (1.31)	12.44 (1.37)

[a] Includes children diagnosed in both private and public practise (medication and/or registered diagnosis)

[b] The percentage is compared with the overall sample. Otherwise, percentage is within the group

Table 3 Mental and behavioural disorders in the group of SDQ ADHD positive without an ADHD diagnosis

ICD-10 Mental and behavioural disorders	*N* (%)
F40–48 Neurotic, stress-related and somatoform disorders	2 (4)
F50–59 Behavioural syndromes associated with physiological disturbances and physical factors	1 (2)
F70–79 Mental retardation	11 (24)
F80–89 Disorders of psychological development[a]	16 (35)
F91–98 Behavioural and emotional disorders with onset usually occurring in childhood and adolescence[b]	16 (35)
In all	46 (100)

ICD-10 International Classification of Diseases 10th Edition

[a] The F.84 diagnosis was excluded

[b] Not F.98.8

Table 4 Results of the logistic regression model predicting the probability for each independent variable occurring in the group of SDQ ADHD positive without an ADHD diagnosis vs. ADHD diagnosed

Variable	OR	95% CI	$OR^{a}_{adjusted}$	95% CI	*P*
Gender					
Boy	Ref.		Ref.		
Girl	1.82	1.48; 2.24	1.83	1.45; 2.29	>0.001
Socioeconomic status					
High	Ref.		Ref.		
Middle	1.27	1.01; 1.59	1.25	0.99; 1.58	0.056
Low	1.54	1.15; 2.06	1.49	1.10; 2.02	0.010
Parents living together	0.95	0.77; 1.18	0.97	0.77; 1.23	0.123
Maternal depression	0.93	0.71; 1.22	0.82	0.62; 1.09	0.184
Place of residence					
Capital region	Ref.				
Central region	1.07	0.81; 1.41	1.03	0.77; 1.38	0.839
Northern region	1.17	0.81; 1.67	1.15	0.79; 1.67	0.475
Zealand region	1.45	1.05; 2.01	1.47	1.05; 2.05	0.027
Southern region	2.08	1.56; 2.76	2.04	1.51; 2.73	>0.001

OR odds ratio, *CI* confidence interval

[a] OR adjusted for each independent variable in the table

scale with higher score reflecting better prosocial behaviour. The differences between the groups were most pronounced on the emotional scale (3.72 vs. 2.77), besides the hyperactivity/inattention scale (Table 5).

Discussion

We found that more than half of the children with parent-reported ADHD behaviour at age 7 were not diagnosed

Table 5 Mean scores on the SDQ subscales for the SDQ ADHD positive and absent ADHD diagnosis vs. ADHD diagnosed children

	SDQ ADHD positive absence of ADHD diagnosis Mean (95% CI)	ADHD diagnosed Mean (95% CI)	*P*
Hyperactivity/inattention	8.51 (8.42; 8.59)	6.27 (6.12; 6.41)	<0.0001
Conduct problems	3.45 (3.31; 6.60)	2.81 (2.71; 2.91)	<0.0001
Emotional problems	3.72 (3.54; 3.90)	2.77 (2.65; 2.89)	<0.0001
Impact	3.19 (3.04; 3.34)	2 (1.87; 2.13)	<0.0001
Peer problems	3.06 (2.89; 3.24)	2.42 (2.30; 2.54)	<0.0001
Prosocial (positive)[a]	6.52 (6.35; 6.69)	7.21 (7.10; 7.33)	<0.0001

[a] The prosocial score is positive, reflecting better prosocial behaviour

with ADHD during follow-up, which corresponds to 1.3% of the total cohort. Our results are consistent with previous studies and the prevalence estimates of children with ADHD behaviour and no diagnosis were in fact quite similar [12, 21]. We further investigated what characterised the children with parent-reported ADHD behaviour and no ADHD diagnosis. We found that 7% of the children were diagnosed with other mental or behavioural disorders, particularly disorders of psychological development and behavioural and emotional disorders during follow-up. We also found that the children in this group were more likely to be girls, to have mothers with low SES and to live in certain regions of the country. Compared to the children who received an ADHD diagnosis during follow-up the children with ADHD behaviour and no diagnosis had significantly higher scores on the SDQ subscales, which is consistent with findings from the study by Cuffe et al. [21].

The number of children who were identified with parent-reported ADHD behaviour but were not identified as ADHD cases (57%) during follow-up point to a high number of children with potential undetected ADHD problems. However, it has been argued that when the SDQ is used in a community sample, quite a few children with clinical range SDQ results will actually be typically developing, i.e., false positives, due to low prevalence rates in the general population. In contrast, when the SDQ is used in a clinical sample, where prevalence rates are higher, fewer children will be false positives [47]. However, the children showed markedly and significantly worse impairments on all SDQ subscales compared to the children who had or received an ADHD diagnosis during follow-up. It is possible that these children would not exceed the threshold for a clinical diagnosis but they could still be in need of special care.

