Childhood ADHD: A Stepped Diagnosis Approach

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Since publication of DSM-IV in 1994, the prevalence of parent-reported diagnosed attention-deficit/hyperactivity disorder (ADHD) has tripled to more than 10% of children. Although it is hard to know for sure whether ADHD is overdiagnosed, underdiagnosed, or misdiagnosed, it is argued that ADHD is especially prone to diagnostic inflation and overdiagnosis. Therefore, we propose a model of stepped diagnosis for childhood ADHD, which may reduce overdiagnosis without risking undertreatment. Calling attention to stepped diagnosis and formalizing the steps may improve its application in clinical practice. (*Journal of Psychiatric Practice* **2014;20:169–177**)

KEY WORDS: attention-deficit/hyperactivity disorder (ADHD), overdiagnosis, undertreatment, stepped diagnosis

When DSM-IV was published in 1994, the prevalence of childhood attention-deficit/hyperactivity disorder (ADHD) in the United States was estimated at 3%–5% and the percentage of youth being treated for ADHD was assumed to be at most at the lower end of this prevalence range.[1–3] While a recent systematic review suggested that ADHD occurs in most cultures in about 5% of children,[4] in the United States, the prevalence of parent-reported diagnosed ADHD rose from 6.9% in 1997[5] to 7.8% in 2003,[6] to 9.5% in 2007,[7] and to 11% in 2011.[8] The increased rate of diagnosis of ADHD among girls contributed significantly to this upward trend.[9,10] This may be related to the fact that DSM-IV in 1994 re-introduced the inattentive subtype of ADHD, which—unlike DSM-III-R—allows for a diagnosis of ADHD even if hyperactive and impulsive behaviors are absent. Biederman et al.[11] found that girls are 2.2-fold more likely than boys to meet criteria for the inattentive subtype of ADHD.

ADHD is commonly treated with stimulants. Between 1987 and 1996 stimulant use jumped from 0.6% to 2.4% of American children.[12] In 2011, 3.5 million American childeren (6.1%) were taking medication, mostly stimulants, for ADHD.[8] Stimulants are prescribed for ADHD as well as for oppositional behaviors,[13] although stimulants are not the only drugs prescribed to children diagnosed with ADHD. For instance, atomoxetine (Strattera) is a non-stimulant treatment approved by the U.S. Food and Drug Administration (FDA) for ADHD. Following its introduction on the U.S. market, its share of total prescriptions for ADHD and other disorders rose to a peak of 17.3% in late 2004.[14] While use of the product as a monotherapy has been in a steady decline since that time, the use of atomoxetine in combination with other psychotropics—especially stimulants—has increased. In 2008, 1.2 million prescriptions for second generation antipsychotic medications were given to patients under 18 years of age, 12% of which were for the treatment of ADHD.[15] The concurrent use of antipsychotics and atomoxetine—a combination used primarily in children with ADHD and related behavioral problems—increased seven-fold in 2006 from 2005.[14] Although little is known about the safety and efficacy of concomitant use of two or more psychotropic agents in children and adolescents, psychotropic polypharmacy is becoming increasingly common in outpatient practice.[16,17]

Like its predecessors, minimal brain dysfunction[18] and hyperactivity syndrome,[19] the validity of the diagnostic concept of ADHD is disputed.[20] In individual cases, the diagnosis tells little about etiology,

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prognosis, and treatment response. As is the case for other psychiatric disorders, there is a paucity of practice-based assessments of clinical diagnoses in relation to research diagnostic interview-based diagnoses. Since there is no criterion standard—such as a blood test or brain scan—for the accurate diagnosis of ADHD,[21] it is impossible to know whether ADHD is overdiagnosed, underdiagnosed, or misdiagnosed. Evidence-based practice parameters[22,23] confer the greatest likelihood of "accurately" diagnosing ADHD in accordance with the established diagnostic criteria, but the ultimate judgment must be made by the individual clinician.[22]

Diagnostic inflation is an issue throughout psychiatry, and it is probably related to, among other things, problems in the delivery of health care services, (child) psychiatric training, and lack of competence among practitioners without ongoing quality (measurement-based) assurance for care. In this article, we first argue that ADHD is especially prone to diagnostic inflation and overdiagnosis. By the term "overdiagnosis," we are referring to unnecessary, avoidable diagnoses. Second, we discuss the risks of unnecessary diagnoses and overtreatment. Finally, we propose a model of stepped diagnosis, which may reduce overdiagnosis without risking undertreatment. The goal is to optimize allocation of scarce resources by giving each individual child and family as much treatment as needed, no more and no less.

