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Autism Spectrum Disorder in the Emergency Department

Definition

Autism refers to a general category of multiple related neurodevelopmental conditions that generally are characterized by some combination of difficulties in communication, impairment in social interactions, repetitive behaviors, and constricted interests.¹ Since the first description of autism in the literature more than 70 years ago, the definition and diagnostic features have changed substantially. The most recent update came with the publication of the *Diagnostic and Statistical Manual of Mental Disorders*, 5th edition (DSM-5) in 2013, which reclassified multiple separate but related etiologies under the umbrella term of autism spectrum disorder (ASD).² Some of the reclassified disorders include pervasive developmental disorder not otherwise specified (PDD-NOS) and Asperger's disorder.³

Classed under neurodevelopmental disorders, ASD has five diagnostic criteria: 1) persistent deficits in social communication and social interaction across multiple contexts; 2) restricted, repetitive patterns of behavior, interests, or activities; 3) symptoms must be present in the early developmental period; 4) symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning; and 5) are not better explained by intellectual disability or developmental delay.³ (See Table 1.) Also included in the diagnostic criteria are specifiers to label comorbidities, such as intellectual impairment, language impairment, comorbid medical or genetic condition, catatonia, and comorbid additional neurodevelopmental disorder, mental disorder, or behavioral disorder. In addition to these criteria for diagnosis, there also exists a set of severity specifiers meant to categorize the level impairment, levels 1 through 3, which are requiring support, requiring substantial support, and requiring very substantial support, respectively.³

Providers not specializing in disorders such as ASD may use a stereotyped definition of autism or only consider a clinical presentation based on old misconceptions. There is a widely held belief that the typical presentation of ASD is that of a nonverbal or minimally verbal child who is unengaged or does not listen to their parent, has behavioral difficulties, and may be aggressive. Although there may be patients who fit this description, there are more patients with ASD who do not. A community has formed around the diagnosis, both for parents of children with ASD as well as for adolescents and adults themselves with ASD.⁴ The terminology used with ASD has changed over the years, with a shift toward adopting a person-first perspective (e.g., person with autism as opposed to autistic person); however, this is not ubiquitous, and there are a significant number who oppose the shift and have attempted to reclaim the descriptor "autistic" as an integral part of their identity.⁵ The developed community also has begun to change the terminology used in reference to ASD. Some terms that may be used instead include "neurodiverse," "neurodivergent," or "neuroatypical."^{4,6}

EXECUTIVE SUMMARY

- Behavioral aspects of autism spectrum disorder (ASD) involve both persistent deficits in social communication and social interaction and restricted, repetitive patterns of behavior, interests, or activities.
- The current prevalence of ASD in the United States is about 2%.
- Adolescents with ASD are more likely to visit the emergency department (ED) than their non-ASD peers.
- Common conditions seen in the ED for patients with ASD include epilepsy, gastrointestinal disorders, and dental disease.
- Pace the ED assessment and treatment of the patient with ASD according to the patient's acceptance of different steps and processes without undue stress.
- Communicate with the patient using methods described by the family or caregiver.
- Anxiolysis and sedation may be required for evaluation or minor procedures.

Epidemiology and Incidence

The reported prevalence of ASD has been rising over the past 30 years. Some of the presumed influences to this increase include a broadening of the definition with the publication of the DSM-IV in 1994, increased public awareness, implementation of screening programs, and increased accessibility of early intervention programs. The current estimated prevalence in the United States ranges from approximately one in 40 to one in 59 or between 1.7% and 2.5% of the population.^{7,8}

Classically, a male predominance has been described, although the rates have varied from as high as 4-5:1 male to female ratio to as low as 2-3:1, with an increasing rate of diagnosis of female patients in recent years.¹ There also are trends in diagnosis across both socioeconomic strata and racial boundaries that suggest continued disparity in the timing of diagnosis. Specifically noted have been lower rates in the Hispanic population compared to non-Hispanic white and Black children. Recently, the prevalence in Hispanics has started to rise as well, with earlier diagnosis and intervention being associated with increased public awareness and screening. Diagnosis in individuals who are more intelligent also tends to be delayed, most prominently in Black and Hispanic children.⁷ Early diagnosis in all cohorts is associated with higher socioeconomic status.

Pathophysiology of ASD

Several theories have been proposed for the cause of autism. There is compelling evidence for a genetic predisposition based on rates between siblings and even more strikingly between twins.⁷ Copy number

variants (when the number of copies of a particular gene varies from one individual to the next) have been shown to be pathogenic (either with duplications or deletions) and associated with ASD.⁷

Environmental factors and multiple perinatal factors have been shown to be associated with an increased risk of development of ASD. These include certain in utero drug exposures, advanced parental ages, and other intrapartum risk factors; however, no causal relationships have been determined. Other associations that have been noted include structural differences in the brain attributed to abnormal prenatal brain development in areas such as neuronal migration and altered neurogenesis.⁷ Another popularly claimed cause of ASD — vaccines — has not been shown to be related to risk for development of ASD.⁷

Diagnosis of ASD

Suspicion for the diagnosis of ASD usually starts in the primary care provider's office. There are several screening tools used in the United States, such as the Modified Checklist for Autism in Toddlers (M-Chat), the Ages and Stages Questionnaire (looks at development in general), and the Communication and Symbolic Behavior Scale.^{9,10} From here, further assessment by psychologists, psychiatrists, or developmental and behavioral specialists may use diagnostic instruments such as the Autism Diagnostic Observation Schedule (ADOS) and the updated version ADOS-2, as well as tools to help assess symptoms and functioning, such as the Childhood Autism Rating Scale.¹¹ These assessments allow for referral to various resources to assist the patient in the areas of functioning in which they have difficulty.

