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INTELLECTUAL DISABILITIES (M FELDMAN AND R CONDILLAC, SECTION EDITORS)

Psychotropic Medication in Intellectual and Developmental Disabilities: Patterns of Use and Recommendations for Monitoring Effects

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Abstract

Purpose of Review The purpose of this paper is to provide a brief review of the patterns of psychotropic medication use in individuals with intellectual and developmental disabilities (IDD) and recommendations for monitoring the effects of these medications.

Recent Findings Challenging behavior (e.g., aggression, self-injury, property destruction) in individuals with IDD is often observed, and both behavioral and pharmacological interventions have been evaluated for their effectiveness in treating these behaviors. Although behavioral interventions have been shown to be effective at decreasing challenging behavior, psychotropic medications are frequently used to treat challenging behavior despite a lack of clinical indication (i.e., psychiatric diagnosis).

Summary Limited evidence exists supporting the effectiveness of psychotropic medication to address challenging behavior. Given the demonstrated effectiveness of behavioral interventions, a comprehensive approach to supporting those with IDD and challenging behavior should include behavioral assessment and intervention, and continuous monitoring of and data collection on challenging behavior.

Keywords Psychotropic medication · Intellectual and developmental disabilities · Challenging behavior

Introduction

Psychotropic medications are primarily prescribed to manage and treat psychopathology in the typically developing population. In those with intellectual and developmental disabilities (IDD), these medications are often used to address challenging behavior in addition to psychopathology [1]. A common observation is the use of psychotropic medication to treat challenging behavior in the absence of a psychiatric diagnosis [e.g., 2–4]. The purpose of this paper is to provide an update regarding the prevalence of psychotropic medication use in the IDD population with attention to its use for treating challenging behavior. A secondary purpose is to provide recommendations for evaluating the effects of psychotropic medication within this population.

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Psychotropic Medication Use in Intellectual and Developmental Disabilities

Research has evaluated the extent to which psychotropic medications are prescribed to individuals with IDD. There are data for prevalence of use in children and adults with IDD; however, there is limited information on patterns of use in the very young, adolescents (who, in published research, are often integrated within either child or adult populations [5]), and the older population with IDD [6]. What is reported in the literature for these populations warrants attention. Research evaluating psychotropic medication use in young children with IDD (i.e., younger than 7 years of age) found that approximately 10 to 41% of children experienced an adverse effect of psychotropic medication prescribed and these effects differed by age and medication [7]. Grouping adolescents with children or adults is less than ideal considering that the development of the adolescent brain is not fully well understood [8],

and given the changes the brain undergoes during adolescence, psychotropic medication may impact these individuals differently than children or adults. And finally, with respect to the older IDD population, there appears to be excessive psychotropic medication use observed which is concerning given the complications in health associated with the aging process [9]. Given the limitations in the current literature, this brief review will focus on the prevalence of psychotropic use by children and adults with IDD.

Patterns of Medication Use in Children Challenging behavior in children diagnosed with intellectual and developmental disabilities (IDD) is common with prevalence rates ranging from 18 to 52% depending upon the diagnostic group studied (e.g., Down syndrome, autism, IDD in general [10, 11]). Both behavioral and pharmacological interventions for challenging behavior have been evaluated, and although behavioral interventions have been shown to be effective at decreasing challenging behavior, psychotropic medications are frequently used to treat these behaviors in children with estimated prevalence of use between 12 and 29.4% depending on medication class [12, 13]. Furthermore, children with autism spectrum disorder (ASD) who present with irritability (i.e., challenging behaviors such as aggression) tend to be treated with psychotropic medications, often in an off-label manner (only risperidone and aripiprazole are approved by the United States Food and Drug administration for the treatment of ASD-associated irritability) [14]. Additionally, children diagnosed with both ASD and other comorbid conditions (e.g., ASD and attention-deficit/hyperactivity disorder; ADHD) are more likely to be prescribed psychotropic medication, although in their sample (i.e., Australian children with ASD), Rasmussen and colleagues reported low antipsychotic use [15]. A meta-analysis of published research on psychotropic medication use, however, found higher estimated percentages of use with 16.6% of children and adolescents diagnosed with ASD prescribed antipsychotic medication [16]. Unfortunately, the impact of these medications on the developing brain of children is not well understood and there is limited research evaluating how psychotropic medications impact the quality of life in children with IDD [17]. Analyses of the effectiveness of psychotropic medication in children with IDD suggest that when these medications are effective at reducing challenging behavior, the effects may be short-lived and the side effects associated with medications appear to outweigh potential behavioral benefits [14]. Indeed, recently Ray et al. reported that children, in their sample, prescribed higher doses of antipsychotic medication had 3.5 times risk of dying compared with children prescribed a different class of medication [18].

