Attention-deficit/hyperactivity disorder: are we helping or harming?

The criteria for diagnosing ADHD are subjective and expanding. **Rae Thomas and colleagues** explain how enthusiastic diagnosis in children with mild symptoms could result in harm, and undermine the value of the diagnosis in children with severe symptoms

SUMMARY BOX

Clinical context—The prevalence of attention-deficit/hyperactivity disorder (ADHD) has increased substantially in the past decade, with most children diagnosed with ADHD described as having mild or moderate ADHD. Medication prescription rates have also increased twofold for children and fourfold for adolescents and adults

Diagnostic change—Definitions of ADHD have been broadened in successive editions of DSM

Rationale for change—Concern that ADHD is underdiagnosed in some children and adults

Leap of faith—Identifying and treating more people with ADHD will improve their quality of life

Impact on prevalence—The prevalence of parent reported diagnosis of ADHD in the US rose from 6.9% in 1997 to 9.5% in 2007. In the Netherlands it doubled over a similar period and other countries have also seen similar rises

Evidence of overdiagnosis—Severity of ADHD criteria is subjective. Prevalence varies markedly within and between countries and there is evidence that inappropriate developmental comparisons, sex, and heuristics contribute to inappropriate diagnoses

Harms from overdiagnosis—Medication costs of inappropriately diagnosed ADHD are estimated to be between \$320m (£200m; €230m) and \$500m in the US and some children have adverse drug reactions. While a diagnosis may help children and families it also carries stigma; children labelled as having ADHD are perceived as lazier and less clever by peers, and teachers and parents have low academic expectations of them potentially creating a self fulfilling prophecy

Limitations—Longitudinal data on the prognosis of ADHD and effects of treatments are limited

Conclusions—Reducing the threshold for diagnosing ADHD devalues the diagnosis in those with serious problems. A conservative stepped diagnostic approach could reduce the risk of overdiagnosis

Prevalence and prescribing rates for attention-deficit/hyperactivity disorder (ADHD) have risen steeply over the past decade, partly in response to concerns about underdiagnosis and undertreatment. ¹ ² But although clinicians have become better at recognising, diagnosing, and treating children with ADHD, recent US data showed that 86% of children diagnosed with ADHD are described as having "mild or moderate" disorder, ³ and some diagnosed without fulfilling diagnostic criteria for ADHD. ⁴

Mental health diagnoses are vulnerable to overdiagnosis because decisions are based predominantly on observed or self reported behaviours and interpretations of the severity of certain behaviours and whether they should be described as abnormal are subjective. There are no definitions in the UK, US, or Australian guidelines or in DSM-5 that quantify mild or moderate ADHD (box 1).⁵⁻⁷ We argue that the overdiagnosis of ADHD resides within the clinical subjectivity of impairment.

What is ADHD?

To be diagnosed with ADHD, a child, adolescent, or adult should meet clear diagnostic criteria outlined in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) or International Classification of Diseases (ICD-10). In the DSM-5 definition symptoms fall within two main areasinattention and hyperactivity/impulsivity-and can include difficulties sustaining attention, disorganisation, lack of follow through on tasks, being easily distracted, restless, and persistently interrupting.8 This results in three subtypes (predominantly inattentive, predominantly hyperactive/impulsive, and combined). The ICD-10 calls the condition hyperkinetic disorder and requires hyperactivity, impulsivity, and inattention to be present. The more restrictive diagnostic criteria of ICD-10 result in smaller prevalence rates than ADHD diagnosed using DSM criteria. 4 However, most practitioners use DSM.

ADHD is diagnosed more often in boys than girls (about 3:1) and usually within the primary school years. However, girls are more likely to meet criteria for the inattentive subtype of ADHD. Although this subtype was dropped from

Box 1 | Mild, moderate, and severe ADHD

DSM-IV and DSM-5 provide no criteria to differentiate mild, moderate, and severe ADHD.