There has been a push toward early diagnosis to facilitate early intervention, including the 2020 Healthy People Campaign which has the goal to increase the proportion of children diagnosed with ASD who receive their first developmental evaluation by 36 months of age.¹² The Centers for Disease Control and Prevention (CDC) also has worked to increase awareness of ASD with marketing campaigns that discuss signs and symptoms of developmental concerns, such as with their "Learn the Signs. Act Early" program.

ASD can be diagnosed as early as 12 months of age, although it is diagnosed more commonly between the ages of 3 and 5 years, with patients with more mild symptoms diagnosed even later.^{7,11} In general, the younger the patient is diagnosed, the more likely they are to have more severe disease and language impairment.⁷

Laboratory testing and neuroimaging are not required, but they may be done to exclude conditions with similar behavior manifestations. Genetic testing has no clinical utility, but can be done for suspicion of comorbidity, concern for syndromic condition, or for educational and academic purposes.¹³

Presentation of ASD

ASD is a heterogenous disorder, the label of which encompasses a wide variety of presentations. Some patients will demonstrate no obvious characteristics of ASD during a clinical encounter, while others are noted to be profoundly affected with significant functional impairment. Adult outcome measures tend to focus on different domains of life, such as ability to work, ability to live independently, and participation in friendships/relationships.¹⁴

Table 1. DSM-5 Diagnostic Criteria for Autism Spectrum Disorder

1. Persistent deficits in social communication and social interaction
Must have involvement of all of the following subdomains:
 - Social reciprocity
 - Nonverbal communication
 - Developing, maintaining, and comprehending relationships
2. Restricted, repetitive patterns of behavior, interests, or activities
Must have involvement of two of the four following subdomains:
 - Stereotyped, repetitive behaviors
 - Insistence of sameness
 - Restricted, fixed interests
 - Altered sensitivity
3. Symptoms begin during the early developmental period
4. Symptoms cause clinically significant impairment in functioning
5. Symptoms are not better explained by intellectual disability or developmental delay

Adapted from: American Psychiatric Association. Neurodevelopmental disorders. In: *Diagnostic and Statistical Manual of Mental Disorders*, 5th ed. 2013:31-86.

Of adults with ASD, an estimated 10% to 33% have intelligence quotients (IQs) that fall within the category of intellectual disability and require substantial support.¹¹ Services for adults with ASD are not as robust as those for children. Depending on the level of support that the patient requires, they may present from an independent living situation, a group home, or with family. The amount of history that the patient can provide on their own also may vary considerably. It also is important to note that while categorization by level of support needed (previously by level of functioning) is now a part of diagnostics and billing, it does not reflect the individual challenges or needs of a person with ASD.

In the pediatric population, functional status is based on the level of support that the patient requires, generally in the school setting since there are many supports and resources through the public school system. Of children with ASD, approximately 30% are minimally verbal and approximately 30% have intellectual disability, with overlap between the two groups.⁷ In a large sample intended to be representative of the population as a whole, for social communication, 30% of the patients were categorized as requiring support, 45% as requiring substantial support, and 25% as requiring very substantial support, whereas for restrictive and repetitive behavior, 44% were labelled as requiring support, 39% as requiring substantial support, and 17% as requiring very substantial support.¹⁵

Many patients with ASD will not have any dysmorphia or visual cues as to their diagnosis. There are a variety of stereotyped behaviors that may be present, both motor and vocal, that may be a tip off that a patient has ASD. Some of the common actions that may be seen include repetition of words or phrases, echolalia (repetition of sounds or words voiced by another); repetition of nonword sounds; repetitive movements, such as hand flapping, rocking, toe walking, object spinning or manipulation, sniffing, head rolling; and movement of objects in the peripheral vision.^{16,17} Patients also may display fixations or restricted interests and a need for strict routine, which may lead to more complex behaviors.

Although stereotyped behaviors are part of the diagnosis of ASD, they do not make the diagnosis alone, and multiple other conditions also can have stereotypy, or the persistent repetition of an act without obvious purpose, as a facet of presentation.¹⁷ Given the restrictive patterns of behavior, changes in routine or environment may present a challenge and precipitate behavioral difficulties as a response to stress. Depending on the level of communication the patient is capable of, it can be difficult for the patient to express their discomfort or anxiety in a way that is understood well by providers and staff.

Sensory processing problems may contribute as well. Notably, sensory modulation difficulties can present as either under-responsiveness or, more commonly,

over-responsiveness, which is an over-reaction to ordinary sensory inputs or an out of proportion response to only mildly noxious input.¹⁸ Some patients with ASD also experience motor apraxia, the difficulty with motor planning and the ability to physically execute tasks, which may look like they are not understanding a request or refusing to participate, but may be an inability to coordinate the action.¹⁹

Comorbidities with ASD

There are multiple developmental comorbidities associated with ASD that can dramatically vary the presentation, functional needs, and treatment of an individual. The patient with ASD may have significant overlap with intellectual disability, language disorders (which previously were part of the diagnostic criteria but no longer are), attention deficit hyperactivity disorder (ADHD), tic disorders, and motor abnormalities. Many of the school-based interventions work toward treating or accommodating for these comorbidities.

