Autism and mental illness in children and young people require standardised approaches for assessment and treatment

Alvina G. Lai, Wai Hoong Chang, and David Skuse

Institute of Health Informatics, University College London, London, UK
Great Ormond Street Institute of Child Health, University College London, London, UK

Autism spectrum disorder (ASD) is a neurodevelopmental condition characterised by heterogeneous behavioural and communication impairments that affect an individual’s adaptive function. Once thought to be an uncommon condition, autism now affects at least one in 160 children worldwide, according to the World Health Organisation. Children with ASD have substantial medical, social, and educational needs. In Ireland, the annual cost to families of caring for a child with ASD is estimated to be €28,000 with an additional annual state expenditure of €14,000. These figures, while startling, fail to capture other hidden costs of ASD on children and their families, especially concerning additional demands from co-occurring conditions such as anxiety and depression.

The range of clinically significant mental health problems associated with ASD was not well appreciated until the past decade. This was largely because ‘autism’ was usually diagnosed among children with poor verbal skills who had a limited capacity to describe their own emotional states. The revised definitions in Diagnostic and Statistical Manual of Mental Disorders (DSM-5) initiated both a recognition that ‘high functioning’ children were not a separate category and gave permission to clinicians to formally record the co-diagnosis of other mental health disorders. Since then, provision of care for associated conditions has grown in importance. For instance, the UK National Institute for Health and Care Excellence (NICE) guidelines recommend an assessment is made for depression and anxiety in children with ASD. However, both the detection and management of emotional disorders in children on the autism spectrum are challenging, and modifications need to be made to conventional practice. NICE recommends employing a conversational and active listening approach to permit the identification of depression in typically developing conditions such as anxiety and depression.

The range of clinically significant mental health problems associated with ASD was not well appreciated until the past decade. This was largely because ‘autism’ was usually diagnosed among children with poor verbal skills who had a limited capacity to describe their own emotional states. The revised definitions in Diagnostic and Statistical Manual of Mental Disorders (DSM-5) initiated both a recognition that ‘high functioning’ children were not a separate category and gave permission to clinicians to formally record the co-diagnosis of other mental health disorders. Since then, provision of care for associated conditions has grown in importance. For instance, the UK National Institute for Health and Care Excellence (NICE) guidelines recommend an assessment is made for depression and anxiety in children with ASD. However, both the detection and management of emotional disorders in children on the autism spectrum are challenging, and modifications need to be made to conventional practice. NICE recommends employing a conversational and active listening approach to permit the identification of depression in typically developing children. Those on the autism spectrum often have difficulty identifying their own emotions, and may instead display symptoms of aggression, compulsiveness, and irritability; they lack the capacity to describe feelings such as anticipatory anxiety or low mood. Self-harm is an increasingly frequent response to such frustrations in adolescents with ASD.

A meta-analysis found that almost 40% of young people with ASD have at least one anxiety disorder. In the USA, psychotropic medication is often used, despite limited evidence on its efficacy. A Cochrane review on tricyclic antidepressants in ASD cautioned against their use due to conflicting evidence on efficacy and side effects. Another Cochrane review on selective serotonin reuptake inhibitors from five randomised controlled trials (RCTs) that involved children found no evidence of effectiveness but emerging evidence of harm. A 2021 systematic review on 13 RCTs on antidepressants and two on anxiolytics observed contradictory results on efficacy; their meta-analysis demonstrated no significant inter-group difference between the placebo and antidepressants in children. An alternative approach, cognitive-behavioural therapy (CBT), can be effective but requires modification for those with ASD.

