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Highlights...

Our page 1 stories look at the need to monitor children on antipsychotics, and disparities in treatment, and at barriers to seeking help among adolescents.

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- The need to prioritize ADHD, irritability, and anxiety in ASD
- The barriers and facilitators to mental health help-seeking among adolescents

Commentary... See page 8

- Inequities in access to education: Lessons from the COVID-19 pandemic
  — *Anne Walters, Ph.D.*

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Free Parent Handout...

- Treatments for substance use disorders for teens and young adults

Medications

Monitoring and treatment disparities for youth on antipsychotics

By Jack Fatica, M.D.

The need for effective interventions in the management of neuropsychiatric conditions in youths has led to increased use of psychotropic medications, particularly antipsychotics. Several are approved by the Food and Drug Administration (FDA) for administration in youths to treat schizophrenia, bipolar disorder, autism-related irritability, and Tourette's disorder. However, by and large, these medications are used off-label to target dysregulated conduct or emotional features such as aggression (48% of treated symptoms), irritability (19%), and impulsivity (11%). Only 5% of prescriptions are for FDA-approved indications.

Antipsychotics have significant side effects. And despite what we know about their side-effect profiles, there are many unknowns regarding their use in youths, including long-term safety, tolerability, and efficacy. Over-prescribing is a concern; it is often difficult to discern the explicit purpose for these medications by looking at provider records, particularly in younger children. Access to longitudinal therapy modalities is limited. Psychotropics have become the de facto replacement for therapy. Finally, antipsychotics are prescribed at disproportionately higher rates for individuals in specific vulnerable populations.

Several organizations have thus created recommendations to assist in making treatment decisions.

There are many reasons to prescribe antipsychotics for youths. Many do benefit from

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OCD

Case report: Functional assessment of behavior in complex diagnoses: A transdiagnostic approach

By Gloria T. Han, M.A.; Andrea L. Gold, Ph.D.; Giulia Righi, Ph.D.; Abbe Marrs Garcia, Ph.D.; and Amy Egolf, M.D.

"Nadine," a 10-year-old female, was referred by her outpatient psychiatrist to the Bradley Hospital Partial Hospital Program for OCD and Related Disorders (OCD PHP) for intensive treatment of her unusual, dangerous, and obsession-like interests, combined with frequent, severe, and developmentally inappropriate tantrum outbursts. These symptoms continued to elicit chronically high levels of family distress and impairment, despite years of interdisciplinary treatments. Nadine expressed a fascination with sharp objects, including knives. Her verbal and nonverbal behaviors reflected her experience of feeling compelled to interact with sharp objects, placing her parents in a constant state of "high-alert" risk monitoring and management. Her fixations and unsafe behaviors had previously resulted in multiple hospitalizations to remove objects that she "could not resist" swallowing or pressing into her ears. Nadine's ongoing high risk of harm to herself, parents, and peers required constant monitoring at home and at her therapeutic school. Additionally, these and co-occurring symptoms led Nadine's parents to engage in extremely high levels of accommodation, in which they modified their own behaviors and family lifestyle in attempts to reduce Nadine's distress and circumvent her unsafe behaviors and tantrum outbursts. For example, they

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parameters is important in protecting the long-term health outcomes of youths prescribed antipsychotics. Youths are often prescribed these medications for extended periods of time, often for longer courses than may be clinically necessary, which can lead to weight gain, worsened metabolic parameters, and an elevated long-term risk of developing cardiovascular disease.

Systems-level solutions

The most prominent factors relating to youth antipsychotic overprescribing include gaps in insurance coverage, shortages of child/adolescent psychiatrists, the lack of alternative treatments, and knowledge gaps surrounding the medications. In response to the epidemic of overprescribing, federal and state governments implemented strategies to curb the increased prescribing trend. By 2013, 45 states were monitoring psychotropic medication use in foster care children. By 2015, 31 states had initiated prior authorization systems, which led to significant reductions in youth antipsychotic use overall. Drug utilization reviews and increased funding for care coordination and wrap-around services have curbed prolonged antipsychotic administration and increased metabolic monitoring. Elective psychiatric consultation programs through in-person or telemedicine networks have resulted in a 52% decrease in youths taking very high doses of psychotropic medications. These programs have also led to a 42% decrease in psychotropic medication use among youths less than 5 years old. Public reporting of quality measures and increased accessibility of other types of treatment have led to similar improvements.