Barriers to receive an ADHD diagnosis may occur at multiple levels, including identification and referral by school personnel, parents' help-seeking behaviour, access to diagnostic services, diagnosis by the professionals, treatment decisions, and acceptance of treatment [48].

Previous national studies suggest that contextual factors like access to psychiatric services and the diagnostic approach of the specialist physicians vary considerably across Denmark; and this affects the probability that a given child is referred to diagnostic facilities and diagnosed with ADHD [10, 25]. This is in line with our results showing that the SDQ ADHD positives and absent ADHD diagnosis children were more likely to be living in particular regions (the Zealand and Southern regions) of the country where the incidence of the ADHD diagnosis has previously been estimated to be lower than in other parts of the country [10]. The study by Madsen et al. demonstrated that in the Southern region several municipalities had an incidence of ADHD diagnosis below the national average and two municipalities even experienced a decrease in incidence between 1990 and 2000 [10]. Our finding supports the notion that there is a difference in identification and referral of children with ADHD as well as an unequal access to diagnostic services.

Similar with other studies, we found that socioeconomic disadvantage was more common in children diagnosed with ADHD [49, 50]. In addition, we found that the children with a positive SDQ ADHD in the absence of an ADHD diagnosis were even more likely than the children diagnosed with ADHD during follow-up to have mothers with a low SES. This is consistent with findings from several other studies showing that socioeconomic disadvantage may be a predictor of non-treatment [12, 51]. The influence of socio-demographic factors such as SES, income and educational level on parent's help-seeking behaviour may depend largely on a country's healthcare system. Studies in several European countries in which healthcare is readily available and where there are no major financial constraints to receiving professional help, have not found any association between SES and help seeking, opposite to studies conducted in the US [52]. As low SES reflects low level of education, the association with SDQ positives and absent diagnosis could reflect that these mothers do not necessarily have any preconditions for understanding the healthcare system and make demands because of a poorer communicative and health literacy [53].

There has been surprisingly little attention in the public media about the issue of possible under-diagnosis. Impact

of negative media publicity on ADHD medication may play a vital role in influencing children with ADHD, their parents, teachers and professionals [54]. Studies have suggested that the media is an important source of information about ADHD for primary care physicians [55, 56]. Like physicians, school personnel find ADHD both challenging and time-consuming. Teachers and school counsellors spend a great amount of time addressing concerns regarding children who exhibit ADHD symptoms; however, educators may have little accurate knowledge about ADHD and may, in some cases, share misperceptions common among parents, i.e., that ADHD is not a real disorder, or that the symptoms are caused by too much sugar, poor parenting, or a stressful family environment [48, 57]. Consequently this may result in a lack of referral of children with ADHD symptoms to psychiatric evaluation. In a study using data from several European countries a third of caregivers for children with ADHD reported a high degree of difficulty in obtaining an ADHD diagnosis for their child, less than half felt that sufficient resources were available, and gaps in support from health care providers and schools were identified [58].

The problem of undetected ADHD in society is supported in the literature, especially in girls [12–16, 21]. We found that the children with an SDQ ADHD and absent ADHD diagnosis were about 80% more likely to be girls compared with the children who received an ADHD diagnosis during follow-up. It has been suggested that the under-identification of girls may be due to gender differences in the phenotypic expression of ADHD with girls presenting with less disruptive behaviour resulting in less problem-recognition by parents and teachers [23]. This is consistent with a study using data from 10 European countries where Nøvik et al. found that gender specific variations had very little influence on paediatric practise suggesting that girls with ADHD might be under-referred [16]. Meanwhile gender differences have also been suggested to play a role in the assessment of children in clinical practise [24]. It goes beyond the current study to answer this, but future research efforts should elucidate which factors might contribute to the under-identification of girls with ADHD at different levels in the pathway to an ADHD diagnosis.

Other possible explanations for the finding of the large number of children with a positive SDQ ADHD in the absence of an ADHD diagnosis could be that the difficulties reported by the parents for some children were transient; and despite difficulties in impulse-control and hyperactivity, symptoms would not exceed the threshold for an ADHD diagnosis. Using screening instruments like the SDQ without further clinical evaluation of the children, we cannot be certain that these children in fact have ADHD symptoms. Even though the children may be under the threshold of a diagnosis according to the ICD-10 or DSM-5 these children may indeed still exhibit problems with functioning and limitations in their everyday lives. Alternatively, the difficulties could be interpreted as part of a different psychiatric disorder, which was the case for about 7% of the children. In addition, children who are traumatized and live under poor and abusive conditions may also display increased levels of ADHD symptoms. Finally, some parents may have opposing views on proposed (medical) treatment of their children and would have resisted further evaluation.