From the medical perspective, significant comorbidity exists between ASD and epilepsy, gastrointestinal disorders (specifically constipation, gastroesophageal reflux disease, inflammatory bowel disease, celiac, and various chronic gastrointestinal symptoms), various genetic syndromes (most notably fragile X, tuberous sclerosis, Angelman, and CHARGE syndrome), previously Rett syndrome — although this has been separated in the DSM-5 — as well as several others), immune dysregulation, and insomnia.

Psychiatrically speaking, there is overlap with anxiety and depression (both of which are common in high functioning individuals), obsessive compulsive disorder, substance use disorders, psychotic disorders, oppositional defiant disorder, eating disorders, and various personality disorders. Of these, anxiety and depression are by far the most common.^{7,20} These comorbidities also help shape the complaints of what brings patients into the emergency department (ED).

Treatment of ASD

The mainstay of treatment for ASD has been behavioral interventions, with the most commonly used being applied behavioral analysis (ABA). This is an intensive intervention intended to break up tasks into step-by-step routines while

simultaneously reducing undesirable interference and reinforcing desired behaviors.²¹ The method is based in operant conditioning, attempting to understand what an undesirable behavior is attempting to achieve, provide alternative expressions (a replacement behavior) to achieve a similar goal, and reinforce appropriate alternative behaviors when they are displayed with positive reinforcement as well as aversive consequences.^{22,23}

There are several subtypes of ABA that are used dependent on the child's age and the type of behavior or targeted skills to be reinforced. In general, most forms of ABA therapy require commitment from parents or guardians since they are intended to be used frequently and with consistency, requiring reinforcement in the home.²⁴

There has been some controversy within the autism community regarding the use of ABA therapy and its potentially negative effects. Some of the concerns involve the use of aversive consequences, which historically involved painful or noxious stimuli that either were stopped when the desired behavior was performed or used as negative reinforcement when an unwanted behavior was performed.²⁵ Many current iterations of ABA no longer incorporate aversive consequences.

Other concerns broached by disability advocates, especially from those within the autism community, include that not all of the behaviors targeted by ABA are maladaptive or harmful and do not help the individual other than in conformation to societal norms, and the use of communication styles the patient struggles with instead of accommodating those they use well.^{25,26} The overarching concern is that the goal and outcomes of ABA therapy are normalization of behaviors to conform with societal expectations rather than providing accommodations and resources to allow the person to best use their strengths and provide support in emotionally healthy ways. Regardless of the controversy, ABA is a frequently used therapy for ASD that may be seen used by caregivers the ED setting.

Other therapies and supports are used based on the individual patient's needs. Speech and occupational therapy are used commonly.²⁷ For patients with sensory processing difficulties, sensory integration therapy may be used.¹

Alternative treatments are used sometimes, although not always, under the supervision of a physician and often with a poor evidence basis. These include vitamin therapy/dietary supplements, heavy metal chelation therapy, intravenous immunoglobulin (IVIG), hyperbaric oxygen therapy, hormonal treatments, dietary alterations, and probiotics.²⁰ Another treatment that has been popular in recent years in social media is the use of "Miracle Mineral Solution," containing an industrial bleaching agent, chlorine dioxide. The U.S. Food and Drug Administration (FDA) has published repeated warnings against its use.²⁸ Patients may present to the ED with complications that develop as a result of these treatments.

Pharmacologic treatments may be used for management of comorbidities. Some of the commonly used medications include antipsychotics, mood stabilizers, stimulants, and selective serotonin reuptake inhibitors (SSRIs), depending on psychiatric and behavioral comorbidities.²⁰

Transition from Pediatric to Adult Care

Multiple interventions demonstrated in the pediatric literature have been shown to improve care of the patient with ASD and to provide a more satisfying and safe medical experience. Pediatric emergency departments often are less noisy, staffed by providers and ancillary staff who are comfortable with a variety of developmental levels, and have resources to help with coping during exams and procedures that are not frequently used or needed in adult emergency departments. Similar themes have been noted throughout primary care offices, pediatric specialist offices, and pediatric dental offices.

The transition from pediatric to adult care coincides with the timing when many adolescents and young adults are leaving school, with the loss of school-provided resources and support. Another often important support is parental figures or guardians — during the transition period to adult care, there is an expectation that the individual will take over most, if not all, aspects of their medical care, and this is a furthered necessity secondary to privacy restrictions, which provide important but sometimes difficult to navigate autonomy for some patients that provokes anxiety.²⁹ Although some patients require a legal

guardian into adulthood, for those who do not, learning to navigate the healthcare system can prove difficult. Some of the supports that are available to adults include vocational training and life skills training, although the evidence for the efficacy of this has not been demonstrated, and these services are not as widely available as pediatric services.¹