Patterns of Medication Use in Adults When we examine psychotropic medication use within the adult IDD population, over the past three decades the prevalence of psychotropic medication use in adults with IDD appears to be increasing with 30 to 56% reported in the 1990s [19] and more recent findings reporting between 49% [20] and 71% [21]. Furthermore, there appears to be an increase in the prescription of antipsychotics with more recent estimates of prevalence between 22% [21] to 45% [22] and an increase in polypharmacy (the use of more than one psychotropic medication [23, 24]).

Increasingly, psychotropic medication appears to be used to treat challenging behavior. In adults with IDD, presentation of challenging behavior varies tremendously based on the type of challenging behavior assessed (e.g., aggression versus self-injury) and the severity [25]. Within various samples, anywhere from 18% [21] to 53% [9] to 83% [26•] of individuals with IDD engage in challenging behavior and research supports that these behaviors remain relatively persistent over one's adulthood [27]. Perry and colleagues reported that of the 90% of their sample taking psychotropic medication, 83% engaged in challenging behavior [26•]. Specifically, antipsychotics appear to be prescribed to address these behaviors. For example, O'Dwyer and colleagues found that of their sample prescribed antipsychotics, approximately one quarter had a psychotic disorder but over half of the individuals engaged in challenging behavior [28]. Another study evaluated antipsychotic prescribing patterns in the UK and found that only 40% of those prescribed antipsychotics had a psychotic disorder diagnosed [29, 30].

Deb and colleagues completed a prospective analysis of psychotropic medication across 6 months in UK in a clinic sample of 100 patients and found slight decreases in polypharmacy but a slight increase overall in the use of psychotropic medication [31]. Thus, it appears that once someone is taking a psychotropic medication, they do not tend to discontinue its use. One explanation is that individuals experience increases in target behavior or "destabilization" when discontinuations are attempted [29, 32]. The more severe the challenging behavior, the higher the dose of antipsychotics prescribed [31]. This pattern of prescribing is concerning for many reasons including that doses prescribed are often higher than what is recommended [31] and there is potential for side effects (some life threatening—neuroleptic malignant syndrome [14, 18, 33]. Additionally, some have raised the question regarding the effectiveness of psychotropic medications for treating challenging behavior [e.g., 2].

Effectiveness of Medication for Treating Challenging Behavior Several clinical trials have evaluated the impact of psychotropic medication on challenging behavior (e.g., U.S. Food and Drug Administration approved the use of risperidone (Risperdal) and aripiprazole (Abilify) for treatment of irritability associated with autism spectrum disorder [e.g., 34, 35]). Much of the research evaluating medication effects on challenging behavior has produced mixed findings. Generally

speaking, except for risperidone, most research findings are limited due to the methodology employed [c.f., 36]. Likewise, findings regarding the effectiveness of antidepressants for the treatment of challenging behavior also appear to be questionable due to mixed results from poorly designed studies [37]. Complicating the issue is that many studies collect data regarding the effectiveness of medication using indirect measures of behavior such as questionnaires rather than collecting direct measures of behavior such as frequency or severity (i.e., extent of injury to self or others).

Research has examined the combined effects of behavioral interventions and psychotropic medication in decreasing challenging behavior and increasing caregiver satisfaction [e.g., 38, 39]. Indeed, multimodal treatment approaches have been found to produce greater reductions in challenging behavior than placebo alone as it can be difficult to effectively manage behavior solely with psychotropic medication [40, 41]. Despite these findings, however, psychotropic medications continue to be a major component of the treatment plan for many individuals with IDD and challenging behavior. Given environmental contributors to behavior, what follows are recommendations for integrating behavioral methodologies into monitoring medication effectiveness.

