PERSPECTIVE

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Editor's Choice

Children's behaviour problems: a NICE mess

The potential harms of medicalisation are well known. A good illustration comes from the medicalisation of children's behaviour problems. National Institute for health and Clinical Excellence (NICE) guidelines on conditions such as Attention Deficit Hyperactivity Disorder (ADHD), Autistic Spectrum Disorder (ASD) and Conduct Disorder (CD) reflect how attempts to regulate medical practice in this area has spawned guidelines based more on wish fulfilment (that getting kids to behave themselves can be accomplished by simple technological interventions that exist independent of context) than scientific evidence. In this perspective piece, I explain why these NICE guidelines are more a reflection of cultural confusion about how to deal with children, than the outcome of sound scientific understanding in this area.

NICE guidelines on ADHD

The NICE Quick Reference Guide on ADHD doesn't mention any concern or controversy over the concept of ADHD. The Full Guideline (which few will read) however has a more in-depth examination of validity (1). They assess validity by the following criteria: whether symptoms of ADHD cluster together; are distinguishable from normal variation and other psychiatric conditions; that symptoms are associated with significant impairments; that there is a characteristic temporal pattern and outcome; and that there is consistent evidence of genetic, environmental or neurobiological risk factors. While the guideline group avoided tackling more notable controversies associated with the diagnosis such as gender, social class and ethnicity distributions; it is hard to understand how it was decided that ADHD met the standards they identified.

With each of the criteria, it takes a leap of faith to conclude that the available evidence supports it. For example, on the question of whether ADHD can be distinguished from normal variation, they conclude 'Most analytic approaches are unable to make a clear distinction between the diagnosis of ADHD and the continuous distribution of ADHD symptoms in the general population' (1, p. 104). On genes, they conclude 'As with all other types of risk factors associated with ADHD, the individual genetic variants associated with the disorder are neither sufficient nor necessary to cause it.' (1, p. 111). With neuroimaging studies they note the lack of consistent findings. They also find a positive association with a large number of familial and environmental adversity indicators. Little evidence is offered that any of the identified weak associated factors are specific to ADHD (as opposed to say conduct disorder) suggesting that if just about everything causes ADHD, then in fact we know nothing about what causes it.

NICE guideline for ADHD, ASD, and Conduct Disorder based on fantasy not fact

NICE really departs from the evidence base when it comes to finding support for using stimulant medication as a first line treatment. The review of pharmacotherapy studies notes the inadequate reporting of drug trial methodology, publication bias, limited reliability of results, inadequate data regarding adverse events and lack of evidence of long term benefit, concluding that the evidence does not support using medication as a first line treatment for 'mild or moderate' ADHD. However, they also conclude that medication should be offered as a first line treatment in 'severe' ADHD with only one reference cited in support of this (2), which concluded that in a 14 month Randomised Controlled Trial, the more severe subgroup showed a larger decrease in symptoms from medication compared with behaviour therapy. Yet, a 36 month follow-up of the same patients, could not find support for continuing beneficial effects of medication over behaviour therapy, regardless of initial severity (3). Other naturalistic studies have come to similar conclusions finding that medication offers little prospect of improving long-term outcomes (e.g. 4). It seems that a 'get out clause' that allows clinicians to categorise the problems as 'severe' was needed to enable existing practice to be maintained irrespective of what evidence was found.

NICE and autism

With regards ASD, NICE guidelines encourages earlier recognition, which is likely to lead to a continuing increase in the numbers diagnosed with an ASD (5). This guideline does not consider evidence on the validity of the diagnosis, assuming its validity is a given. A diagnosis that is believed to be biologically driven and lifelong is clearly at risk of causing significant harm through the negative impact of these

assumptions on perceived competence, particularly if there are no objective findings to validate such a construct and no specific treatments available. The numbers are considerable as prevalence has expanded from 4 per 10,000 to 160 per 10,000 in just 4 decades – an over 3500% increase – but this impressive expansion has not come about through any new scientific discovery (6).