Given the lack of a standardised approach for assessing and treating anxiety and depression in children with ASD, the US-based ATN/Autism Intervention Research Network on Physical Health Anxiety Workgroup developed five recommendations for the assessment of anxiety and four recommendations for treatment that may serve as a starting point. As in the UK nowadays, most children with ASD are seen initially by paediatricians. The Workgroup recommended that assessment of anxiety in youths with ASD should involve the following: (1) conduct a developmentally appropriate multi-method assessment; (2) evaluate anxiety symptoms related to the core features of ASD; (3) assess and treat other comorbid conditions that may exacerbate anxiety; (4) address suboptimal behaviour and stressors that may contribute to anxiety; (5) evaluate the degree of anxiety-related impairment. In terms of treatment, four recommendations were proposed: (1) psychoeducation and coordination of care; (2) employ modified CBT techniques; (3) consider medication but start with low doses;
(4) refer to a child psychiatrist if the child is not responding to interventions. A national clinical guideline by the Healthcare Improvement Scotland also considered the use of CBT with the following adaptations: (1) a structured approach with the use of visual information, (2) avoid the use of ambiguous language, and (3) incorporate special interests of the individual into therapy, such as the use of computers.

A major problem with interpreting the implications of trials of medication in people with ASD is the heterogeneity of the participants entering the RCTs. The sources of heterogeneity are rarely discussed, in terms of their relevance to the interpretation of outcomes. First, there is typically a very wide range of IQ with a bias toward individuals with learning disabilities (IDD). The proportion of specific genetic anomalies associated with ASD is substantially greater in the IDD population. Second, a wide age range may extend to both children and adults. Third, there is usually a substantial preponderance of males, reflecting a bias in ascertainment. All these factors could influence outcomes, and the interpretation of poorly designed RCTs in such a complex neurodevelopmental disorder is (to say the least) problematic.

To conclude, this article underscores an urgent need to develop methodologies for the formal recording of heterogeneity in the recognition, assessment, and treatment of anxiety and depression in children with ASD. Overall, few treatments are thought to be effective and we need to develop better ways of identifying ‘what works for whom’: a goal of personalised medicine. Further research investigating the provision of psychiatric services and the diagnostic and prescribing trends are required, alongside better designed RCTs.10

Declaration of interests
None declared.

Author contribution
AGL wrote the initial draft. WHC performed literature searches. AGL and DS revised and finalised the Comment.

References
1 Roddy A, O’Neill C. The economic costs and its predictors for childhood autism spectrum disorders in Ireland: How is the burden distributed? Autism. 2010;14:1106–1118.
2 National Institute for Health and Care Excellence. Depression in children and young people: identification and management. https://www.nice.org.uk/guidance/ng144/chapter/Recommendations. NICE guideline [NG144]. Published: 25 June 2019.
3 Van Steensel FJA, Bögels SM, Perrin S. Anxiety disorders in children and adolescents with autistic spectrum disorders: a meta-analysis. Clin Child Fam Psychol Rev. 2011;14:302–317.
4 Spencer D, et al. Psychotropic medication use and polypharmacy in children with autism spectrum disorders. Pediatrics. 2013;132:831–840.
5 Hurwitz R, Blackmore R, Hazell P, Williams K, Woolfenden S. Tricyclic antidepressants for autism spectrum disorders (ASD) in children and adolescents. Cochrane Database Syst Rev. 2012;3:CD008372. https://doi.org/10.1002/14651858.CD008372.pub2.
6 Williams K, Brignell A, Randall M, Silove N, Hazell P. Selective serotonin reuptake inhibitors (SSRIs) for autism spectrum disorders (ASD). Cochrane Database Syst Rev. 2013;8:CD004677. https://doi.org/10.1002/14651858.CD004677.pub3.
7 Deb S, et al. Randomised controlled trials of antidepressant and anti-anxiety medications for people with autism spectrum disorder: systematic review and meta-analysis. BJPsych Open. 2021;7:e179. https://doi.org/10.1192/bjo.2021.1003.
8 Vasa RA, et al. A systematic review of treatments for anxiety in youth with autism spectrum disorders. J Autism Dev Disord. 2014;44:1215–1229.
9 Vasa RA, et al. Assessment and treatment of anxiety in youth with autism spectrum disorders. Pediatrics. 2015;135:S115–S125.
10 Collins R, Bowman I, Landray M, Peto R. The magic of randomization versus the myth of real-world evidence. N Engl J Med. 2020;382:674–678.