Recommendations for Monitoring Medication Effects

Psychotropic medication impacts behavior, but they also have the potential to impact the conditions under which challenging behavior is likely to occur. In a recently published study examining if changes in psychotropic medication regimens impacted outcomes of functional analyses of challenging behavior in adults with IDD, researchers found that all participants experienced some degree of change in challenging behavior (frequency and/or severity) with more remarkable changes for some participants than others [42]. What accounted for this change was not known, but researchers speculate that perhaps there are certain functions of behavior that may be more likely to be impacted by medication than others. This focus on function of behavior to drive pharmacological treatment is not new [43]. What the shift in treatment target requires, however, is a reconceptualization of medication effects on challenging behavior; namely, medication effects can serve as potential motivating operations [44].

Behavioral Conceptualization and Assessment Motivating operations are generally defined as events or states that alter how effective (i.e., increase or decrease in effectiveness) reinforcers and punishers are under those states thereby altering the frequency of behavior associated with the consequences [45]. For example, in the animal literature, research has elucidated how neurotransmitters can mediate the reinforcing qualities of stimuli and how their release can further serve as reinforcers themselves as in the case of dopaminergic activity in the nucleus accumbens. Couppis and Kennedy found that when mice were required to perform an operant task (nose pokes) to gain access to another mouse in which then aggression ensued, mice engaged in high rates of nose poking [46]. However, when a dopamine antagonist was administered, rates of nose poking decreased in a dose-dependent fashion (movement was not impacted so decreases in nose poking were not attributed to inability to engage in the response). This finding suggests that psychotropic drugs, brain activity, and behavior function are interrelated.

Considering the possible effects that psychotropic medications can have, finding a way to assess if medications are truly impacting the conditions under which challenging behavior occurs becomes important when contemplating the effectiveness of behavior support plans which are in place or at least should be in place for these behaviors. Evaluating this line of question can have larger impact down the line of treatment such as determining if certain aspects of a behavior plan have been rendered ineffective.

Conducting Behavioral Assessments One recommendation is to repeat assessments (i.e., functional assessment of behavior, reinforcer/preference assessments) once medications have reached a steady state to ensure that the function of challenging behavior has not been impacted by the initiation of or change in medication [42]. One method for determining the cause of problem behavior and subsequently developing the most appropriate behavioral intervention is a functional analysis. A functional analysis is an experimental assessment conducted to determine the function of problem behavior by systematically manipulating stimuli (e.g., presented or removed) in order to mirror natural contingencies thought to maintain problem behavior [47]. These manipulations test whether behavior is maintained by negative reinforcement, positive reinforcement, and/or automatic reinforcement (non-socially mediated). Although research has demonstrated how medications may impact functional analysis outcomes [e.g., 48–50], there is limited research examining how psychotropic medication impacts outcomes on reinforcer and/or preference assessments [51]. The existing research has predominately focused on the effects stimulant medications have on reinforcer assessment outcomes, but more work needs to be done [e.g., 52–54]. These assessments should be done after psychotropic medications are altered and have reached stable levels to more effectively address symptoms, and assessments should also be conducted when attempts to wean or discontinue these medications occur.

Measurement of Behavior Considering the importance and need for continued monitoring of behavior function (in addition to monitoring frequency and intensity of behavior) in

order to determine the most efficacious treatment, the data caregivers are tasked with collecting carries particular significance as these data provide information to design more effective behavior support plans and monitor how medication impacts behavior.

Of additional note is that psychotropic medications can potentially impact the presentation of all behavior, not merely challenging behavior such as aggression and self-injury but also stereotypic and adaptive behavior which can affect engagement in treatment plans. Knowing how often and for how long challenging behavior occurs is important; but knowing about intensity of behavior, context for behavior, and corresponding states (e.g., fatigue, mood, hunger) is also extremely important. For example, a recent study has found that those with IDD are more likely to be prescribed psychotropic medication than the general population but *less* likely to be given pain management medication than the general population [55]. How often are we collecting data on pain and the experience of pain for those to whom we provided services? Qualitative data on pain state are important despite the challenges that assessing pain in those with IDD may pose as the presence of pain may impact behavior.

Measurement of Adverse Side Effects Data should also be collected on the presence of side effects to determine their existence and potential impact on challenging behavior [56•]. Admittedly, some side effects may not be observable; others, however, are either because they are movement-related disorders or because there are other behaviors that may suggest their presence (e.g., drink requests and thirst). Care providers and clinicians need to be aware of what side effects may be likely, how they might manifest, and when the best time to assess them is (e.g., insomnia requires recording data in evenings, decreased appetite at meal times). Additionally, adaptive behavior may also be important to assess as some side effects may impact those as well (e.g., communication skills and memory issues).