We found a considerable number of children with an 'unlikely' SDQ ADHD prediction who had or later received an ADHD diagnosis during follow-up ($n = 727$). According to the study by Goodman (2001) up to 26% (and even more according to other studies [43, 44]) of children with ADHD in the sample may screen negative for ADHD by the SDQ [42]. Second, there may be some children with parent-reported ADHD who are treated and thus have fewer symptoms and finally, there is a possibility of a later onset of ADHD symptoms.

Strengths and limitations

The major strength of this study was the use of data from Danish registers on clinical diagnoses and prescription of central stimulants. Using registers, only death and migration cause attrition. Unlike parental reports of diagnosis, the register-based information on diagnoses and prescriptions is clinically confirmed. Although ADHD is a disorder most often occurring early in childhood, the follow-up time allowed for a delay in the referral of children and the diagnostic processes. A considerable amount of time may pass from when parents or teachers raise concern about a child with ADHD-like behaviour until referral and confirmed diagnosis [16]. The study by Nøvik et al. demonstrated that the mean time interval between first awareness of child symptoms to seeking treatments was about 2.5 and 1.5 years from seeking treatment to an ADHD diagnosis [16]. In contrast to a cross-sectional design, the follow-up design used here allowed us to include information on diagnostic status until the children were between 10- and 17-years-old.

The present study is based on the DNBC cohort, which is a large general-population-based sample of Danish children recruited in early pregnancy throughout Denmark during 1996–2002. A previous study found that the cohort is not representative in terms of socioeconomic factors [59]. However, in an analysis of the representativeness of childhood psychiatric diagnoses, we found that children with a registered ADHD diagnosis are only modestly underrepresented (between 1 and 9%), whereas children using ADHD medication are present in the DNBC to the same extent as in the general population [61]. However, the relatively poor

representativeness of low SES groups in the DNBC may have caused an underestimation of children with positive SDQ ADHD in the current study.

Some important limitations of the present study have to do with the use of the SDQ for measuring ADHD behaviour. First, we only have parent-provided ratings of the SDQ, which could be a problem since the manifestation of ADHD symptoms in multiple contexts is important. The performance of SDQ in predicting ADHD is reported to be somewhat better when both a parent and a teacher report [42–44]. We therefore decided only to include children with a hyperactivity/inattention score above 7 and an impact score above 2 (from more than one setting) to increase specificity. However, the impact score might refer to the other domains of the SDQ resulting in misclassification.

We were not able to follow all children for an equal amount of time because the cohort was born between 1996 and 2003. This problem could cause misclassification as some more recently born children may receive a diagnosis after the end of follow-up. However, the mean age at the end of follow-up was the same in the overall sample, the ADHD diagnosed group and the group of children with a positive SDQ ADHD and no ADHD diagnosis. In addition, a Danish study found that most children have been diagnosed and received treatment by the age of 12 years [60]. Additionally, we do not have information on children diagnosed in private practises who have not redeemed prescribed medication. The lack of information could have led to an overestimation of children with a positive SDQ ADHD and negative ADHD diagnosis.

We did not have adequate information on the parent's psychopathology, besides maternal depression. This could have had an influence, since parental psychopathology has been associated to a higher degree of problem-recognition but not help-seeking or utilisation of mental health services [52].

Finally, the use of prescribed central stimulants as a proxy measure for ADHD can cause misclassification regarding children being treated because of narcolepsy. However, this number is presumed to be negligibly low in Denmark and such misclassification would probably not have an impact on the presented results [43].

In conclusion (and noting the limitations above), our study identified a considerable number of children with parent-reported ADHD behaviour at age 7 and no registered diagnosis during a long follow-up. Our results correspond with previous studies suggesting that a number of children with ADHD symptoms might go undetected and that these children might have considerable associated mental health problems. In addition, our study demonstrated that the children exhibiting ADHD behaviour in the absence of an ADHD diagnosis were more likely to be girls, more likely to have mothers with a low SES and to be living in certain regions of the country. These results may point to socio-demographic factors as important drivers in the pathway to an ADHD diagnosis.

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Compliance with ethical standards

Ethical approval The Danish Data Protection Agency and the DNBC Steering Committee approved the study.

Conflict of interest On behalf of all authors, the corresponding author states that there is no conflict of interest.

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