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The UK, US, and Australian guidelines do not mention mild ${\rm ADHD}^{5\text{-}7}$

Moderate ADHD

Guidelines from the UK National Institute for Health and Care Excellence (NICE) define moderate ADHD as having symptoms in either hyperactivity/impulsivity, inattention, or a combination of both and that the individual must have moderate impairment but do not define "moderate"

Moderate ADHD is not mentioned in the Australian draft guidelines and not defined in the US clinical practice guidelines

Severe ADHD

Severe ADHD is defined in the NICE guidelines as having symptoms in the hyperactive/impulsive and inattention categories, corresponding with the ICD-10 criteria

Neither the US nor the Australian guidelines define severe ADHD

There is no consistent way to assess severity of ADHD symptoms. These terms usually refer to impairment of an individual's level of functioning. There are some assessment scales that attempt to quantify impairment (eg Children's Global Assessment Scale) but many use frequency as a proxy for impairment or rely on lay (parent, teacher) interpretations of "normal" and "abnormal" behaviour

DSM-III-R, it was reintroduced in DSM-IV, corresponding to a substantial increase in diagnoses among girls. ¹¹

ADHD is usually diagnosed by paediatricians and psychiatrists after a child in whom the diagnosis is suspected has been referred by their primary care physician. ⁵ 12 13 In the US, however, primary care paediatricians predominantly provide diagnoses. ⁶ Diagnosis depends on an evaluation of the child's behaviour in at least two contexts (usually home and school or workplace) and different people (often parents and teachers) completing the evaluations. Symptoms must impair functioning in social, academic, or work settings. ⁸ Although there are some assessment scales that attempt to quantify impairment (such as the Children's Global Assessment Scale), the DSM-5 and national

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ADHD guidelines leave it to individual clinicians to decide impairment severity.⁵⁻⁷ Guidelines suggest that medical, psychosocial, and developmental assessments are also carried out.⁵⁻⁷

Children who meet DSM's ADHD criteria always have problems in academic achievement¹⁴ and social interaction. Often children also experience peer rejection and an increased risk of injury.¹⁵ ¹⁶ Longitudinal studies show that they are less likely to attend tertiary education, more likely to be unemployed or perform suboptimally at work,¹⁷ more likely to engage in delinquent or criminal behaviour,¹⁸ and more likely to use alcohol, tobacco, and illegal drugs than those without ADHD.¹⁹ Observational studies suggest that untreated adults with ADHD are more likely to have car crashes and traffic violations than treated adults and adults without ADHD.²⁰

Rising diagnosis and treatment

The reported prevalence of ADHD is rising in several countries. ²¹ In US population surveys the prevalence of parent reported diagnosis of ADHD rose from 6.9% in 1997 to 9.5% in 2007, ³ and there is wide variation in point prevalence rates within ²² and between countries, ²¹ raising questions about diagnostic practices contributing to part of the rise. It is likely that clinicians are better at detecting and diagnosing ADHD but it is also thought that some of the rise reflects overdiagnosis or misdiagnosis. ²³ ²⁴

In parallel, prescribing rates for commonly used drugs such as dexamfetamine, methylphenidate, and atomoxetine for children diagnosed with ADHD have increased. Australian data on prescribing rates for ADHD medication show an increase of 72.9% between 2000 and 2011. ²⁵ In the UK prescription of these same medications increased twofold for children and adolescents between 2003 and 2008 and fourfold for adults. ²⁶ Prescribing of methylphenidates and amfetamines in the US increased steadily between 1996 and

2008, with the greatest increase in adolescents aged 13-18 years. ²⁷ In the Netherlands prevalence and prescribing rates for children who had ADHD diagnosed doubled between 2003 and 2007. ²⁸

How effective is treatment?

Systematic reviews reach differing conclusions about the benefits of treatment in the short term, ²⁹ ³⁰ and few studies have examined long term benefits.³¹ Parent training programmes are effective for preschool children and their families.³⁰ Among children aged 6 years and older drug treatment with or without parent training was effective, but parent training alone had no benefit. 29 31 The longest trial of ADHD treatment outcomes available is the Multimodal Treatment Study of Children with ADHD. Although not without methodological controversies, the study reported short term benefits for medication alone and combination treatments compared with behaviour treatment alone or community care. At three, six, and eight year follow-up, children were, on average, performing better than at baseline, although they were still underperforming compared with their peers and there were no differences in treatment groups.32