Care of the Patient with Autism

Patients with ASD can present to the ED for any reason that patients present in general. Certain complaints comprise a greater percentage of ED visits, based on frequent comorbid conditions and unique risk factors. Adolescents with ASD have been shown to access ED services at rates four times as often as peers, although these rates are variable based on age, gender, and rural vs. urban EDs.³⁰ Females with ASD use the ED at higher rates than males with ASD.³¹ These trends in ED use continue into adulthood.³²

In both adolescents and adults, visits with a psychiatric complaint comprise a greater percentage of visits than in the general population.^{30,32} There is a lack of appropriate outpatient resources, especially mental health resources for adults with ASD which may predispose to increased ED usage.³² Other common reasons for ED visits include epilepsy, diabetes, and falls. Higher admission rates have been documented in both adolescents and adults with ASD.^{30,32}

For adolescents, neurologic complaints, including seizures, and gastrointestinal complaints make up a higher percentage of visits than in adolescents without ASD.^{30,33} Some of the risk factors associated with increased ED use in adolescents include older age, female sex, comorbid psychiatric disease, and comorbid intellectual disability.³¹

Although there is little literature on the care of adult patients with ASD in the ED, many of the interventions identified in the pediatric literature can be applied to adult patients. Care in non-pediatric facilities is quite different than care in pediatric facilities, suggesting that the application of these interventions may improve care.³⁴ Multiple studies across various healthcare professionals have shown a discomfort and feeling of insufficient education on the care of patients with ASD in general.^{35,36}

One study by Nicholas et al looked at parental perspective on ED experiences and noted a theme of parental hesitancy to come to the ED due to anticipation that the visit would be a struggle for the child. Some of the concerns noted were related to ED processes, such as transition/movement to different departments (e.g., radiology), sensory stimulation in the ED, misinterpretation of complaints due to lack of understanding of communication difficulties or ineffective communication with the patient, lack of staff knowledge about ASD, perceived judgment of behavioral challenges, lack of interaction with the child at all (only addressing the parents even when addressed by the child), availability/allowance of distraction techniques to be used, lengthy waits or strict timelines (not allowing time prior to a procedure to adequately prepare a child), and unnecessary or overuse of restraint or sedation.

Some of the potential interventions described as helpful by parents included minimizing staff in the room, shortening wait times (due to the uncontrolled environment, sound level, and bright lights), increased staff education about ASD, clear communication, focus on individual needs of the child, and incorporation of parental suggestions as to how to best interact with the child. In multiple surveys, parents have recognized the importance of patients being seen in order of acuity and did not express that as the specific challenge, but rather the environment in which they were waiting.^{34,37}

Based on the findings noted earlier by Nicholas et al, further work was done with development of focus groups made up of ED clinicians, ED administrators, and parents of children with ASD to try to assess the status of current ED care and delineate priorities for improvement with the aim to further expand on issues raised in the initial study as well as to propose possible solutions. Specific areas of gaps in care include the identification and early addressing of individual sensitivities, management of difficulties associated with ED wait, use of restraints and sedation, and staff training (specifically in de-escalation skills). Some suggestions borne from this project include the development of a standardized method for identifying and collating ASD-related needs, such as a screening tool, alternative waiting spaces, use of child-focused resources such as child

life, and staff education. Another questionnaire directed at parents of children with ASD who had received care in an ED or urgent care noted similar themes, with the predominant driver of the quality of the interaction and patient satisfaction being the interpersonal and communication skills of the staff.³⁸

A survey by Muskat et al looked at an issue that is taken for granted: the disclosure of a diagnosis of ASD. Prior data had shown that not all visits by patients with ASD were recognized as such, and this survey attempted to investigate what some of those reasons may be. It was noted that parental disclosure of a child having ASD was not a given, although it is part of the medical history, secondary to a concern for stigma and negative labeling or because they did not want to disclose in front of the child. The benefits of disclosure were recognized by parents and include a hope for reducing judgment (specifically around behavioral concerns), receiving more individualized care, and possibly expedited care.³⁹ As was noted with the benefits described, disclosure can be a positive experience and trying to optimize the facets of care that have been shown to be a challenge to patients with ASD can help to continue validating decisions to disclose.

Special Considerations for Patients with ASD

Patients with ASD experience some healthcare concerns that are less common in other populations and may affect their ED evaluation and management. Given the difficulties some individuals experience with sensory modulation, taste, texture, and smell can become problematic, leading to restrictive diets. Some of these diets are so restrictive that uncommon nutritional deficiencies can be seen, leading to diseases such as scurvy, vitamin A deficiency, vitamin D deficiency, iron deficiency anemia, pyridoxine deficiency, and thiamine deficiency.⁴⁰ Although presentations of these diseases are not common in general ED practice, it is important to keep them in mind when assessing patients with ASD. Scurvy, for example, can cause pain and limp, which may be mistaken for an infectious or traumatic cause.^{41,42} There have been case reports of status epilepticus in the setting of pyridoxine deficiency, hepatic dysfunction in the setting of thiamine

deficiency, and ophthalmologic complaints in the setting of vitamin A deficiency.^{40,43}

These same sensory issues, as well as communication challenges, can make dental care difficult to provide to patients with ASD. Dental caries and dental infections are common in patients with ASD and may go untreated secondary to difficulty in obtaining care.⁴⁴ Dental trauma may be secondary to a variety of factors, including self-injurious behavior, bruxism, and higher rates of malocclusion.^{44,45} This may be a source of pain or infection in a patient who is unable to communicate effectively.

