Epidemiology and Psychiatric Sciences

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Editorial

Cite this article: McLaren JL, Lichtenstein JD (2019). The pursuit of the magic pill: the overuse of psychotropic medications in children with intellectual and developmental disabilities in the USA. *Epidemiology and Psychiatric Sciences* **28**, 365–368. https://doi.org/10.1017/S2045796018000604

Received: 14 September 2018
Accepted: 28 September 2018
First published online: 24 October 2018

Key words:
Autism; child psychiatry; evidence-based psychiatry; psychotropic drugs

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CAMBRIDGE UNIVERSITY PRESS

The pursuit of the magic pill: the overuse of psychotropic medications in children with intellectual and developmental disabilities in the USA

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Abstract

Children with intellectual and developmental disabilities (IDD) are likely to receive high-risk prescribing practices, such as polypharmacy, long-term use of psychotropic medications, and overuse of antipsychotics. Behavioural interventions, such as applied behavioural analysis, are evidence-based practices for children with IDD and should be the first-line treatment. Short-term use of psychotropic medications may be helpful in reducing the severity and frequency of challenging behaviours while evidence-based behavioural interventions are pursued. In this essay, we offer practical guidelines for better care.

Introduction

'Do no harm' is the most basic principle of medical ethics. Yet, following this principle when treating children with intellectual and developmental disabilities (IDD) presents an enormous challenge. Consider these examples from our clinical practice:

A male child with autism had been through 26 different psychotropic medication trials, gained 100 pounds, and developed type II diabetes mellitus, yet had no significant improvement in his challenging behaviours.

A female child with intellectual disability experienced significant sedation on five different psychotropic medications. She struggled to stay awake in school, was not making educational gains and did not learn self-care skills for many years. Once being tapered off some of her psychotropic medications, she experienced a decrease in sedation and started to make educational and functional gains.

According to the International Association of Child and Adolescent Psychiatry and Allied Professionals (IACAPAP), children with IDD are one of the most 'disadvantaged groups in most countries' (Ke and Liu, 2012). Vulnerability to harmful interventions occurs for several reasons. These children are often unable to communicate their experiences, pains and wishes. Their behaviours often bewilder and vex parents and other caregivers. Few healthcare professionals have the specialised training, expertise and skills to assess and treat them effectively (World Health Organization, 2018). Finally, children with IDD are involved with multiple, poorly integrated service systems, which leads to fragmented, inconsistent care and a limited understanding of how the child is functioning in different environments.

As illustrated above, well-meaning caregivers and providers hope that psychotropic medications will be a 'magic pill', but the evidence does not support these expectations. Instead, children with IDD are likely to receive high-risk prescribing practices, such as polypharmacy, long-term use of psychotropic medications and overuse of antipsychotics. In this essay, we explain the dilemma and offer practical guidelines for better care.

The challenge

The overall prevalence of IDD in children is about 7% in the USA: 2.8% of children with autism, 1.1% with intellectual disability and 4.6% with other developmental delays (Zablotsky *et al.*, 2017). Children with IDD suffer many stressors: they are marginalised, stigmatised, abused and bullied. They experience high rates of trauma, fourfold greater than those without IDD (Sullivan and Knutson, 2000). The rate of co-occurring psychiatric diagnosis in children with IDD is 40%, with high prevalence rates of depression, anxiety and attention-deficit/hyperactivity disorder (Leyfer *et al.*, 2006; Munir, 2016).

Challenging behaviour in individuals with IDD has been defined as 'culturally abnormal behavior(s) of such intensity, frequency or duration that the physical safety of the person or

others is likely to be placed in serious jeopardy, or behavior which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities' (Emerson *et al.*, 2001). Challenging behaviours consist of verbal aggression, physical aggression, sexual aggression, self-injury, property destruction or severe non-compliance. Such behaviour affects the child and family's quality of life and may lead to more restrictive and expensive care. Children with challenging behaviours experience unintended consequences including rejection by peers and caregivers, reduced access to education, decreased social interactions, exclusion from community settings, exposure to restraints and serious side effects of psychotropic medications.

The prevalence of challenging behaviours in children with IDD varies widely across studies, populations and settings. Overall, about 10–15% of children with IDD in England exhibit challenging behaviours (Emerson *et al.*, 2001). The rates are higher in those with more disabilities, overall lower functioning, communication deficits, sleep difficulties, gastrointestinal problems and challenges in social functioning (McClintock *et al.*, 2003; Mazurek *et al.*, 2013; Mazurek and Sohl, 2016).

