Management of Individuals With Autism Spectrum Disorder in Clinical Settings

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Lessons Learned at the Interface of Medicine and Psychiatry

The Psychiatric Consultation Service at Massachusetts General Hospital sees medical and surgical inpatients with comorbid psychiatric symptoms and conditions. During their twice-weekly rounds, Dr Stern and other members of the Consultation Service discuss diagnosis and management of hospitalized patients with complex medical or surgical problems who also demonstrate psychiatric symptoms or conditions. These discussions have given rise to rounds reports that will prove useful for clinicians practicing at the interface of medicine and psychiatry.

Prim Care Companion CNS Disord 2024;26(2):23f03584

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Have you wondered how best to support your patients with a diagnosis of autism spectrum disorder (ASD)? Are there ways we can offer support to these individuals in clinic or hospital settings? Have you been uncertain about when to recommend medications to manage challenging behaviors? Have you considered using telemedicine visits rather than in-person visits to monitor and treat these individuals and their families? If you have, the following case vignette and discussion should prove useful.

CASE VIGNETTE

AB, an 8-year-old boy with ASD and attention-deficit/hyperactivity disorder (ADHD), was brought by his parents to the emergency department (ED) with worsening behaviors that started in the past week. At his baseline, AB had occasional episodes of anger when overwhelmed, the most severe of these episodes resulted in him biting his hand or hitting family members. Several days ago, these episodes arose multiple times a day, both at home and at school. AB's parents brought him to the ED because they were worried that he was in pain. They believed his behavior was due in part to a recent inability to follow his bedtime routine, which led to several nights of poor sleep; his sister's recent move out of the home to attend college was an additional stressor.

In the ED, AB exhibited a minimal desire to communicate with the treatment team. They observed AB hitting the side of his head with his hand, particularly when there were loud noises. The ED physician called AB's outpatient provider, who indicated that AB's history was notable for a speech delay and that he used a communication board. The outpatient provider advocated for a full physical examination, as they also suspected that AB was in pain, and offered a list of strategies that were used by clinic staff during outpatient appointments to help AB remain calm during transitions.

DISCUSSION

What Is ASD?

ASD is a clinical diagnosis used to describe individuals with (1) an impairment in social interaction and communication and (2) restrictive/repetitive behaviors, interests, and activities. Impairments in social interaction and communication include deficits in social-emotional reciprocity, in nonverbal communicative behaviors, and in creating relationships. Restricted/repetitive behaviors include stereotyped movements, inflexibility, and limited interests. Symptoms arise early in life and cause significant impairments in daily functioning.[1]

The symptoms of ASD are typically identified around the age of 2 years, but the time to diagnosis varies depending on the child's presentation and the family's access to health care.[2,3] According to the 2020 data from the Autism and Developmental Disabilities Monitoring Network, the prevalence of ASD has increased over previous years, in part due to heightened awareness of the disorder. Historically, white non-Hispanic males were more likely to be diagnosed with ASD; however, the diagnosis of ASD in non-White children and girls has steadily increased. For unclear reasons, there has been significant variability among the prevalence across states.[4]

Clinical Points

- Focus on behavioral interventions before considering use of medications for patients with autism spectrum disorder (ASD); behavioral interventions should involve contributions from the family, school, and outpatient therapists in collaboration with the primary doctor, speech therapist, occupational therapist, and/or behavioral therapist.
- If medications become necessary, guanfacine and clonidine should be considered for anxiety or mild agitation; agitation that presents a safety threat may be managed with second-generation antipsychotics.
- Due to the limited resources for pediatric outpatients with ASD, consider recommending telehealth alternatives, as early data are promising.

Screening is recommended throughout early childhood as well as at well-child visits with their pediatrician. Screening methods in young children include the Checklist for Autism in Toddlers,[5] Early Screening of Autistic Traits,[6] Modified Checklist for Autism in Toddlers,[7] Infant Toddler Checklist,[8] Quantitative Checklist for Autism in Toddlers,[9] and Screening Tool for Autism in Children aged 2 years.[10] Diagnosis can be via a structured interview or use of observational measures. Structured interviews include the Autism Diagnostic Interview-Revised (ADI-R),[11] Diagnostic Interview for Social and Communication Disorders,[12] and Developmental, Dimensional, and Diagnostic Interview.[13] Observational measures include the Autism Diagnostic Observation Schedule[14] and Childhood Autism Rating Scale.[1,15] Early diagnosis of ASD allows for earlier treatment and better outcomes.

