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# ORTHOPAEDIC FORUM

# Preparing for Autistic Patients in Orthopaedic Surgery

Tips for a Successful Health-Care Interaction

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Investigation performed at Arrowhead Orthopaedics, Colton, California

**Abstract:** The prevalence of autism in the United States has been climbing for the last 3 decades, and this comes at a time when the medical community is poorly equipped to address the various needs of individuals with autism spectrum disorder (ASD). Because busy orthopaedic surgery practices will invariably encounter more patients with ASD, they may want to develop pragmatic strategies and protocols that will promote a successful health-care interaction with these patients.

Autism spectrum disorder (ASD) is a developmental disability that is characterized by deficits in social and communication skills, repetitive behaviors, self-stimulation (stimming), ritualistic behaviors, rigidity, restricted interests, and/or sensory processing issues (as noted by the criteria of the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition [DSM-5]). Individuals with ASD often make poor eye contact and have difficulty interpreting facial expressions and other nonverbal communicative behavior. They may have limited speech and difficulty conveying their emotions. Unfamiliar environments and changes in routine can provoke confusion or anxiety, leading to meltdowns, physical aggression, self-injury, or an inability to function<sup>1</sup>. Individuals with ASD often have sensory processing issues in which they are overly sensitive to touch or they have either an extremely high or low tolerance to pain. In addition, they can get overstimulated by too much noise, movement, or lights in their environment. It is estimated that >40% of children with ASD have average-to-aboveaverage intellectual ability<sup>2</sup>. Yet, these children often have comprehension issues and learning disabilities that substantially

impair their functioning. Nearly 30% of autistic adults have co-occurring epilepsy, and 70% have  $\geq 1$  concurrent psychiatric disorder (i.e., attention deficit hyperactivity disorder [ADHD], anxiety disorder, mood disorder, or an obsessive-compulsive disorder [OCD])<sup>3,4</sup>. Autism prevalence has been climbing for the last 3 decades; ASD is more prevalent in boys than in girls<sup>5</sup>. According to data from the Centers for Disease Control and Prevention (CDC) Autism and Developmental Disabilities Monitoring (ADDM) Network, nearly 1 in 59 children are identified as having ASD<sup>5</sup>. The increase in prevalence of ASD has been attributed to improved awareness of ASD and changes to the DSM. The rise in ASD comes at a time when the medical community is ill-equipped to address the various needs of individuals with ASD. Most health-care providers have little exposure to and familiarity with ASD, making it difficult to treat these patients<sup>6</sup>. Research has shown that health-care providers report the need for more training in how to provide care to individuals with ASD7,8.

Given the increased prevalence of ASD in the U.S., it is inevitable that specialties such as orthopaedic surgery will

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encounter more patients with ASD. There is little-to-no research detailing the particular orthopaedic needs of adolescents and adults with ASD. Nevertheless, research has shown an increased risk of fractures of the hip, the forearm, and the lumbar spine in patients with ASD as a consequence of lower bone mineral density compared to those without ASD<sup>9</sup>. A recent study of >18,000 children and 4,215 nonelderly adults (≤50 years of age) affected by autism showed that males had double the hip-fracture rate of males without autism, while females with ASD had 8 times the hip-fracture rate of females without autism<sup>10</sup>. Moreover, adult women with ASD are at a higher risk of upper-extremity and spine fractures compared to those without ASD<sup>9,10</sup>. Researchers are still in the process of identifying the determinants that contribute to the increased risk of fracture among those with ASD. However, it is known that patients with ASD tend to have unique dietary patterns because of food preferences and aversions. In addition, families often place a patient with ASD on specific fad diets (e.g., gluten-free or casein-free) to address the core symptoms of autism. These restricted eating patterns may lead to nutritional deficiencies, which may contribute to reduced bone mineral density and increased fracture risk9.

Given their idiosyncratic behavior, caring for patients with ASD can be challenging. Therefore, it is ideal for orthopaedic surgery practices to prepare their staff and practitioners for patients with ASD. Orthopaedic surgery practices may want to consider how the office/hospital environment can negatively or positively impact a patient with ASD. They may also find it helpful to educate their staff regarding the unique characteristics of patients with ASD so that they can anticipate and implement strategies to hopefully avoid problematic behaviors, but be able to address any problems that may arise during the visit or the hospital stay.

#### **Preparing Patients with ASD for the Orthopaedic Visit**

Some medical and surgical practices utilize a registration questionnaire that is administered by the front office staff to screen and collect data on new patients. This is particularly helpful in identifying patients who may have ASD. This questionnaire should allow caregivers the opportunity to discuss the patient's condition and behavioral coping techniques in order to minimize anxiety that may be associated with the orthopaedic visit. Orthopaedic practices should be open to suggestions from caregivers about specific accommodations, such as removing unnecessary equipment from the examination room, the use of specific role-playing activities, the use of the Picture Exchange Communication System (PECS), or the use of distractors (e.g., music, earplugs, books, toys, videos, and tablets). In addition, some patients with ASD may benefit from the assistance of a service animal or an emotional support animal (e.g., a dog) during the visit. It is important to note that emotional support animals, comfort animals, and therapy dogs are not considered service animals under Title II and Title III of the Americans with Disabilities Act (ADA) of 1990; only service animals are protected under the ADA, and cannot be excluded from hospitals, doctor's offices, patient

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rooms, and other health-care facilities unless they endanger patient care.