Interventions

Numerous studies and practice guidelines, including those from Autism Speaks, the American Association of Intellectual and Developmental Disabilities (AAIDD), Cochrane Library, and the National Institute of Health and Care Excellence (NICE), have recommended behavioural interventions as the first-line treatment for challenging behaviours in children with IDD. A clear consensus has arisen that psychotropic medications should not be utilised as the sole treatment modality. The AAIDD issued a position statement regarding management of challenging behaviour stating, 'People with developmental disabilities and those who support them must have access to positive behavioral supports that focus on improved quality of life as well as reductions in the behaviors' (American Association of Intellectual and Developmental Disabilities and The Arc, 2015).

Behavioural interventions, in particular applied behavioural analysis (ABA), have a 'preponderance to conclusive evidence' in reducing challenging behaviours in individuals with IDD (Didden *et al.*, 2006; Roth *et al.*, 2014). The components of ABA include the following: functional behavioural assessment, reinforcement strategies and functional communication training (Fitzpatrick *et al.*, 2016). Functional behavioural assessment carefully evaluates the child's challenging behaviour including the antecedents and the consequences that maintain the challenging behaviour and is the basis of a behavioural plan; reinforcement strategies teach adults how to reward desirable behaviours and how/when to ignore challenging behaviours; functional communication training teaches children how to properly make requests (Fitzpatrick *et al.*, 2016). Researchers have studied each of these components of ABA and found them to be evidence-based treatments for challenging behaviours (Roth *et al.*, 2014; Wong *et al.*, 2015; Fitzpatrick *et al.*, 2016).

Behavioural interventions are not easy implement. They require a significant amount of change on the part of the caregiver and others involved in the child's life (school supports, after-school programmes and so on). An unfortunate truism of behavioural interventions is behaviours usually get worse before they get better, which can be difficult for caregivers and schools. Another barrier is limited access to well-trained behavioural specialists within the public mental health sector. This confluence sets up families and providers to seek an easier solution, such as a psychotropic medication as the magic pill.

Behavioural interventions remain the first-line therapy for challenging behaviours; however, psychotropic medications are appropriate for some children with co-occurring mental health diagnoses and IDD. Risperidone and aripiprazole have been (FDA) approved in the USA to treat irritability associated with autism (Warren *et al.*, 2011). Risperidone and aripiprazole show a moderate-to-large effect in decreasing irritability and aggression in children with autism spectrum disorders for short-term treatment (McLaren *et al.*, 2018). Antipsychotics are more often prescribed to children with IDD than children without IDD; specifically, children with autism have the highest rates of antipsychotic treatment of all children (Brophy *et al.*, 2018). However, antipsychotics have not been well studied for long-term treatment in children with or without IDD.

The majority of studies on psychotropic medications in children with IDD only follow outcomes for a short period of time (e.g. 8–12 weeks). Yet in real-world settings, children remain on these medications for years. We do not know the long-term efficacy of these medications or how long-term use of psychotropic medications affects the developing child's cognitive functioning, endocrine system, growth and behaviour.

Children with IDD are more sensitive to the side effects of psychotropic medications. For example, 18% of children with autism experience irritability on stimulants (Research Units on Pediatric Psychopharmacology Autism Network, 2005) compared with 2–4% of typically developing children (Jensen, 1999). Clinical trials show psychotropic medications reduce challenging behaviours in children with autism, but also cause increased rates of adverse events such as somnolence, upper respiratory infection, and increased appetite and weight gain (McCracken *et al.*, 2002; Marcus *et al.*, 2011). A multi-site, placebo-controlled, randomised trial of citalopram in children with autism showed an increase in adverse events in the citalopram group including increases in energy, hyperactivity and impulsivity (King *et al.*, 2009). A cohort study of Welsh children prescribed antipsychotics, found elevated rates of post-intervention respiratory disease, epilepsy and diabetes. Further, this study demonstrated that among children prescribed antipsychotics, those with lower intellectual functioning or autism experienced higher rates of physical injuries and hospitalisations for depression compared with children without intellectual disability or autism (Brophy *et al.*, 2018). Finally, many children with IDD are unable to effectively communicate their side effect symptoms verbally. Instead, they express their discomfort in other ways, often through their behaviour and/or a worsening of challenging behaviours.

Children with IDD often receive numerous psychotropic medications with high rates of long-term use, polypharmacy and off-label use, typically in the absence of adjunctive behavioural interventions (McLaren *et al.*, 2018). A recent study of more than 5000 children with autism noted that one-third of those receiving antipsychotics were not receiving behavioural interventions (Lake *et al.*, 2017). Polypharmacy in children with IDD is also common. Children often receive one medication with some benefit, but when the effect wears off, another medication is added and so on and so on. A study of commercially insured children with autism spectrum disorders revealed that 35% received two or more psychotropic medications, 15% received three or more psychotropic medications, 34% of those under a year of age received psychotropic medications, including 10% treated with more than one psychotropic medication (Spencer *et al.*, 2013). There is no research evidence to support polypharmacy in children with IDD.

https://doi.org/10.1017/S2045796018000604 Published online by Cambridge University Press

The inappropriate use of psychotropic medication extends beyond the medical provider setting; recent reports indicate that US migrant detention centres have been utilizing psychotropic medications to control the behaviour of children, without their parents' consent (Dyer, 2018). Disoriented children – separated from their families and living in a world of chaos – are allegedly being subdued with the government-sanctioned use of psychotropic drugs. Clearly, the issues at stake are larger than healthcare and bespeak a misunderstanding of appropriate use of psychotropic medications. Unfortunately, a laissez-faire attitude towards the use of psychotropic medications in children is widespread; both parents and medical providers can be overzealous in the use of these medications.