Another consideration for children with disabilities is the possibility of child abuse and nonaccidental trauma, which is encountered at higher rates in this population. This is thought to be secondary to a combination of increased vulnerability, higher caregiver stress, and an elevated dependency on caregivers.⁴⁶ Although these same risk factors are applicable to many patients with ASD, the limited data available are mixed regarding rates of referrals, investigation, and substantiation, but they do show a trend toward increased rates of child maltreatment.⁴⁷⁻⁴⁹ This may be at least partially due to the heterogeneity of ASD and the range of developmental delay and intellectual disability, both of which would predispose individuals to maltreatment. It is important to keep a high index of suspicion for nonaccidental trauma and child abuse for patients with ASD, especially for those with difficulty in communicating.

Care Approaches

There have been multiple approaches described for the care of patients with ASD in various settings, but one ED-specific approach described is the child and family centered care in the ED model, which has six components: respect for the child and family, rapid assessment of ASD needs, wait time management, sensory environment containment, collaboration, and responsiveness in care.³⁷ This highlights some of the key issues that can be focused on to help improve experiences in the ED for patients with ASD as well as for providers.

Another approach specific to ED care is the “See-Hear-Feel-Speak” protocol.⁵⁰ “See” refers to reducing excessive visual stimuli, dimming the lights when possible, and reducing any flickering or flashing of

lights. “Hear” involves reducing any excessive auditory stimuli, including alarms, beeping, muting the television, trying to pick a room in a quieter area of the ED, and being aware of environmental sounds such as air conditioners or the sounds of using the computer during the interaction. “Feel” suggests looking at tactile inputs and can include asking patients or caregivers if there are any textural inputs that the patient finds either calming or aggravating to see if these stimuli can be either provided or avoided as appropriate. “Speak,” the final component, recommends saying aloud in simplistic language everything that will be done even if the patient is nonverbal, such as prior to physical exam maneuvers or procedures. Additionally, speaking to the patient should be done from directly in front of the patient to avoid difficulties in sound localization.⁵⁰

One group published a model for an instrument to be completed by patients and caregivers prior to the necessity of ED care that could be kept on file to allow for more personalized care. Some of the items encompassed in this instrument included descriptions of the patient’s baseline in terms of normal interactions, communication abilities, social interaction, medical history, dietary patterns, sleep patterns, comfort objects, environmental factors or communication techniques that the individual may find agitating, how the patient typically expresses themselves (in terms of choices, pain, or frustration), techniques that work for the patient for calming or distraction, and previously used medications for pain or sedation.⁵¹ Although this instrument or something similar is not in widespread use at this time, it does provide a framework for some of the questions it may be helpful to ask depending on the clinical scenario.

Other care approaches, such as the medical home, patient and family centered care, and circles of care, have been described, although they focus more on the primary care setting and coordination of care across the medical system, which may involve the ED as well as various subspecialties and therapies. These approaches generally advocate for availability of information to all providers to help in providing the most individualized care so patients may have a medical passport either to bring with them or in the electronic medical record, integration of

both the patient and caregivers as key parties working collaboratively in conjunction with physicians toward healthcare goals, and treating all parties with dignity and respect.⁵²⁻⁵⁴

It should be noted that all approaches are generalizations and should be adjusted as necessary to incorporate specific needs as brought up by the patient or caregiver. Asking general questions of the patient or family such as “Do you need any accommodations?” and “Do you have any special needs?” can be a helpful screening for patients that may require more thoughtfulness. More nuanced questions such as “What is your preferred communication method,” “What helps you cope with pain or stress,” and “What things in the doctor’s office or hospital bother you?” may help tailor care to provide the best experience for all involved.

Pharmacologic Anxiolysis and Procedural Sedation

Frequently used methods for facilitating exams and procedures in a safe manner are pharmacologic anxiolysis and procedural sedation. Often thought of for painful procedures specifically, procedural sedation also has been widely used in pediatric populations in situations where immobility is required. For patients with ASD, one of the more common uses of sedation includes dental exams; however, use of sedation has been well described for ophthalmic exams, painful procedures, and to facilitate diagnostic imaging.^{55,56} One notable difference between the use of sedation in populations with ASD and in those without is that there is an increased use for minor procedures (e.g., gastric tube replacement, rectal enemas, and peripheral intravenous catheter placement).⁵⁵ Sedation can be used to facilitate physical examination.⁵⁵

Various agents have been used for procedural sedation, many of which are familiar to emergency medicine physicians. (See Table 2.) For painful procedures, typical agents — primarily ketamine — are used commonly for patients with ASD.⁵⁵ Propofol, although typically less commonly administered in children for sedation than in adults, also is used. There have been case reports of alternative agents, such as intranasal ketamine, oral ketamine, and intranasal or oral dexmedetomidine.⁵⁷⁻⁵⁹ Multiple dosing strategies

have been studied for oral ketamine; the combination of ketamine 3 mg/kg PO and midazolam 0.25 mg/kg PO has been used successfully.^{58,60}