The presenting problems and needs of children with ASD vary as widely as its etiologies. Genetic etiologies include tuberous sclerosis, fragile X syndrome, Angelman syndrome, Rett syndrome, and Down syndrome. The presentation of ASD can be further complicated by ASD's comorbidities with other problems, which include ADHD, anxiety disorders, attachment disorder, developmental language problems, obsessive or compulsive behaviors, social anxiety, intellectual disability, fetal alcohol syndrome, and epilepsy.[16] The heterogeneity of ASD's myriad presentations can leave clinicians at a loss for knowing how to address these behaviors in an office visit.

What Are Some of the Suspected Etiologies of ASD?

Multiple frameworks for understanding autism have been developed. Consideration for a genetic etiology has been supported by the heritability of ASD, which in a large population-based cohort study showed a median heritability of 81%; however, no single gene has been found as a common etiology of ASD.[17]

Neurotransmitter alterations in expression have been implicated in ASD, as have alterations in glutamate expression and metabolism; however, no US Food and Drug Administration (FDA)–approved medications target the glutamatergic system in autism.[18] The dopamine hypothesis attributes dopamine dysfunction in the mesocortical system to the genesis of deficient social interactions, and dopamine dysfunction in the nigrostriatal system contributes to the stereotyped mannerisms observed in ASD.[19]

The disrupted connectivity theory postulates a difference in the brain's ability to synchronize. Several functional magnetic resonance imaging (fMRI) studies have shown decreased frontal-posterior connectivity, whereas other studies have shown overconnectivity in selected brain regions. Gaining a consensus on this research has been limited by use of different methodologies and subjects. The psychological counterpart of the disrupted connectivity theory is the intense world theory, in which overconnected regions allow for heightened attention, emotion, and memory that can be observed in some individuals with ASD. In addition, fMRI studies have also shown differences in response to social and nonsocial rewards in those with ASD; however, the data are mixed.[20–22]

What Characteristics Can Individuals With ASD Manifest in the Clinic?

In health care settings, individuals with ASD may show a lack of emotional reciprocity on interview. They may display a lack of desire to respond to others' gestures or facial reactions. These patients will be limited in their ability to infer your intentions or behaviors. Restrictive behaviors that might be observed in the office include difficulty transitioning into and out of the appointment, an atypical reaction to sensory stimuli (particularly if the office is loud), and repetitive play (opening and closing doors, turning lights on and off, lining up objects). Patients may also have an overattention to specific objects, which may be observed.[23,24]

How Can Stressors in Patients With ASD Be Managed in Health Care Settings?

When first working with a patient with ASD, it is important to learn about the patient from the parents, school, and other caregivers, as direct interviews of the patient may not provide a full picture of their needs. It is often helpful to ask caregivers about the child's communication strategies, including voice output devices and visual aids. When patients are hospitalized, it is useful to learn about preferred and nonpreferred foods (eg, texture and flavor), as people with ASD can have sensory sensitivities or be picky eaters.

If a patient requires hospitalization, continuing preadmission routines can facilitate the best chance of success for minimizing distress, particularly bedtime routines. The treatment team should be encouraged to utilize the child's specific communication strategies.

Distress can also be minimized if they have their favorite items with them or are accompanied by family members. Embarking upon a multidisciplinary approach to the patient is prudent. It helps to identify the patient's unique triggers and signs that they are becoming distressed and then provide these to the treatment team as they enter the room, especially as triggers may not be obvious.

If a child is presenting with a behavioral disturbance and has limited communication skills, it is even more critical to investigate potential medical etiologies. Seizures and sleep changes can be mistaken for behavioral disturbance. If ASD has an associated genetic etiology, this can suggest other sources of stress.[25]

Are There Typical Triggers for Disruptive Behaviors?