Pharmaceuticals have been heralded as part of the marvels of modern medicine – seemingly simple solutions to complicated problems. Parents and caregivers often seek pharmacologic answers to behavioural problems. When the evidence does not support particular medications for particular conditions, however, we need to exercise caution.

Beyond the magic pill: practical recommendations

Children with IDD often struggle with communication difficulties, limiting their ability to advocate for themselves and preventing providers from fully understanding their experiences and perspectives. Providers should expand their evaluation and treatment repertoire to include information beyond the discrete clinical encounter. This requires obtaining information from school systems, social service agencies, home providers and parents. This collateral information helps the provider develop a thorough and accurate biopsychosocial formulation. A psychiatric assessment of children with IDD requires more time than typical encounters, but the initial time investment to fully understand the child and develop a thoughtful treatment plan based on the biopsychosocial formulation pays massive dividends in maximizing care and minimizing future time-consuming crises. A biopsychosocial approach is the foundation for evaluation and treatment planning for children with IDD and challenging behaviours.

Short-term use of psychotropic medications may be helpful in reducing the severity and frequency of challenging behaviours, while evidence-based behavioural interventions are pursued. We suggest several guidelines.

1. As children with IDD respond to lower doses than typically developing children, start the medication at a low dose and slowly titrate.
2. Make one medication change at a time to clarify that any benefit or side effect is due to the medication.
3. Coordinate with the child's behaviourist or team to provide behavioural data at each medication follow-up visit.
4. Closely monitor for side effects because of the increased sensitivity children with IDD have due to psychotropic medications.
5. Once a child is receiving appropriate behavioural interventions and has a sustained period of stability, consider slowly deprescribing psychotropic medications in a step-wise approach, starting with the medication with the least benefit or the most serious side effect profile for that child.

Children and their caregivers need education prior to starting a psychotropic medication to fully understand the potential benefits, risks and side effects. Caregivers need to understand the therapeutic targets and have realistic expectations of what a medication is capable of altering. Too often caregivers seek psychotropic medications to improve a myriad of issues that such medications simply will not improve. They seek to target behaviours that are functional in nature and will not change with medications. For example, we saw the family of a 9-year-old female with mild intellectual disability who would have frequent temper tantrums (yelling, screaming, crying and refusing to do things) in the home setting. She had a history of treatment with multiple different psychotropic medications including several second-generation antipsychotics and mood stabilizers. Her parents were frustrated as none of these pills had worked, and they felt like they just had not found the correct medication. The evaluation process demonstrated that when confronted with the child's challenging behaviours, the parents were unable to ignore them or adhere to firm limits; thus, they were inadvertently reinforcing the very behaviours they hoped to change. Additionally, the parents' communication style and requests were beyond the patient's functional capacity. We provided parents with further education regarding their child's intellectual disability and appropriate expectations for her. We recommended a slow taper in a step-wise approach off the four psychotropic medications that she was taking without benefit. Furthermore, we recommended a functional behavioural assessment with a positive behavioural support plan.

Looking beyond the challenging behaviour to determine the aetiology and function of the behaviour is of the utmost importance. Behaviour is a form of communication and the challenging behaviour may be due to physical pain, stress, anxiety, other underlying mental health issues or may serve a purpose for the child (e.g. attention seeking, avoidance, escape, etc.). Ideally, mental health providers would educate families regarding evidence-based treatments and help them move beyond the pursuit of a magic pill and into a more holistic approach for their children. We are all well-intentioned mental health providers caring for a complex patient population without a magic pill in hand. We need to slow down, think and do no harm.

Conclusion

Behavioural interventions, such as ABA, are evidence-based practices for children with IDD and should be the first-line treatment. Short-term use of psychotropic medications may be helpful in reducing the severity and frequency of challenging behaviours, while evidence-based behavioural interventions are pursued. Avoid polypharmacy and once a child has a sustained period of stability, consider slowly deprescribing psychotropic medications.

Data

Not applicable.

Acknowledgements. We are grateful to our colleagues in the Vulnerable Children Research Group for their continued support and encouragement.

Financial support. This research received no specific grant from any funding agency, commercial or not-for-profit sectors.

Conflict of interest. None.

Ethical standards. Not applicable.

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