Although oral dexmedetomidine is not widely used, it has been used in the preoperative setting. There have been studies that have shown that an oral dosing of 1–4 mcg/kg can achieve a relaxed state that may be useful as a premedication for procedural sedation or conducive to the performance of nonpainful activities.⁶¹ Intravenous dexmedetomidine, although infrequently used in the ED, also has been shown to be safe and efficacious for non-painful procedures.^{62,63}

Oral and intranasal midazolam are used frequently for anxiolysis and facilitation of brief procedures and exams in pediatrics in general as well as for patients with ASD.⁶⁴ Use of intranasal medications may be limited by the weight of the individual since volumes greater than 1 mL per nostril may not be fully absorbed.⁵⁷ A survey of pediatric medical directors also showed that for patients with ASD, some facilities used inhaled nitric oxide (NO).⁶⁵

It has been theorized that patients with ASD may require higher doses of medication for procedural sedation, but this has not been borne out in the literature.^{55,66} Adverse event rates seem similar, although there may be a slightly increased risk of emergence reaction when ketamine is used; however, the data are mixed.^{55,65} Some patients with ASD may have received one or more of these medications in the past. If it is a consideration for current treatment, talk with the patient and family about what has or has not worked previously.

Environmental Modification

The ED is not a particularly friendly environment for individuals with sensory processing issues, communication difficulties, or a low tolerance for frustration, which makes the visit inherently more difficult for a person with any of these barriers. Some of the minor annoyances of the ED — bright lights, alarming monitors, uncomfortable, restrictive attachments (such as blood pressure cuffs), and being approached by strangers — can become overwhelming. One study that measured autonomic responses to auditory stimuli noted that children with ASD generally

Table 2. Sample of Medications for Anxiolysis and Moderate Sedation

Medication	Dose	Onset	Duration	Notes
Ketamine	IV: 0.5 to 1.0 mg/kg IN: 0.2 to 1 mg/kg Oral: 3 mg/kg	< 1 min < 10 min 15-30 min	5-10 min 45-60 min 1-4 hours	Risk of emergence reactions; May cause tonic-clonic movements
Propofol	IV: 1 mg/kg to 1.5 mg/kg loading dose followed by 0.25 mg/kg to 0.5 mg/kg q 3-5 min	< 1 min	3-10 min	May cause hypotension and respiratory depression
Dexmedetomidine	Oral: 1 mcg/kg to 4 mcg/kg IV: 0.5 mcg/kg to 1 mcg/kg IN: 2.5 g/kg to 3 g/kg	30-40 min 5-10 min 20-30 min	1-2 hours (dose dependent) 30-70 min 30-45 min	May cause bradycardia and hypotension with IV use
Midazolam	Oral: 0.25 mg/kg to 0.5 mg/kg IV: 0.025 mg/kg to 0.1 mg/kg IN: 0.2 mg/kg to 0.3 mg/kg	10-20 min < 5 min 20-30 min	45 min < 2 hours 30-60 min	May cause respiratory depression
Nitrous oxide	Inhaled: 50% NO/50% O ₂ to 70% NO/30% O ₂	< 5 min	4-5 minutes	Washout with 100% O ₂ for 3-5 min following to decrease adverse effects

IV: intravenous; IN: intranasal

Sources: Meredith JR, O'Keefe KP, Galwankar S. Pediatric procedural sedation and analgesia. *J Emerg Trauma Shock* 2008;1:88-96.

Greenfield L. Nitrous oxide for pediatric sedation. *EM Resident*. Published 10/08/2015. <https://www.emra.org/emresident/article/nitrous-oxide-for-pediatric-sedation/>

Cravero JP, Roback, MG. Selection of medications for pediatric procedural sedation outside of the operating room. UpToDate. Updated April 14, 2020. <https://www.uptodate.com/contents/selection-of-medications-for-pediatric-procedural-sedation-outside-of-the-operating-room>

had stronger sympathetic activation at rest as well as in response to auditory stimuli in comparison to children without ASD. Also shown was a correlation between higher levels of sympathetic reactivity and problematic behavioral responses to sound in daily life.

There was also a subset of patients with increased sympathetic reactivity who were reported to have behaviors more consistent with an under responsive reaction to sound in daily life, which suggests that the behaviors in either direction can be a symptom of the same dysregulation.¹⁸

Some of these inputs can be managed by interventions, such as placing the patient in a private room when possible, dimming the lights, turning off monitors when unnecessary or setting alarms appropriately to prevent unproductive beeping, turning any flashing lights away from the patient, placing the patient away from the busier areas of the ED, and limiting the number of staff members in and out of the room.⁶⁷ Noise cancelling headphones, ear plugs, or white noise may be helpful in reducing sensory input. Certain textures or sensations may provide difficulty, such as the hospital

gown, ID bracelet, or monitor leads.