WHY ADHD IS PRONE TO DIAGNOSTIC INFLATION

In DSM-5,[24] ADHD is defined as a neurodevelopmental disorder characterized by inattentive, impulsive, and hyperactive behaviors that cause significant impairment in social, academic, or occupational functioning. The behaviors should be present before the age of 12 years and in two or more settings (at school/work and at home). The behaviors should not occur exclusively during the course of schizophrenia or another psychotic disorder and should not be better explained by another mental disorder.

Classic severe cases of ADHD are obvious, but the diagnosis of ADHD merges imperceptibly into typical degrees of inattention, hyperactivity, and impulsivity. The behaviorally based DSM definition of ADHD is extensible. For example, all 18 behavior criteria include the word "often." However, how often is often remains unclear.

In psychiatry, the linkage between symptoms and functioning is rather weak,[25,26] and the DSM impairment criterion is an attempt to separate those who need clinical attention from the many others who display behaviors and emotions to an extent that may be annoying or distressing but not outside the typical range. This criterion is especially important when it comes to ADHD, since ADHD behaviors are common in the population but not inherently distressing.[27] Assessments of clinical impairment substantially decrease ADHD prevalence rates.[28–30]

However, the impairment criterion is hampered by two problems. First, an operational definition of clinically significant impairment is lacking in the DSM, leaving it to the individual clinician to decide how impairment should be assessed and when impairment is severe enough to diagnose a mental disorder. Second, it is difficult to know in individual cases whether impairment is the effect, cause, or concomitant of ADHD behaviors. It is often assumed that impairment is a consequence of inattention and hyperactivity, but impairment may also be the cause of it. A child with below average intelligence who does not understand his or her teachers' classroom instruction may consequently have difficulty focusing attention and start to daydream or fidget and squirm.

Because ADHD behaviors (without impairment) are common in the typical population and the DSM definitions of impairment and behavior criteria are vague and extensible, ADHD is especially vulnerable for diagnostic inflation. ADHD lends itself to being misused to justify pediatric psychiatric interventions to target aggression, irritability, and other related problems which do not easily cohere into a syndrome. In addition, although ADHD medication can improve the ability to concentrate in many individuals (not only those diagnosed with ADHD), a diagnosis of ADHD is generally seen as a precondition for the prescription of stimulants, perhaps further contributing to overdiagnosis.[31]

Last but not least, ADHD is prone to diagnostic inflation because it has an established medical treatment which makes it the target of promotion by drug companies. These companies sponsor research trials,[32] and they may engage experts to serve as consultants or to carry out that research, who may also serve as experts in the development of the DSM[33] or of practice guidelines.[34] Companies may also educate teachers about ADHD and medical treatment,[35] and they may influence public opinion via Internet web-

sites,[36] by hiring celebrities to increase awareness of ADHD,[37] and by supporting patient advocacy groups such as Children and Adults with Attention Deficit/Hyperactivity Disorder (CHADD[38]) in the United States and the National Attention Deficit Disorder Information and Support Service (ADDISS[39]) in the United Kingdom.

IS ADHD UNDERTREATED?