Evaluating new potentially unsafe behaviors requires a structured approach. In the home and school settings, triggers for disruptive behavior may arise from a variety of sources, including the behaviors that serve as a means of communicative intent or awareness of pain or discomfort.[24] In the hospital, disrupted routines are common and can serve as a trigger for a child who is particularly reliant on routines; this is further complicated by the numerous and ever-changing members of the treatment team. Sensory processing concerns are common in individuals with ASD, and loud sounds, bright lights, and painful interventions contribute to further distress. Each of these triggers causes a child with a history of agitation to be at risk for becoming agitated in the hospital.[26]

Which Pharmacologic Strategies Can Be Used in Patients With ASD and Behavioral Dysregulation?

Unfortunately, there are no pharmacologic strategies that can effectively treat the core components of autism. For this reason, medications should not be considered as the first-line management of behavior, especially if behavioral changes are acute in development. Instead, it is more useful to focus on behavioral interventions. In cases where agitation might lead to safety concerns for the patient, medications should be utilized.

When hospitalized, irritability and agitation can be managed with α_2 agonists, including guanfacine and clonidine.[12] Severe agitation is often treated with second-generation antipsychotics (SGAs); the 2 FDA-approved medications are risperidone and aripiprazole; however, other SGAs may be considered based on their side effect profile.[27] These same medications can also be used on an outpatient basis for longstanding behavioral concerns. The target symptoms should be identified after extensive discussion with the family to avoid polypharmacy and unclear expectations. Collaboration with a child psychiatrist, child neurologist, and/or developmental pediatrician are recommended in these instances. Medications to avoid in those with ASD include benzodiazepines and medications with a high anticholinergic burden, as these can lead to a paradoxical worsening of behavior.[27]

What Training Is Available for Office and Hospital Staff Caring for Patients With ASD?

Medical students and pediatric residents have reported that they feel ill-prepared to manage the behaviors commonly seen in those with ASD. This is further complicated by misunderstandings of how to best communicate to children and adults with ASD.[28] Many toolkits have been born out of this need, including the Autism Speaks tool kit[29] and the American Academy of Pediatrics autism tool kit,[30] which provide handouts for parents and health care providers. The Autism Case Training curriculum includes case-based learning opportunities, with residents showing an objective and self-perceived improvement in knowledge around the management of autism-related behaviors.[31]

Can Telemedicine Visits Facilitate Timely and Effective Care for Patients With ASD?

Telemedicine can be more convenient, more cost effective, and less stigmatizing, particularly as its availability has improved during the COVID-19 pandemic. Throughout the pandemic, families below the poverty line or in rural populations have suffered disproportionately from access to care and timely diagnosis of autism (as earlier diagnosis is critical for immediate intervention and better outcomes).[32] This was reinforced before the pandemic in studies of evaluation for language deficits, which showed a high correlation and reliability with in-person evaluations.[33] Since the start of the COVID-19 pandemic, research on the efficacy of telemedicine has rapidly increased due to the increased reliance on these services and the improvement of technology that surrounds them.

Reviews of technology, its availability, and the specific modality have shown mixed results. Applied behavioral analysis, functional communication training, and social communication have been effective when delivered via telehealth interventions.[32] Brief behavioral interventions for ASD have been effective and have increased family satisfaction.[34]

What Does the Future Hold for Individuals With ASD?

Although FDA-approved medications for autism behavioral treatment is limited to aripiprazole and risperidone, many medications are under consideration for treatment of ASD. These include medications that address the lower GABA activity (eg, bumetamide, cannabinoids, arbaclofen) and the mitochondrial dysfunction (Anavex 2–73) observed in many subtypes of ASD. Oxytocin has shown early promising results

in its utility for social aspects of ASD. Gene therapy is still in its earlier stages of development; however, it has been shown to be promising for other genetic disorders and is a rapidly growing field of study.[35]

Given the rapid growth of autism research, the Lancet Commission on the future of care and clinical research in autism has placed an emphasis on studies that can directly impact the therapeutic management of autism, particularly in the effectiveness of new interventions across the life span.[36] This emphasis supports the benefit on quality of life that has been previously observed in more individualized treatment plans.[36]

What Happened to AB?

Using the outpatient provider's recommendations, the ED team made a concerted effort to reduce sensory stimuli for AB (eg, dimming the lights, silencing alarms, and providing him with headphones to muffle sounds). A full examination was performed, and his ears were found to have erythema and bulging of the tympanic membrane. Antibiotics were initiated for his ear infection. His parents and treatment team encouraged him to use his communication board throughout the remainder of his encounter. With adequate pain treatment, AB's parents were reassured they could bring him home. AB and his parents followed up several days later in the clinic and reported AB's behaviors had returned to normal. The outpatient provider decided after further discussion with AB's parents that starting a medication to manage aggression would be unnecessary, as his behavior was more likely a result of his ear infection.