Consider allowing patients to remain in their own clothing when feasible and offer alternate placement of the hospital bracelet to noncritical patients.⁶⁸ Monitoring should be done as medically appropriate, but in a thoughtful fashion. Allowing breaks in between exams, tests, and procedures also can help prevent overstimulation.⁶⁹

Although some of the key modifications that can be made are subtractive in nature, there are some instances in which adding stimulation may be helpful. Providing distractions can be a helpful coping mechanism for many patients with ASD. Electronics (smartphones and tablets) are used frequently by those with ASD and can help with distraction both while waiting and during exams or procedures.⁷⁰ Fidget objects or sensory toys can allow the patient to control input and provide distraction as well. Weighted blankets and lap pads may provide a grounding sensation or, again, allow controlled input to help overcome stress from unusual, new, or discomforting sensations.⁶⁷ Radiology lead aprons also can be used in place of weighted blankets.⁷⁰

In general, routine is helpful for many patients with ASD, especially for those more functionally impacted. Bringing some of the home routine into the ED may be helpful, especially for those patients with longer lengths of stay.^{71,72} This includes interventions such as administration of home medications at the times they are taken at home, promotion of home sleep/wake cycles, and allowing the presence of comfort objects. Visual schedules, for prolonged stays or boarding, may be helpful.⁶⁸ Allowing a caregiver or support person also may help bring familiarity to the situation and increase comfort.

Communication Adjuncts Used in ASD

The amount by which a patient with ASD is able to communicate verbally is highly variable. For those patients who are less verbal, there are several adjuncts they may use to help improve communication. Communication adjuncts may be generally known as augmentative and alternative communication (AAC), which encompasses a wide breadth of options to assist in communication throughout

different situations.⁷³ These methods can be unaided, such as gestural communication or sign language, as well as aided by various technologies.

Some of the simpler aided systems include physical symbols (such as presenting a cup when thirsty), printed or digital symbol sets, communication books (generally using the written word but also can use symbols), and dynamic display devices (either a dedicated device or installed on a smartphone or tablet that work via selection of symbols or words that then generates an audible message via a microphone).

One common method of communication mentioned is the Picture Exchange Communication System, which is associated with ABA therapy and is used to help people express wants and desires. It uses similar tools as the symbol sets but creates a whole framework for use that becomes more complex as the learner advances, with an intention to improve communication overall, including verbal communication.⁷³ Patients may use any combination of verbal expression and one or more of the discussed systems.

Communicating with Patients with ASD

There are diverse means by which those with ASD communicate, which can be quite nuanced. Ascertaining how patients communicate in their daily lives will help in developing communication strategies that will work in the ED. Do not be alarmed or offended if patients choose to communicate in ways that are unfamiliar or do not engage in social norms. Eye contact, for example, can be quite challenging and stressful for some patients with ASD and lack of eye contact does not mean that they are not engaged in the encounter. Unusual body language also may be present and does not necessarily signal disinterest.⁶⁸ Use resources as necessary. Social workers can be helpful in assisting in the performance of psychosocial assessment to best allow for appropriate accommodations, especially in the adult setting without availability of services like child life.⁷⁴ In a pediatric setting, child life can be immensely helpful. In a mixed ED, consider asking for suggestions, resources, or materials even if they are unable to be directly involved in the care of adult patients.

Communicating what will be done before it happens is important to give warning to patients of what to expect. For example, prior to performing a physical exam, let the patient know that it will be done and what portions of their body will be touched and with what.⁷⁵ For some, modeling exams and procedures prior to carrying them out may be helpful.⁷⁶ This can take the form of demonstration on an accompanying party or an inanimate object as well as showing the equipment that will be used. Medical play is less likely to be effective in this population compared to similarly aged children.⁷¹ Avoid abrupt, fast movements. Desensitization strategies may be helpful with a slow approach, allowing patients to examine equipment, and starting exams peripherally and working centrally.⁶⁹

Step-by-step explanations of upcoming actions also will be helpful for some patients.⁵¹ Short, clear questions and instructions may be better received as opposed to multistep directions or lengthy questions. Allow time for patients to answer questions, as comprehending the question asked, formulating an answer, and being able to communicate the answer may take longer than in patients without ASD. In general, it is best to speak directly to patients when appropriate, even if they are nonverbal, since there often is a gap between receptive and expressive language. If/then or first/then statements, such as “If I look in your throat, you can have some apple juice” or “First I will listen to your lungs, then we can turn the TV on” can be helpful for setting expectations and engaging the patient in their care, allowing them to understand the order of events to come. Reminders, such as a timer or counting, also may help the patient understand when something will begin or end, allowing them to be prepared.⁷⁵

One small-scale study from the dental literature developed and tested a communication board, like those used as a communication adjunct, which shows promise in improving communication with patients with ASD.⁷⁷ Although this has not yet been validated, similar products exist in the intensive care unit (ICU) setting for use with intubated but awake patients or those otherwise unable to speak and may be worth exploring as an adjunct. There is no one way to communicate with patients with ASD — be flexible, adaptive, and

creative, allowing the patient to guide your interaction.

Managing Challenging Behaviors

ED providers have a wide range of experiences in managing behavioral difficulties secondary to a myriad of causes throughout the domains of medical, traumatic, and psychiatric. Many of those skills are applicable to patients with ASD. Agitation and aggression are not uncommon responses to stress, fear, or overstimulation, especially in patients with difficulty communicating.⁷⁵ While employing some of the interventions to decrease the stress involved in ED visits may help avoid some situations of challenging behavior, there still will be times when it is difficult to effect medically necessary care secondary to a patient’s actions. In these cases, there are multiple strategies that can be employed. Some measures that are particularly helpful with ASD include asking about or looking for triggers, such as environmental factors that may be able to be removed, evaluation and treatment of underlying conditions, and offering coping mechanisms and distractions or room to retreat to a quiet space. If a patient’s behaviors are unable to be redirected and they present a danger to themselves or others, there are no changes to medications used for agitation, although there is a preference toward antipsychotics.^{69,72}

If the patient is cooperative, consider offering an oral medication. Patients may have been exposed to medications in the past, so if possible ask the patient or a caregiver, they may be able to comment on what has or has not worked well or not worked well. As with all patients, restraints should be used as seldom as possible and for the shortest possible time when used.