While the focus has been on several of the negative aspects associated with youth antipsychotic use, it is important to highlight that these medications serve an important function for many individuals with significant psychiatric comorbidity. Their use requires mediation on a case-by-case basis to ensure proper use. However, on a population level, these medications are being used in ways that pose a consequential risk of causing harm, especially without adequate monitoring. Certain highly vulnerable groups are at a greater risk of being prescribed these medications and at higher doses, though some do also have greater access to other treatment modalities and metabolic screening. Despite the upswing in antipsychotic prescribing from the early 1990s through the late 2000s, state, federal, and other organizational initiatives to curb use have proven to be successful. Continued attention to antipsychotic use in youths is of paramount importance. It is critical that this awareness is raised for all parties, including treatment providers, school officials, families, and patients themselves.

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OCD

From page 1

removed sharp objects from Nadine's immediate environment, both in and out of their home, and at times avoided entering otherwise safe and positive environments because of potential exposure to sharps, such as going out to stores, restaurants, or peer playdates.

Among other psychiatric disorders, Nadine was previously diagnosed with disruptive mood dysregulation disorder (DMDD), which could explain frequent and intense outbursts, but not her abnormal interests. Prior to her OCD PHP admission at Bradley, Nadine received a full range of medical and behavioral interventions (e.g., occupational therapy, equine therapy, home- and school-based supports). To reduce her tantrum outbursts, Nadine's parents had worked diligently with her providers to find the appropriate pharmacologic regimen. She arrived in the OCD PHP taking two anticonvulsant medications, an atypical antipsychotic along with metformin to offset weight gain, a tricyclic antidepressant, a beta-blocker, and acetylcysteine (NAC). Her parents and previous providers had considered an inpatient admission to adjust her medications, as past attempts to do so in the outpatient setting had led to worsening behavioral dysregulation. Most recently, Nadine was diagnosed with obstructive sleep apnea secondary to significant weight gain from medications. While there was an impression that her medications helped reduce behavioral outbursts, inadequate sleep resulted in increased irritability and tantrums during the day. Treatment with CPAP started *3* weeks prior to admission had seemed to help reset this balance, resulting in decreased aggression and impulsivity, though by no means resolution of these symptoms.

At an outpatient visit with a psychiatrist they had recently started seeing, Nadine's parents learned about obsessive compulsive disorder (OCD) and a related condition called Tourettic OCD (Mansueto & Keuler, 2005). Nadine's presentation seemed to fit the bill. The psychiatrist described Nadine's "obsession" with sharp objects, frequent and intrusive thoughts about harm, "compulsive" actions, and "explosive" episodes in terms of this diagnosis, leading to her referral to the Bradley OCD PHP. After over *4* years of exhaustive, yet ineffective efforts to understand and treat their daughter, Nadine's parents experienced enormous relief upon learning about Tourettic OCD. Fearing that they were on the imminent path to residential treatment for their daughter, her mother tearfully expressed to their new clinicians at the OCD PHP, "This is our last hope."

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Nadine's story captures multiple aspects of challenging cases that we encounter as clinicians: severe, chronic, high-risk, and dangerous symptoms; a history of multiple failed

treatments; and a diagnostic profile that is at once complex and atypical. Nadine's 2-week OCD PHP admission consisted of intensive and collaborative care including assessment, observation, and psychoeducation among Nadine, her parents, and her interdisciplinary treatment team. Although aspects of her behavior could be partially explained by DMDD and/or OCD symptoms, Nadine's OCD PHP treaters established a formal diagnosis of autism spectrum disorder (ASD). ASD offered a new, unexpected conceptual framework that helped Nadine's parents understand their daughter's challenges, reflecting a paradigm shift that would guide a treatment plan tailored to her unique biopsychosocial needs.