Since epidemiological studies, such as the National Health and Nutrition Examination Survey (NHANES[40]) and the National Comorbidity Survey Adolescent Supplement (NCS-A[41]), show that many children meeting ADHD criteria do not receive treatment, it could be argued that ADHD is still undertreated. However, one should bear in mind that for reasons of cost, such large studies are conducted using lay interviewers. Some experts question whether briefly trained lay interviewers are able to judge whether the symptoms they elicit are severe enough to cause clinically significant distress or impairment.[42] Hence, many of those not in treatment may have been false positives, misidentified by lay interviewers who do well at counting any listed symptom criteria but who do not have the experience to make judgments about clinical significance.

The possibility of methodological bias in these epidemiological studies could include exaggerated rates of mental disorders, perhaps leading doctors to overdiagnose and overtreat. In addition, pressure may come from parents looking for some kind of label in order to avoid the feeling that "I am to blame" for the child's troubles and perhaps in some way to obtain access to extra school services or other reimbursed help, such as medication to help their child achieve academically.

RISKS OF OVERDIAGNOSIS AND OVERTREATMENT

The prevalence of ADHD diagnoses is higher among children with health insurance.[43] Since insurance companies reimburse treatments for confirmed diagnoses, an ADHD label opens the door to treatment and to special education services at school. However, the label also risks negative outcomes for a child:[44] negative parental and teacher expectations which may lead to underperformance via the self-fulfilling prophecy, stigmatization, low self-esteem and self-efficacy, and difficulties in getting insurance or jobs. In addition, a label may create the false impression that we understand the problem and have to look no further, thereby missing opportunities for interventions in the living conditions of the child.

Medication for ADHD, although beneficial in the short term, is often accompanied by side effects such as loss of appetite and insomnia.[45] In addition, the long-term safety of these drugs is still not known.[46,47] For example, a recent intensive pharmacosurveillance study identified some unexpected adverse reactions to medications used to treat ADHD, such as weight gain, hepatotoxicity, suicidal ideation, and drug interactions.[48] Last, but not least, a disadvantage of treating child behavior problems with medication is that parents, teachers, and children may have less opportunity to learn to cope with a specific type of behavior: pills don't teach skills. Jumping to medication may reflect biological reductionism, which, in this case, implies that any atypical behavior is the result of brain dysfunction. Medication can be an easy way of dealing with child behavior problems, and once people have become acquainted with this easy way, it becomes harder to work on coping strategies that are time and energy consuming.