Although it is assumed that ASD must be genetic, thus far molecular genetic studies including whole genome scans, have found evidence for a non-significant proportion of the assumed total genetic risk with these small genetic associations being heterogeneous, crossing psychiatric diagnostic boundaries and more strongly related to learning difficulties than a diagnosis of ASD per say. Thus, recent reviews of the genetic research in ASD published in Nature concluded, 'Many research teams have searched for genes that may be involved. They have not turned up any prime candidates yet, only dozens, maybe hundreds of bit players' (7, S2) and 'Genome Wide Association Studies have failed to turn up any parts of the genome with statistical significance' (8, S5).

Similarly autism neuroimaging studies have been plagued by heterogeneity issues resulting in a characteristic lack of consistently replicated findings with new theories regularly arriving and then departing. For example, studies focussing on the cerebellum have documented larger than average, smaller than average and no difference in cerebellar volume among children diagnosed with ASD compared with controls (6).

There is also no evidence of methodologically sound and replicated research that demonstrates that particular interventions (whether educational, psychological, social or physical) specifically and differentially help those who have any form of autism (when compared with other children with behaviour or learning problems). Until specific treatments for ASD are adequately demonstrated through replicated controlled trials, we cannot and should not assume that the diagnosis has clinical value, at least in terms of treatment implications (6).

With regards prognosis, the same behaviourally defined syndrome (ASD) is applied to residents of institutions with little hope of living independently and has been suggested for men who have achieved greatness (such as Mozart, Van Gogh, Einstein, Edison and Darwin). From an 'impairment' perspective, this is virtually the entire human spectrum, suggesting ASD, as it is defined, is too heterogeneous to have prognostic value. Not surprisingly recent prospective studies have shown remarkably diverse outcomes, with many who have been diagnosed with an ASD in childhood reportedly having little or no symptoms by adulthood (9).

NICE and conduct disorders

Having painstakingly tried to avoid the possibility that ADHD or ASD could be thought of as being connected with adverse environmental experiences, when it comes to CD, the reverse is true. CD, we are told in the summary guide is associated with a greater likelihood of the child experiencing harsh and inconsistent parenting, parental mental health problems, environmental factors such as poverty and being looked after, and individual factors such as low educational attainment and other mental health problems. The treatment recommendations thus focus on parent training programmes and other systemic interventions (10).

There is a worrying recommendation of using Risperidone off licence despite the poor evidence base for efficacy and the considerable health risks associated with it, but essentially we are left with no doubt that unlike ADHD and ASD, CD is the result of poor environments. The solutions offered remain technical in nature, involving the usual tendency to give lip service to taking account of diversity, followed by recommending structured one-size fit all programmes.

Behaviour problems are not NICE compliant

A major dilemma for guideline developers is how to translate the considerable uncertainties in the evidence, often found in the full guideline, into workable recommendations. Rather than reflecting these uncertainties, the three NICE quick reference guides referred to above convey the false impression that children presenting with behaviour problems can be accurately categorised and from there a correct (and one-dimensional) process for stopping deviant behaviour can emerge. Sadly or gladly (depending on your perspective), in the real world children's behaviour does not emerge out of predictable algorithms that enable us to accurately identify separate features caused by genes, parents, teachers etc., which then allows us to choose the 'correct' treatment. None of our medications treat a known biological abnormality and none have been shown to improve long-term outcomes. Furthermore, much evidence suggests that for mental health problems matching treatment model to diagnosis has a negligible impact on outcomes including with children and young people. Personally, I think it is wonderful that the uniqueness of the children and families I see in practice, challenges me to take the time to understand their specific worries, health problems, goals, dreams and talents, in a way that makes formulaic guidelines

seem, not only redundant but also a hindrance to enacting the standards of good medical practice expected of us. If child psychiatry has anything to teach the rest of medicine, it is surely this – that for many presentations there is no shortcut to understand the whole person through their unique context – good outcomes often depend on this.

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Disclosure

None.

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