We derived this shift in conceptualization by applying a functional assessment of behavior, an approach that goes beyond what symptoms are present to focus on how symptoms manifest as observable behaviors, what prompts them, and the functions they serve within a given context. The former, referred to as *symptom topography*, refers to what the behavior looks like when observed, whereas the latter, called *symptom function*, reflects how the behavior operates within its context, including the antecedents and consequences of the behavior. Based on observable symptoms, such as temper outbursts, Nadine could "fit" into multiple diagnostic categories. Applying functional assessment to probe and identify the antecedents, consequences, and underlying functions of Nadine's behaviors, together with her developmental and treatment history, we identified ASD as a potential organizing framework that captures both observable symptoms and their root cause. Notably, this approach was effective despite her "atypical" presentation both as a female with ASD and an individual with intact cognitive functioning and no language delays, a subgroup that is often mis-, under-, or never diagnosed until later in life. Atypical presentations tend to heighten family burden and delay access to effective interventions. By sharing our insights from Nadine's unique case, we seek to illustrate the utility of conducting a functional assessment of behavior to guide differential diagnosis, develop an organizing framework, and personalize treatment selection among high-risk, complex, and atypical patients.

A functional assessment of behavior provides a framework for distinguishing between symptom topography and symptom function. Based on symptom topography only, many of Nadine's behaviors could be explained by OCD, DMDD, or ASD, which share several overlapping features. Clarifying her diagnostic profile required thinking beyond symptom topography and delving into symptom function.

Symptom overlap and function: OCD and ASD

Symptom overlap is prominent between ASD and OCD, both of which can be characterized by rigidity and inflexibility. In OCD, individuals suffer from obsessions, or intrusive, unwanted thoughts, impulses, or images that trigger intense distress, and they engage in compulsions, or behaviors to neutralize the anxiety and distress prompted by the obsessions. Obsessions and compulsions observed in OCD appear topographically similar to restricted interests and repetitive (sometimes ritualistic) behaviors described in ASD. For example, restricted interests may be described as an "obsessive" interest in stuffed animals or knives, while repetitive behaviors may reflect a "compulsive" need to do something the same way every time. However, a key differentiating factor between OCD and ASD involves the function of these behaviors. In OCD, individuals are troubled by or in disagreement with their obsessions, thereby reflecting egodystonic symptoms. As such, obsessions and compulsions in OCD are maintained through cycles involving *negative reinforcement*, such that individuals increasingly engage in behaviors (e.g., hand-washing rituals) that provide relief from aversive stimuli (e.g., anxiety and distress stemming from contamination obsessions). In ASD, however, individuals report enjoyment and satisfaction when they engage with their restricted interests, representing egosyntonic symptoms. Accordingly, repetitive behaviors in ASD are maintained through cycles involving *positive reinforcement*, in which individuals are inherently rewarded by and thus motivated to increasingly engage with circumscribed interests and behaviors.

In Nadine's case, parents described her as having a "fascination" with sharp objects, such as knives and pieces of glass. Instead of engaging in compulsions to reduce distress from knives and dangerous objects (i.e., reflecting a negative reinforcement function as expected in OCD), Nadine was compelled to touch and reach for sharp objects. That is, her engagement with sharps served a rewarding function and was maintained through a positive reinforcement cycle as expected in ASD. In addition to her interest in sharp objects, parents described Nadine's intense interests in shiny, bumpy, and fluffy textures, and strong urges to engage in dangerous, "adrenaline-seeking" behaviors. At a petting zoo, her parents held her back from touching an animal because they were worried that the intensity of her interest ("I just need to touch it!") would end in completely unintended harm to the animal. Examples of dangerous behaviors included expressing her desire to ride her bike into the road or asking a friend to break her bones for the "feel of it." Her parents also described how Nadine could become overwhelmed in loud, chaotic environments (e.g., large crowds, birthday parties) and how she was a "picky eater" with a preference for "starchy" foods and aversions to certain textures. In fact, aberrant sensory processing is a common feature for individuals with ASD, who may display both hypo- and hyper-responsivity to various sensory stimuli (Tomchek & Dunn, 2007). Consequently, individuals with ASD may exhibit behaviors associated with both sensory-seeking (e.g., interest in specific textures; over-excitement to touch animals at the petting zoo) or sensory-avoiding functions (e.g., refusal to eat foods with certain textures or avoiding crowds due to overstimulation).