CONCLUSION

ASD is an umbrella term for a set of features that come from a varying and ever-expanding list of etiologies. Due to the common features of rigidity and difficulties with social communication, navigating the health care system brings a unique set of challenges to outpatient and inpatient settings. Since there are no medications that treat the core symptoms of autism, medications may be considered if there is a safety concern or if agitation is not sufficiently addressed by behavioral interventions. If there is an acute change in behavior, it is important to assess for any possible underlying medical etiologies that may be contributing to the patient's presentation. Although there have been many advancements in the management of ASD via telehealth and the promise of medications ahead, further research is still needed.

Article Information

Published Online: March 5, 2024.
https://doi.org/10.4088/PCC.23f03584

Submitted: June 16, 2023; accepted December 13, 2023.

To Cite: Burke H, Jiang S, Stern TA. Management of individuals with autism spectrum disorder in clinical settings. *Prim Care Companion CNS Disord.* 2024;26(2):23f03584.

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Relevant Financial Relationships: None.

Funding/Support: None.

References

1. American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders*. 5th Edition, Text Revision. 2022.
2. Lai M-C, Lombardo MV, Baron-Cohen S. Autism. *Lancet.* 2014;383(9920):896–910.
3. Cohen D, Pichard N, Tordjman S, et al. Specific genetic disorders and autism: clinical contribution towards their identification. *J Autism Dev Disord.* 2005;35(1):103–116.
4. Maenner MJ, Warren Z, Williams AR, et al. Prevalence and characteristics of autism spectrum disorder among children aged 8 Years–Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2020. *MMWR Surveill Summ*. 2023;72(2):1–14.
5. Baird G, Charman T, Baron-Cohen S, et al. A screening instrument for autism at 18 months of age: a 6-year follow-up study. *J Am Acad Child Adolesc Psychiatry.* 2000;39(6):694–702.
6. Swinkels SH, Dietz C, van Daalen E, et al. Screening for autistic spectrum in children aged 14 to 15 months. I: the development of the Early Screening of Autistic Traits Questionnaire (ESAT). *J Autism Dev Disord.* 2006;36(6):723–732.
7. Robins DL, Fein D, Barton M. *The Modified Checklist for Autism in Toddlers (M-CHAT).* Self-published; 1999.
8. Wetherby A, Prizant B. *The Infant Toddler Checklist From the Communication and Symbolic Behavior Scales*. Baltimore: Brookes Publishing; 2002.
9. Allison C, Baron-Cohen S, Wheelwright S, et al. The Q-CHAT (Quantitative CHecklist for Autism in Toddlers): a normally distributed quantitative measure of autistic traits at 18-24 months of age: preliminary report. *J Autism Dev Disord.* 2008;38(8):1414–1425. Published online Feb 1, 2008.
10. Stone WL, Coonrod EE, Turner LM, et al. Psychometric properties of the STAT for early autism screening. *J Autism Dev Disord.* 2004;34(6):691–701.
11. Rutter M, LeCouteur A, Lord C. Autism Diagnostic Interview–Revised. Los Angeles: Western Psychological Services. 2003, 2008.
12. Wing L, Leekam SR, Libby SJ, et al. The Diagnostic Interview for Social and Communication Disorders: background, inter-rater reliability and clinical use. *J Child Psychol Psychiatry.* 2002;43(3):307–325.
13. Skuse D, Warrington R, Bishop D, et al. The Developmental, Dimensional and Diagnostic Interview (3di): a novel computerized assessment for autism spectrum disorders. *J Am Acad Child Adolesc Psychiatry.* 2004;43(5):548–558.
14. Lord C, Risi S, Lambrecht L, et al. The Autism Diagnostic Observation Schedule-Generic: a standard measure of social and communication deficits associated with the spectrum of autism. *J Autism Dev Disord.* 2000;30(3):205–223.
15. Chlebowski C, Green JA, Barton ML, et al. Using the Childhood Autism Rating Scale to diagnose autism spectrum disorders. *J Autism Dev Disord.* 2010;40(7):787–799.
16. Gjevik E, Eldevik S, Fjæran-Granum T, et al. Kiddie-SADS reveals high rates of *DSM-IV* disorders in children and adolescents with autism spectrum disorders. *J Autism Dev Disord.* 2011;41(6):761–769.
17. Bai D, Yip BHK, Windham GC, et al. Association of genetic and environmental factors with autism in a 5-country cohort. *JAMA Psychiatry.* 2019;76(10):1035–1043.
18. Montanari M, Martella G, Bonsi P, Meringolo M. Autism spectrum disorder: focus on glutamatergic neurotransmission. *Int J Mol Sci.* 2022;23(7):3861.
19. Pavăl D. A dopamine hypothesis of autism spectrum disorder. *Dev Neurosci.* 2017;39(5):355–360.
20. Vasa RA, Mostofsky SH, Ewen JB. The disrupted connectivity hypothesis of autism spectrum disorders: time for the next phase in research. *Biol Psychiatry Cogn Neurosci Neuroimaging.* 2016;1(3):245–252.
21. Markram K, Markram H. The intense world theory–a unifying theory of the neurobiology of autism. *Front Hum Neurosci.* 2010;4:224. >
22. Clements CC, Zoltowski AR, Yankowitz LD, et al. Evaluation of the social motivation hypothesis of autism: a systematic review and meta-analysis. *JAMA Psychiatry.* 2018;75(8):797–808.
23. Hyman SL, Levy SE, Myers SM; Council on Children With Disabilities, Section on Developmental and Behavioral Pediatrics. Identification, evaluation, and management of children with autism spectrum disorder. *Pediatrics.* 2020;145(1):e20193447.