Drivers of overdiagnosis

Shifting definitions

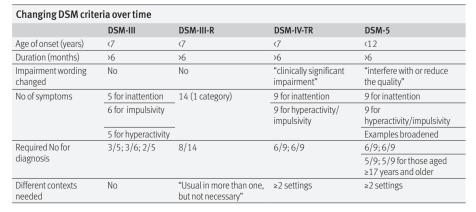
An important contributor to the increasing prevalence of ADHD is changes to the diagnostic criteria in differing editions of the DSM (table). ^{21 33} The figure shows individual and average pooled prevalence from 104 studies that used DSM criteria. These show a significant increase in ADHD prevalence between each version of DSM. Field trials of proposed changes to ADHD diagnostic criteria (from DSM III-R to DSM-IV) flagged an expected increase in prevalence of 15%. ³³ However, the increase exceeded this prediction, and prevalence is expected to rise further with the adoption of DSM-5, launched earlier this year.

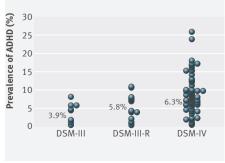
DSM-5 widens the definition of ADHD by expanding behavioural descriptions to include more examples and increasing the maximum age of symptom onset from 7 to 12 years. These changes are a cause for concern because they increase the risk of confusing ADHD with normal development processes, such as pubertal restlessness and distractibility. And although the term impaired functioning remains a constant diagnostic criterion from DSM-IV to DSM-5, the wording has changed from "clinically significant" to "interfere with or reduce the quality of social, academic, or occupational functioning." DSM-5 has also included, for the first time, criteria for diagnosis of ADHD in adults.

Unmet criteria

The DSM criteria for ADHD state that behavioural symptoms must be present in different contexts, be severe, affect functioning, have occurred for more than six months, and have started in childhood or early adolescence.8 However, behavioural measures often characterise severity and impairment by frequency rather than compromised functioning. Frequency is not the same as impairment, and disregarding this important criterion increases reported prevalence.4 36 Many prevalence studies use parent or teacher report of symptoms and do not apply the severity or time criteria included in the full DSM diagnostic criteria. 37 38 Unsurprisingly such studies report higher prevalences than those in which clinicians have diagnosed ADHD.³⁹ 40

ADHD diagnosis may also be influenced by heuristics and gender stereotypes. In one study, specialists in child and adolescent mental health (including child psychologists, psychiatrists, and social workers) were asked to identify children with ADHD from a series of vignettes. ⁴¹ Although the study provided participants with information on the optimal and minimal behavioural symptoms for diag-





Prevalence of ADHD in studies using different DSM criteria³⁴

Box 2 | Stepped diagnostic approach to ADHD

Step 1: Gather baseline data from more than one source—eg school and home. If problems are urgent, recurring, or persistent and specific go directly to step 6. For other cases follow steps 2-5 first

Step 2: Look for other explanations of behavioural problems—for example, concentration problems and agitation may be a result of sleep deprivation, over challenging in school, workload, or tensions at home or at school

Step 3: Watchful waiting—assess, monitor, and follow-up with no pretence of a definitive diagnosis or active treatment

Step 4: If problems remain, offer a minimal intervention like bibliotherapy (such as information brochures) or self help training for parents of hyperactive children. Avoid the term ADHD, and speak in terms of concentration problems, restlessness, or behavioural difficulties Step 5: If minimal intervention is not sufficient provide brief (five or six sessions) counselling using simple techniques to teach new attitudes and coping skills for dealing with hyperactivity and concentration problems

Step 6: If concentration and behaviour problems and impairment persist, more intensive therapy, usually in secondary care, is needed. Refer the patient to a developmental paediatrician or psychiatrist for definite diagnosis and treatment

nosis, 20% of clinicians diagnosed ADHD when criteria were not fulfilled.

Commercial influence

Among the work group advisers of DSM-5 for ADHD and disruptive behaviour disorders, 78% disclosed links to drug companies as a potential financial conflict of interest. ⁴² Despite disclosure, transparency does not mitigate bias and whether this affected decisions regarding changes to ADHD criteria is unknown.