Additionally, there are direct measures of side effects that can and should be taken [c.f., 57]. Biological measures such as blood glucose levels are important to monitor when atypical antipsychotics are prescribed as this class of medication is associated with the development of metabolic disorders and a potential relationship between challenging behavior and oscillating glucose levels has been found [e.g., 58]. Clinical measures (e.g., weight, blood pressure, heart rate) may also indicate the presence of side effects. Finally, monitoring the development and progression of movement-related side effects is important as Sheehan and colleagues found that those with IDD experience movement-related side effects (e.g., tardive dyskinesia) of antipsychotic medication more often than the typically developing population [59].

Data Collection Training caregivers on how to assess and collect data on regarding target behavior and side effects becomes vital. In the absence of data collection protocols, it is possible that changes in medication are made based on caregiver perception rather than objective data. Indeed, research has found that a large predictor of psychotropic medication use is challenging behavior as reported by caregivers [60]. Caregivers (particularly direct care staff) often do not understand the purpose of psychotropic medication and thus have unrealistic expectations regarding how medications work, what the impact on behavior will be, and what the associated potential side effects are [61••].

Research has identified two factors that impact data collection by caregivers: understanding the need for data collection and complexity of the data collection system [62, 63]. When caregivers understand how the procedures will benefit a client, caregivers are more likely to comply with the instructions [62]. However, if the instructions/data collections system is too complex, the likelihood for errors increases as does staff resistance to data collection [63]. These issues may be addressed by selecting relevant behaviors and side effects to monitor and providing extensive caregiver training on data collection including the rationale for it. Furthermore, data collection could be included as a component of staff performance evaluation requiring that supervisors monitor and provide feedback on compliance and accuracy.

Working With Prescribers Li and Poling surveyed behavior analysts on their involvement in decisions regarding psychotropic medication use by their clients with IDD [64•]. They found that behavior analysts are often not involved in the process for many reasons primarily the limited training/knowledge regarding psychotropic medication use. Behavior analysts, however, do have the expertise to work with prescribers to identify the relevant behaviors to monitor, train others on data collection, and assess how behavior and environment interactions are evolving. Indeed, Molina-Ruiz and colleagues (2017) outlined best practices for psychiatrists working with those with IDD [65••]. Within their recommendations are clear opportunities for behavior analyst involvement and partnership. For example, they specify that psychotropic medication should be used to address a diagnosis rather than to decrease behavior that could better be addressed by individualized behavioral intervention. Behavior analysts could also play a critical role in the active monitoring of behavior (i.e., progress or improvement, or worsening).

Much like ear aches [66] or menstrual pain [67] are biological variables that behavior analysts consider in relation to challenging behavior, the effects of psychotropic medication are also biological variables that should be considered in relation to behavior. When medication effects are conceptualized in this manner, we can begin to identify the ways in which medication, when its use is deemed a necessary component of

the treatment plan, can become more efficacious with minimum adverse side effects.

Conclusions

There is ample evidence to support that physicians prescribe psychotropic medication in an off-label manner to address challenging behavior of individuals with IDD. This practice has become so common that an international movement, supported by the Royal College of Psychiatrists in the United Kingdom, has begun to address the issue. This movement is known as STOMP, stopping over medication of people with a learning disability, autism, or both (https://www.england.nhs.uk/learning-disabilities/improving-health/stomp/). This initiative emphasizes the most effective, least restrictive intervention for challenging behavior. Admittedly, there are individuals who require psychotropic medication to address co-morbid conditions (e.g., schizophrenia) but the hope is that for those who do not have a co-morbid condition, psychotropic medication is reserved for situations in which other less intrusive and less restrictive interventions (e.g., behavioral) have been demonstrated to be ineffective. This requires greater access to qualified professionals (i.e., behavior analysts), consistent and dynamic monitoring of behavior, and a treatment team approach to supporting those with IDD and challenging behavior. Future research could then evaluate how a greater focus on alternative treatment methods impacts the prevalence and circumstances under which psychotropic medication is prescribed.

Compliance with Ethical Standards

Conflict of Interest Maria Valdovinos declares that she has no conflicts of interest.

Human and Animal Rights and Informed Consent This article does not contain any studies with human or animal subjects performed by any of the authors.

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