24. Mandell DS, Novak MM, Zubritsky CD. Factors associated with age of diagnosis among children with autism spectrum disorders. *Pediatrics*. 2005;116(6):1480–1486.
25. McGuire K, Erickson C, Gabriels RL, et al. Psychiatric hospitalization of children with autism or intellectual disability: consensus statements on best practices. *J Am Acad Child Adolesc Psychiatry.* 2015;54(12):969–971.
26. Thom RP, Hazen MM, McDougle CJ, et al. Providing inpatient medical care to children with autism spectrum disorder. *Hosp Pediatr.* 2020;10(10):918–924.
27. Hazen EP, Ravichandran C, Rao Hureau A, et al. Agitation in patients with autism spectrum disorder admitted to inpatient pediatric medical units. *Pediatrics*. 2020;145(suppl 1):S108–S116.
28. Austriaco K, Aban I, Willig J, Kong M. Contemporary trainee knowledge of autism: How prepared are our future providers? *Front Pediatr.* 2019;7:165.
29. Autism Speaks. Tool Kit. Accessed February 15, 2024. https://www.autismspeaks.org/tool-kit
30. American Academy of Pediatrics. Caring for Children With Autism Spectrum Disorder: A Practical Resource Toolkit for Clinicians, third edition. Accessed February 15, 2024. https://publications.aap.org/toolkits/pages/Autism-Toolkit?autologincheck=redirected
31. Major NE. Autism education in residency training programs. *AMA J Ethics*. 2015;17(4):318–322.
32. Ellison KS, Guidry J, Picou P, et al. Telehealth and autism prior to and in the age of COVID-19: A systematic and critical review of the last decade. *Clin Child Fam Psychol Rev.* 2021;24(3):599–630.
33. Sutherland R, Trembath D, Hodge MA, et al. Telehealth and autism: are telehealth language assessments reliable and feasible for children with autism? *Int J Lang Commun Disord.* 2019;54(2):281–291.
34. Corona LL, Stainbrook JA, Simcoe K, et al. Utilization of telemedicine to support caregivers of young children with ASD and their Part C service providers: a comparison of intervention outcomes across three models of service delivery. *J Neurodev Disord.* 2021;13(1):38.
35. Aishworiya R, Valica T, Hagerman R, et al. An update on psychopharmacological treatment of autism spectrum disorder. *Neurotherapeutics.* 2022;19(1):248–262.
36. Lord C, Charman T, Havdahl A, et al. The Lancet Commission on the future of care and clinical research in autism. (published correction appears in Lancet. 2022 Dec 3;400(10367) *Lancet.* 2022;399(10321):271–334.