Examining symptom function allowed us to conceptualize Nadine's interests as being inherently rewarding, and to understand her dangerous behaviors as a way to placate strong sensory urges. Whereas her observable behaviors could topographically resemble "obsessions" and "compulsions," a functional assessment indicated that they were better accounted for by ASD-specific symptoms (i.e., egosyntonic restricted interests and aberrant sensory processing). This led to a shift in our clinical conceptualization promoting ASD as an organizing framework to explain her unusual and high-risk behaviors.

Symptom overlap and function: DMDD and ASD

In addition to identifying OCD, Nadine's prior treaters also diagnosed her with DMDD in the context of her irritability and temper outbursts. The *DSM-5* DMDD exclusion criteria require that the behaviors are not better explained by another mental disorder, including ASD. Given the evidence suggesting ASD as a potential organizing framework, we applied a functional assessment of Nadine's irritability and temper outbursts to clarify her diagnostic profile. In fact, the hallmark symptoms of DMDD, anger-irritability and temper outbursts, are common in children with ASD, with some studies estimating rates as high as 45% (Mayes et al., 2015).

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At the OCD PHP, Nadine's irritability and behavioral dysregulation were observed during her intake interview, where she refused to engage with her clinicians and instead screamed, broke two floor lamps, and aggressed toward her parents, attempting to bite, kick, and punch her dad. Notably, when her clinician offered her a stuffed animal, Nadine was pacified, and the outburst came to an immediate halt. After a few moments of soothing with the stuffed animal and talking about the "stuffies" with her dad and the psychologist, she apologized for her behavior and expressed feeling "scared and unsure about coming to the hospital." Her parents shared that she was often distressed in novel, unfamiliar environments or in response to unplanned changes in routines, which is typical for individuals with ASD. Instead of using her words to articulate her feelings, irritability and anger often escalated to the point of physical aggression. This added context prompted us to hypothesize that her tantrum behavior was primarily a consequence of ASD-related processes.

Considering that irritability and temper outbursts are not part of formal diagnostic criteria for ASD, individuals with ASD may be inaccurately diagnosed with DMDD when presenting with such overt and severe behaviors. As previously mentioned, restricted interests and repetitive behaviors (RRBs) reflect a core symptom domain of ASD and are maintained through cycles of positive reinforcement. Thus, limiting access to preferred interests and routines increases distress, leading to both behavioral inflexibility and dysregulation. Whereas behavioral inflexibility speaks to topographic similarity between ASD and OCD, behavioral dysregulation is common across both ASD and DMDD. In DMDD, chronic irritability and tantrum outbursts tend to be preceded by the removal or prevention of obtaining rewarding objects, reflecting a construct called "frustrative non-reward" (Brotman et al., 2017). Although empirical data have yet to be established, clinical insights suggest that individuals with ASD may experience high rates of irritability given chronic and repeated instances of frustrative non-reward stemming from RRBs. That is, daily demands inherently limit access to RRBs; for example, expectations that youth engage with nonpreferred interests at school, interactions with peers with different interests, and inevitable deviations from routines and preferences. In conversation with Nadine's parents, they revealed that Nadine had a strong interest in stuffed animals and dolls. Reluctant to add more dolls to her already extensive collection, her parents limited her access to toy stores out of fear that refusing to buy specific dolls would prompt public meltdowns. This is consistent with the hypothesis that prevention of access to a preferred, restricted interest could lead to dysregulation as seen in ASD. Examining Nadine's behaviors within their context highlighted that disruptive behaviors were accounted for by core symptoms of ASD, thereby excluding her previous DMDD diagnosis.