Experience of Pain

Patients with ASD may experience pain differently, display it differently, or communicate it differently than neurotypical individuals. Previously, it was thought that individuals with ASD did not experience pain or did not experience it to the degree that those without ASD did. This has been shown to be untrue. Prior iterations of the DSM have included as features of ASD either ignoring pain or a high pain tolerance, but these have since been removed.

As was noted regarding sensory input, patients can have over- or under-responsive reactions to stimuli, which may not be fully indicative of what they are experiencing. One study that looked at pain response noted that in individuals with low behavioral reactivity to pain, there were elevated heart rates and elevated plasma beta-endorphin levels that were suggestive of physiologic stress, even though the patient did not otherwise display signs of stress. It also was noted that after the painful event, approximately 60% displayed behaviors such as self-injury, social withdrawal, stereotypy, and aggression that suggest some distress.⁷⁸ Not all individuals with ASD have a hypoactive response to pain; some have a hyperactive response and others have no change in response from usual.

The variable behavioral response to pain creates unique challenges in caring for patients with ASD. The variable perception and display of pain can lead to under-recognition of medical conditions requiring a thorough physical exam, high index of suspicion, and broad differential. Physical discomfort also may present with agitation in patients with difficulty communicating.⁷⁹

Multiple tools are available for assessment of pain for both pediatric and adult patients who are unable to communicate their level of pain, such as the Non-Communicating Pediatric Pain Checklist (NCPCC) and the Non-Communicating Adult Pain Checklist (NCAPC).⁸⁰ Consider using adjuncts to help assess pain in patients with difficulty communicating.

Vaccination

Although routine childhood vaccination is usually done in the primary care setting, there are vaccines that are given frequently in the ED, notably tetanus vaccination and rabies vaccination. While there is no evidence-based link between ASD and vaccines, there was a paper published in the late 1990s that raised concern for a link between the measles, mumps, and rubella (MMR) vaccination and ASD. This created significant public concern and, although the research was later debunked, the article retracted, and multiple further studies undertaken that did not show any connection with the MMR vaccination, the effects on vaccination and public concern have continued.

Some of the allegations involved thimerosal, a compound containing mercury, as the responsible agent, and although this also was not substantiated, thimerosal has since been removed from the MMR vaccine.⁸¹ Although the evidence does not support any relationship between vaccination and ASD, it has been demonstrated that the vaccination rates in children with an older sibling diagnosed with ASD are lower than in those without.⁸² There also are data showing that those with ASD are less likely to be fully vaccinated than peers by age 6 years, suggesting that families may delay or refuse further vaccination after a diagnosis of ASD.⁸² The ED is another point of contact with the healthcare system in which the lack of a causal or even correlative relationship between ASD and vaccines can be emphasized to patients and their families.

Conclusion

The first step in improving care of the patient with ASD in the ED is awareness and education. It is important that this education is not only for ED physicians, but also for nurses, technicians, and other ancillary staff, since they often make up a large bulk of the bedside time spent with the patient. Identification and use of resources, such as child life, social work, psychiatry, or a friend/caregiver, also may be helpful. Not all patients with ASD will require a change to clinical care, and a diagnosis of ASD may not be relevant to the patient's ED stay. However, there also are cases in which it can create significant challenges to regular workflow. ASD is a very individual diagnosis with individual needs, which generally can be best described by the patients themselves or an advocate who has presented with the patient. Patience, accommodation, and flexibility are key skills to the clinical care of patients with ASD.

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2. What population with ASD has increased emergency department (ED) use?
 - a. Males
 - b. Adolescents
 - c. Preschool-age children
 - d. People with a higher intelligence quotient
 3. Which of the following is *not* an additive stimulation technique that provides distractions to help patients with ASD cope with the ED environment?
 - a. Electronics — smartphones, tablets
 - b. Weighted blankets
 - c. Limiting the number of individuals who walk in and out of the room
 - d. Fidget objects or sensory toys
 4. What is true regarding the response to pain in a patient with ASD?
 - a. They typically have a very exaggerated response to pain.
 - b. They usually ignore pain or have a high pain tolerance
 - c. Regardless of response at the time, delayed behaviors often suggest some distress.
 5. Patients with ASD are at higher risk of which disease process?
 - a. Urinary tract infections
 - b. Dental disease
 - c. Trauma
 - d. Pneumonia
 6. Which statement regarding the use of ketamine for procedural sedation in patients with ASD is true?
 - a. Ketamine is contraindicated.
 - b. The recommended oral dose of ketamine is 3 mg/kg.
 - c. Ketamine should not be combined with a benzodiazepam.
 - d. The duration of sedation after oral administration is 30 minutes.

CME/CE Questions

1. Which statement about the prevalence of autism spectrum disorder (ASD) in the United States is *not true*?
 - a. It is more common in males.
 - b. The current prevalence is about 2% of the population.

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