FALSE POSITIVES AND FALSE NEGATIVES

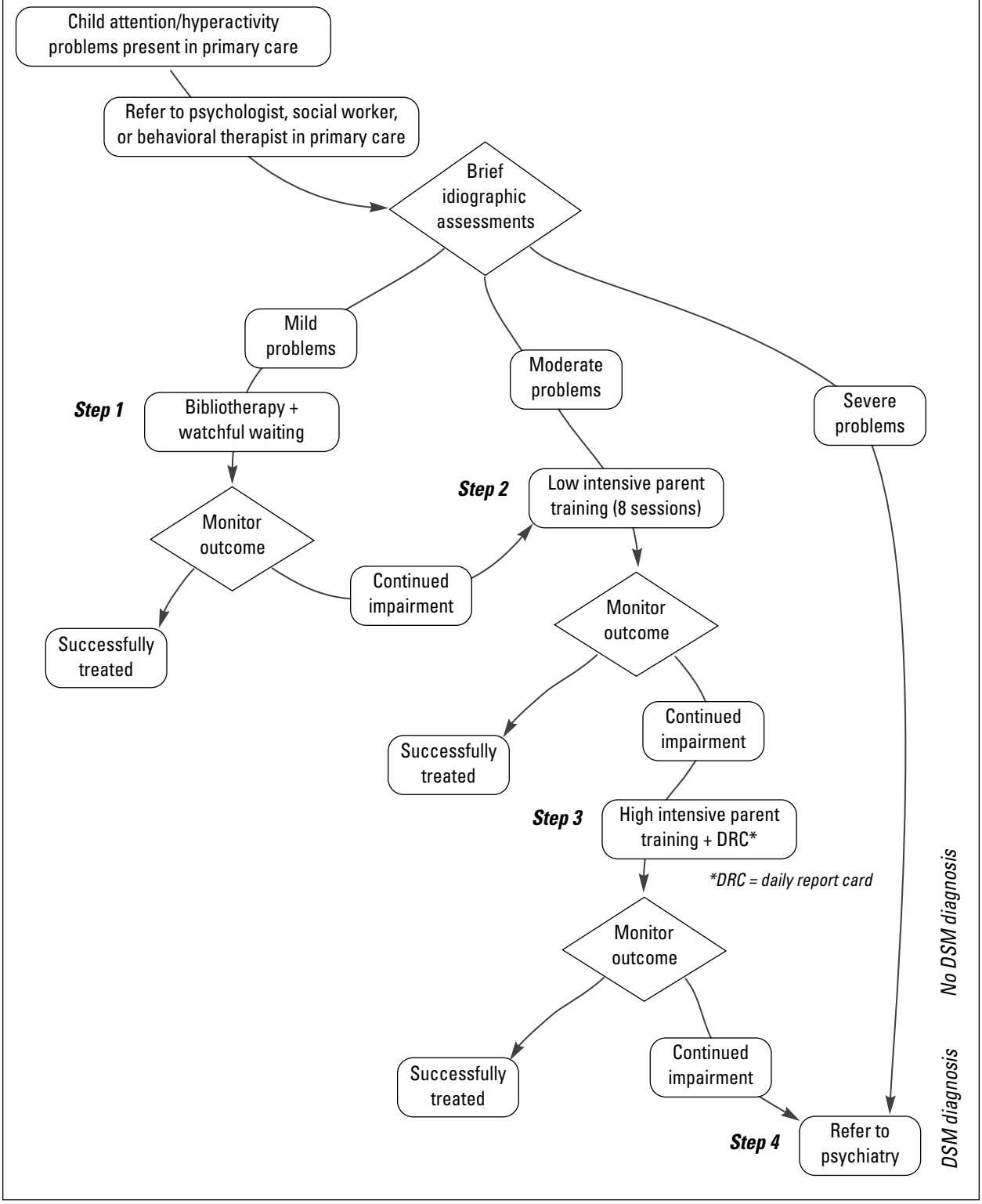
For the reasons discussed above, it seems important to avoid "false positives" whenever possible. However, every reduction in false positives may lead to an increase in false negatives, implying that children who would truly benefit from diagnosis and treatment are missed. We propose an approach for dealing with hyperactive and inattentive child behaviors that may reduce overdiagnosis without risking undertreatment and takes into consideration possible social dimensions of the problem behavior. This approach is outlined in Figure 1 and is discussed in the next section.

STEPPED CARE AND STEPPED DIAGNOSIS

Stepped Care

Stepped care is a model of healthcare delivery in which the first-line treatment is the least intensive of those currently available but is still likely to provide significant health gain.[49] More intensive and expensive treatments are reserved for those who do

Figure 1. A stepped diagnosis approach for childhood ADHD



not benefit from simpler first-line treatments. Continuous assessments of results of treatment and the condition of clients are crucial for stepped care, and changes should be made ("stepping up") if an intervention is not achieving significant health gain.

Stepped care is particularly feasible for less severe cases. If circumstances are urgent or child behavior is severely disturbed (for example, if parents report they can't handle the child one day longer because of his extreme behavior or that the "impairment" is so severe that the child's functioning at home and at school is imminently imperiled), early intensive treatment is required because, in these situations, intensive treatment is more clinically effective and cost-effective than a minimal intervention.[49] In cases of mild, sudden, and/or reactive child behavior problems (for example, parents report that concentration and hyperactivity became a problem after their divorce a few months ago), primary care clinicians could start with a minimal intervention in combination with watchful waiting (step 1). Examples of minimal interventions are bibliotherapy (e.g., the book *Incredible Years* by Webster-Stratton[50]), referral to a help line for parents, or one or two sessions with a counselor or a community social worker. Watchful waiting is defined as "assessment with scheduled follow-up in primary care but no active medication or psychotherapy treatment."[51] Watchful waiting requires careful monitoring of problems, for example, weekly telephone calls by the practitioner in charge of the case. If child behavior problems persist or worsen within a period of 2 months, or in cases of moderately severe behavior problems at the first visit, an evidence-based but low-intensity psychosocial intervention (e.g., 8 weekly group parent training sessions[52]) may be implemented (step 2). Substantial evidence indicates that parent management training is helpful in reducing ADHD problems in children.[53] More intensive family therapy (step 3), if desired, supplemented with teacher-implemented Daily Report Cards[54] (DRC), might be effective for those children who benefit insufficiently from the previous steps.