Atypical presentation: The female autism phenotype

A first-time diagnosis of ASD as a 10-year-old is notably late, as diagnostic instruments are reliable in individuals as young as 14 months of age. However, Nadine's presentation posed challenges even for providers with significant familiarity with ASD because of her restricted interest in sharps/knives that appeared topographically similar to OCD-related symptoms (but now better understood by ASD-related sensory processing differences), and because of her gender. Recent theories suggest that ASD may be especially underidentified in females without co-occurring intellectual impairment due to social and gender norms that lead social communication symptoms of ASD to manifest differently in girls. Furthermore, RRBs may also appear differently in females relative to males. Instead of stereotyped repetitive behaviors (e.g., hand flapping, rocking), repetitive behaviors in females may present as cognitive and behavioral rigidity (e.g., fixations on certain topics, inflexibility around deviations from expectations and preferred routines) (Kreiser & White, 2014).

Whereas diminished interest in developing age-appropriate relationships is commonly observed in males with ASD, females often report interest in social relationships but struggle to achieve meaningful friendships due to marked lack of social skill. This was the case for Nadine. She was highly motivated to engage socially with others, and her verbal skills afforded her the ability to interact with peers and adults. However, even with abundant opportunities for interactions with peers, parents consistently witnessed her unsuccessful attempts at relationship building. For example, in the OCD PHP, Nadine eagerly engaged with peers but had trouble maintaining natural back-and-forth conversations. In group settings, her contributions to conversations were repetitive, and she sometimes retold the same jokes without awareness that peers and program staff were losing interest. Atypical speech and abnormal expressive prosody are also common in individuals with ASD, but higher verbal abilities in females may camouflage idiosyncratic speech and abnormal prosody. To her psychologists at the OCD PHP with expertise in ASD assessment, Nadine's speech was readily identified as monotone with repetitive and idiosyncratic phrases, yet her parents and other, prior treaters had not noticed these subtleties. This difference in perception reflects an important aspect of the female ASD phenotype, where verbal abilities may not translate to effective communication skills, or the ability to effectively match language to a specific social context. A strong social desire coupled with an inability to build deep social connections can lead to significant emotional challenges for females with ASD. In recent years, Nadine's parents had become more concerned for her emotional well-being, as her ineffective efforts to engage with peers often resulted in low self-esteem, bullying, and, most recently, suicidal statements of wanting to end her life.

Developing an organizing framework and paving a path forward

Like working on a thousand-piece jigsaw puzzle, capturing Nadine's complexity required not only sorting pieces based on hue or shape, but also differentiating their unique roles in the overarching landscape. Blue pieces may share topographic similarity but serve vastly different functions — one intended to color an azure sky while another represents part of a cresting wave. Ultimately, completing a puzzle requires differentiating between pieces based on their appearance and function, considering how individual pieces are joined with their neighbors to construct the greater gestalt. Though DMDD and OCD captured circumscribed aspects of her observed behavior, they did not offer a deeper understanding of "how" and "why," and had failed to lead to successful treatment.

Through in-depth observation and extended assessment during Nadine's PHP admission, including thorough developmental and treatment histories, a precise, functional assessment identified ASD-specific processes that best explained her unique and complex presentation. Formal testing using the gold standard assessment tool, the Autism Diagnostic Observation Schedule, 2nd Edition (ADOS-2), provided further

evidence for diagnosis of ASD, and highlighted high levels of ASD symptom severity. Nadine was discharged from the OCD program with a more appropriate referral to the Center for Autism and Developmental Disabilities PHP at Bradley Hospital.