The influence of direct to consumer advertising by pharmaceutical companies on driving patient demand for, and doctors' prescribing rates of, drug treatments is well known. 43-45 Advertising on the internet through "mental health information websites"46 is also an effective tool to promote discussion about mental healthcare. Mitchell and Read reported that pharmaceutical funding was ubiquitous in business, non-government organisation, educational, professional, and consumer websites providing information on ADHD. 46 Pharmaceutical companies have also used celebrities to "raise awareness" of ADHD47 and sponsor websites that promote self diagnosis (and potentially misdiagnosis) using six questions and seeking help. 48

Patient advocacy groups are not immune from potential bias either. Financial support and medication information is provided by drug companies to both the US advocacy group Children and Adults with Attention Deficit/Hyperactivity Disor-

der ⁴⁹ and the National Attention Deficit Disorder Information and Support Service ⁵⁰ in the UK.

Potential harms of overdiagnosis

Medication costs

About 87% of children diagnosed with ADHD in the US in 2010 subsequently received medication. 12 Decreasing symptom thresholds for impairment may mean unnecessary and possibly harmful medical treatment for some individuals. Data from the Centers for Disease Control and Prevention show that most children with ADHD are classified as having mild (46.7%) or moderate (39.5%) problems. Less than 14% have severe ADHD.3 On the basis of a relative age effect where children with birthdays in the latter part of the school year were more likely to have ADHD diagnosed than children born earlier in the year, Elder estimated that between \$320m (£200m; €230m) and \$500m is spent annually on medication for individuals inappropriately diagnosed with ADHD.51

Prescription rates for children in paediatric primary care exceeded expected community based care prescription rates and children in primary care were more likely than those in specialist mental health clinics to be prescribed medication. ⁵² When per capita use of ADHD medication is compared with a nation's gross domestic product, Australia, the US, and Canada have greater than expected use, and subsequent cost, of ADHD drugs. ⁵³

Adverse events

The main medications for ADHD are methylphenidates and amfetamines, ²⁷ ²⁸ which can cause adverse reactions such as weight loss, hepatotoxicity, and suicide ideation, ⁵⁴ and in the short term may suppress pubertal growth. ⁵⁵ Longitudinal studies from childhood to adulthood have not been completed and so long term effects on growth are not known. ⁵⁶ Correll et al reported significant gains in weight, body mass index, and waist circumference in children and young people taking risperidone (used off-label for ADHD) over 12 weeks. ⁵⁷

Psychological harms

A diagnostic label is value laden and has the potential to cause harm and, paradoxically, increase mental health problems. Compared with children with asthma, children with ADHD have been described as lazier, less clever, and less caring, and they are also more likely to be stigmatised and socially excluded. ⁵⁸ Teacher and parent expectations of academic achievements are also low, and these are associated with actual lower achievement scores. ⁵⁹

Towards conservative diagnosis and treatment

Severe cases of ADHD are obvious, but in mild and moderate cases—which constitute the bulk

of all ADHD diagnoses³—subjective opinions of clinicians differ. For these cases, we propose a conservative treatment approach similar to that recommended by UK guidelines.⁵ These advocate a watchful waiting period of 10 weeks, referral to a parent training programme (without the need for a diagnosis), and then referral to secondary care if symptoms do not improve. In addition to stepped care, we propose stepped diagnosis, an approach including five steps of care before definite diagnosis (box 2). The goal is to reduce unnecessary diagnoses without risking undertreatment of those who really need psychiatric help.

Some evidence suggests that evidence based parent management training programmes may be effective for preschool children "at risk" of ADHD³⁰ and effective and cost effective for some families of older children.⁶⁰ However, it is unclear whether interventions like parental training are prescribed in mild to moderate cases of ADHD and if outcomes for these children were similar or better than medication alone. Data from the Multimodal Treatment of ADHD study show that even if medication is still indicated, lower doses are needed if parental training is tried first.³²

Unanswered questions

Despite extensive research into factors contributing to ADHD aetiology, we are no closer to understanding the cause or causes of this disorder. Social factors such as political environment, education funding, and disability services may contribute to seeking a diagnosis of ADHD and are under-researched. Much research funding is funnelled into biomarkers and neurobiological causes of ADHD that have limited clinical value at present. Less emphasis is placed on methodologically sound trials comparing different treatment options that may provide helpful information, particularly about mechanisms of change, and for whom different interventions work best.

The broadening of the diagnostic criteria in DSM-5 is likely to increase what is already a significant concern about overdiagnosis. It risks resulting in a diagnosis of ADHD being regarded with scepticism to the harm of those with severe problems who unquestionably need sensitive, skilled specialist help and support.

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