Stimulant medication is often considered a first-line treatment for ADHD in children.[22,23] In our view, pharmaceutical treatments should be saved as a last resort in the treatment of less severe cases (step 4), in which psychosocial interventions are a worthy alternative. According to recent figures from the U.S. Centers for Disease Control,[7] most children diagnosed with ADHD have mild (46.7%) or moderate (39.5%) problems. Fewer than 14% have severe ADHD. Watchful waiting (including minimal interventions) and evidence-based parent training as first-line treatments may reduce the number of medicated children and lower medication doses in those for whom parent training is insufficient and additional pharmaceutical treatment is warranted.[52] In cases where these steps prove insufficient, pharmaceutical interventions could be considered.

Stepped Diagnosis

Stepped care could be combined with stepped diagnosis. A full diagnostic process requires both classification and explanatory hypotheses of problems.[55] A DSM classification requires grouping of a patient's identified problematic experiences and behaviors. Besides listing and classifying symptoms, a diagnosis requires individualized therapeutic analyses to identify causal and sustaining factors. While classification allows the search for proven effective interventions, explanatory diagnoses ultimately provide the key targets for treatment tailored to the individual or family.[56] In cases of multiple problems (comorbidity) functional analyses will reveal which problem should be the first focus of treatment.

Parent training does not require a psychiatric classification in order to be effective. Some experts have argued that personalized (idiographic) approaches are much more useful than classifications of problems.[57,58] In targeting specific behavioral problems, a therapist aims to identify factors that cause or maintain these problems in a child and his or her family. If, for example, a child's regular tantrums are the main problem, a therapist aims to identify factors that cause or maintain these tantrums. Such factors may include a child's difficulties dealing with unexpected events, manipulation by the child, his or her excess energy (or lack of opportunities to channel it), or a reaction to tensions between the parents. The first will be seen more frequently in children classified as having pervasive developmental disorder not otherwise specified (PDD-NOS), the second with those classified as having oppositional defiant disorder (ODD), the third with those classified as having ADHD, and the fourth with children in troubled families. Of course, this is a simplified presentation. Some children classified as having ODD find it hard to deal with unexpected events, and some children

classified as ADHD use tantrums to get their way. In addition, comorbidity is the rule rather than the exception in psychiatry in general.[59] In clinical practice, the specific intervention will depend more on the function of the behavior of the individual child than on his or her DSM classification. We conclude that a diagnostic label is not an inevitable prerequisite for effective intervention. Solution-focused therapy is an example of an effective behavioral treatment that does not require a specific diagnosis.[60,61]

In light of this view, we not only advocate a stepped care approach in helping families who are dealing with child behavior problems, we also recommend a stepped diagnosis approach. This means that watchful waiting (step 1) and psychosocial interventions (step 2 and step 3) start without a classifying label. When presented with mild to moderate attention and hyperactivity problems in a child, a general practitioner or primary care clinician might speak in terms of "behavior problems," "difficult temperament," or "pedagogical difficulties," actively avoiding terms such as "ADHD" or "bipolar." He or she could refer the patient to a psychologist or a behavioral therapist working in primary care. This therapist assesses the severity of the problems and decides to watchfully wait or to start a short evidence-based parent management training, if necessary, followed by a more intensive behavioral treatment. Elaborate diagnostics, including psychiatric classification, is averted and the behavioral therapist formulates idiographic functional explanations of the behavior and misbehavior. Only in cases in which this proves insufficient would the child be referred to psychiatry (step 4) for elaborate assessment and—if appropriate—pharmacological treatment.