Our functional assessment supporting ASD as an organizing framework helped us to identify treatment targets and select effective treatment approaches. For example, Nadine's high-risk behaviors were perpetuated by positive reinforcement cycles linked to ASD-related processes, as opposed to negative reinforcement cycles maintaining obsessions and compulsions in OCD. As such, exposure and response prevention, the gold standard treatment for OCD, was contraindicated for treating Nadine's high-risk behaviors. Instead, a shared deficit across Nadine's symptoms was difficulty with self-regulation, including emotional, cognitive, behavioral, and interpersonal dysregulation. In addition to coordinating care with other members of her clinical and therapeutic school teams, we introduced her family to a new treatment approach: the Emotion Regulation Skills System (Brown, 2015). Though this intervention was not specifically developed for individuals with ASD, it adapts skills from dialectical behavioral therapy for individuals with cognitive challenges and co-occurring high-risk behaviors to target emotional, cognitive, behavioral, and interpersonal dysregulation. Thus, this intervention was selected to target Nadine's skills deficits.

Though we did not fulfill their "last hope" of treatment for OCD, as anticipated, Nadine's family left our program on a new path, grounded in newfound hope. Upon reviewing the assessment feedback and providing our integrated treatment recommendations on a Friday afternoon, we assigned Nadine's parents homework to look into the two-hour online "Skills System" training (https://skillssystem.com). Nadine's parents appeared refreshed when they arrived at our family therapy session on Monday, their faces and voices expressing relief and resounding hope. They excitedly shared that they already completed the training over the weekend, and earnestly remarked, "This treatment was made for our daughter."

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We hope to share Nadine's story to illustrate a general approach for assessing individuals with complex and atypical profiles. As shown throughout the case report, our process for understanding and serving Nadine's family benefited from the following steps:

- Explore history of both past diagnoses and treatments. Understanding the timeline and thought process of past treaters provides helpful hints into not only the causes of impairment but also the developmental course of these relevant patterns of behavior. This is especially relevant in child and adolescent psychiatry, as complex diagnostic profiles often occur against the backdrop of a broadly challenged neurodevelopmental landscape. In Nadine's case, considering but not committing to past labels was crucial, as openness and flexibility allowed us to explore novel insights and observations.
- Consider both symptom topography and function to guide differential diagnosis. Before adding more diagnostic labels, and especially when diagnostic categories have overlapping symptoms, consider both the observable behaviors and their underlying functions. This provides clues into causal processes to inform differential diagnosis and targeted intervention. For example, when symptoms from one disorder can be accounted for by another disorder, emphasis should be given to the diagnostic category that has the most explanatory power for the patient's symptom profile. Underlying processes in Nadine's case that guided our thinking included sensory processing, reward processing, social skills deficits, and emotion dysregulation due in part to poor emotional awareness and expressivity.
- Prioritize an organizing framework. Diagnostic labels are useful for clinical utility. While they provide a shortcut for describing patients based on observable symptoms, they are not in and of themselves sufficient to inform an individualized treatment plan. An organizing framework captures symptoms, underlying processes, and skills deficits, thus providing insights for treatment selection and personalized intervention. For Nadine, ASD provided an organizing framework that could explain her behaviors, as well as their antecedents and consequences.
- Link the organizing framework and functional deficits to personalized treatment selection. Evidence-based treatments strive to target the underlying process of dysfunction. Thus, skillful intervention planning should rely less on the intervention itself, but on the fit between the intervention's skills targets and the patient's skills deficits. Given that Nadine found knives and sharp objects to be inherently rewarding, the standard treatment for OCD involving repeated exposures to distressing stimuli would have been contraindicated, as it would have increased rather than decreased her desire to engage with these dangerous objects. Instead, the Skills System provided a behavioral intervention that could mitigate her specific skills deficits related to emotional, cognitive, interpersonal, and behavioral dysregulation, and gradually shape desired behaviors using reinforcement principles over time.

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