Advantages of Combined Stepped Care and Stepped Diagnosis

An approach involving a combination of stepped care and stepped diagnosis has several potential advantages. First, it may reduce the number of children incorrectly diagnosed with a psychiatric disorder. Children who improve enough with a behavioral intervention without a classifying label benefit from treatment without having to bear the negative consequences of a label. Second, children who do need a psychiatric diagnosis and psychiatric treatment are not missed. Better resource allocation may especially benefit children with severe problems in impoverished, under-resourced communities, in which underdiagnosis may be a problem. Third, since, in less severe cases, unnecessary and expensive diagnostic procedures are averted, time and money will be saved. Fourth, some research has suggested that many people choose not to pursue mental health services because they want to avoid a diagnostic label.[62] The provision of specialized help without a confirmed diagnosis may lower the threshold for children and families to receive help that may benefit them. Fifth, since a confirmed psychiatric classification is not a component of the first three steps of the stepped diagnosis approach, children who are impaired but do not meet DSM criteria for ADHD are not deprived of help for their problems. Finally, sixth, problems with inter-rater reliability regarding the assessment of impairment are minimized. Classic severe cases of ADHD are obvious and inter-rater reliability will be high. In severe cases, most practitioners will go to step 4 of the stepped diagnosis model immediately. Reliability problems emerge in mild and moderate cases, in the grey area between typical and severely impairing degrees of inattention, hyperactivity, and impulsivity. The difference between mild and moderate problems is less important in the model, since, in both instances, the practitioner will go to step 2.

Problems of Combined Stepped Care and Stepped Diagnosis

First, when presented with child behavior problems, health care providers might hesitate to "wait and watch." Experts tend to worry the most about missing a case that should be treated, and much less about false positives,[63] given that they may be held responsible for the negative consequences of undertreatment.[64] This is exactly why weekly monitoring, during watchful waiting, mostly by telephone, is important in a stepped care and stepped diagnosis approach.

Second, a stepped approach may also delay appropriate pharmaceutical treatment in those children for whom parent training and other forms of psychosocial help are not sufficiently helpful. Therefore, a stepped care approach is not feasible for severe and urgent cases. However, the majority of cases with ADHD have mild or moderate problems.[7] In addition, establishing a DSM diagnosis does not automatically imply knowing what treatment is optimal.

Pure classifications are the exception rather than rule,[59,65] while lack of treatment specificity is the rule rather than the exception.[66] However, the question may remain whether the possible harm involved in a delay in pharmaceutical treatment outweighs the benefit of avoiding taking this path too quickly. Nevertheless, given that medication is often prescribed to children without their consent,[67] and that the long-term safety of most pharmaceuticals for children is not known, we suggest the practice of prescribing medication to children in less severe cases should be the last option after behavioral interventions have turned out to be insufficiently helpful.

A third problem with stepped diagnosis is that, in most countries, the only way to obtain funding for behavioral and other treatment is through a formal diagnosis. This may have promoted the "search for pathology"[68] in less severe cases, thereby leading to expensive expert hours being spent on diagnostic procedures that are not really needed.

CONCLUSION

With our double stepped approach, we suggest postponing psychiatric classification until it has been shown that psychosocial interventions are insufficiently successful. Avoiding expensive and unnecessary diagnostic processes will reduce the societal costs of childhood psychiatric disorders. It may also spare many children the burden of a diagnostic label, without risking undertreatment of children and families with more extensive needs.

Our proposal is in line with the United Kingdom's National Institute of Health and Clinical Excellence (NICE) ADHD guideline, which advocates a cautious and stepped care approach and access to interventions at the primary care level within the community at a pre-diagnostic stage.[69] However, the current high levels of diagnosis and medication use indicate that stepped care and stepped diagnosis may be underutilized. Calling attention to stepped diagnosis and formalizing the steps (Figure 1) may greatly improve its application in clinical practice.

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