During the registration process, the caregiver should be informed about the possible need for laboratory work, radiographs, the application of durable medical products, cast and suture removal, manipulation of fractures, injections, splinting, and casting, all of which can lead to anxiety and problematic behaviors in patients with ASD. By informing the caregiver ahead of time, the office allows the caregiver to prepare the patient on what to expect during the visit. These accommodations and strategies have been linked to successful health-care interactions for patients with ASD<sup>11</sup>.

#### Waiting Room Environment for Patients with ASD

Overbooking appointments is a common strategy of healthcare providers who see high volumes of patients. This can lead to noisy and crowded waiting rooms, long wait times, and frustrated patients. Those with ASD often find noisy environments stressful and overstimulating, which can trigger an uncontrollable meltdown. Thus, eliminating long wait times for patients with ASD is important for improving the patient-care experience. Ideally, patients with ASD can be ushered straight to the examination room once they arrive and therefore bypass the need to transition from the waiting room where their anxiety may build. Otherwise, orthopaedic surgery practices may want to consider having a process to prioritize appointments for patients with ASD. These patients could be seen in the early morning or the early afternoon as the first patient on the schedule when the waiting room is least busy.

#### **Outpatient Considerations for Patients with ASD**

The literature shows that patients with ASD have higher anxiety levels compared with typically developing children<sup>12</sup>. Patients with ASD are prone to agitation due to overstimulation from their environment. Consequently, it is usually recommended to place patients with ASD in dimly lighted examination rooms away from the noisiest areas of the clinic, and to limit the number of medical personnel who interact with these patients in order to minimize anxiety levels. Patients with ASD require substantial structure and regimented daily routines, and any deviations from the norm can drastically escalate their anxiety. It is important to not keep the patient longer than necessary in the office because patients with ASD find these environments unsettling.

Since some patients with ASD are nonverbal, caregivers may be the best source of information; they can provide necessary insight that may aid in the diagnosis of a musculoskeletal condition in these patients. In addition, a thorough assessment is needed to identify potential orthopaedic injuries. When examining patients with ASD, it is important for clinicians to remember that patients with ASD often do not like to be touched. Some of these patients have impaired responses to tactile stimulation that are characterized by mixed pain and numbness on multiple areas of skin, including the face, the mouth, the hands, and the feet<sup>13,14</sup>. Moreover, in patients with The Journal of Bone & Joint Surgery - JBJS.org Volume 100-A - Number 20 - October 17, 2018 PREPARING FOR AUTISTIC PATIENTS IN ORTHOPAEDIC SURGERY

autism, musculoskeletal pain can be atypical in its experience and expression<sup>15</sup>. Therefore, clinicians may need to adjust their method of examination and way of communicating with the patient. The orthopaedic provider should use simple, direct communication and avoid phrases or idioms because this can confuse and frustrate patients with ASD<sup>16</sup>. In addition, the patient should be allowed extra time for linguistic processing. Visual aids and prompts also can be useful in communicating with patients with ASD. Positive reinforcements such as verbal praise, preferred comfort items, and sometimes breaks during the visit may improve cooperation and lessen possible tantrums or meltdowns. Orthopaedic practices that are affiliated with hospitals may be able to request a certified child life specialist to assist in calming and communicating with the patient during the appointment. In addition, the child life specialist can help children and families in planning for hospital stays, procedures, or surgery.

In the event that a patient with ASD has a meltdown due to agitation, anxiety, pain, or overstimulation, the office staff should work with the caregiver to calm the patient down. Talking to the patient calmly and allowing him or her to take a short break from the examination may help to de-escalate the behavior. If the tantrum or meltdown persists, the caregiver may prefer to end the clinic visit early and reschedule for another time. The patient may need an alternative exit to avoid the waiting room area.

#### Perioperative Considerations for Patients with ASD

When patients with ASD require surgery, there are special considerations in the evaluation and perioperative management process. The literature supports that children with ASD seem to have similar perioperative experiences to patients without ASD<sup>17</sup>. However, research by Oliveira et al. suggested an association between ASD and mitochondrial respiratory chain disorder<sup>18</sup>. The authors concluded that mitochondrial dysfunction occurs in approximately 7.2% of children with ASD<sup>18</sup>. Surgical procedures for pediatric patients with mitochondrial dysfunction usually require general anesthesia. Some patients with mitochondrial defects may be susceptible to adverse reactions to commonly used anesthetics such as propofol<sup>19-21</sup>. Primary complications associated with mitochondrial myopathies can include respiratory failure, conduction defects, dysphagia, metabolic decompensation, cardiac depression, and loss of developmental skills following anesthesia<sup>22</sup>. Others have proposed good hydration, minimal fasting, maintenance of normal blood glucose levels, avoidance of lactated Ringer solution (due to elevated blood lactate levels), minimization of orthopaedic tourniquet times, and maintenance of the acid-base balance to help reduce risks during anesthesia in autistic patients with co-occurring mitochondrial dysfunction<sup>22,23</sup>. It is recommended that patients with ASD meet with the anesthesiologist prior to surgery, and caregivers should be made aware of the risks involved in procedures requiring general anesthesia or sedation.

Another perioperative consideration in patients with ASD is that they may benefit from sedative premedication to

facilitate the induction of anesthesia. Previous research has shown that noncompliance at induction increased from 22% to 50% when patients with ASD were not given a premedication<sup>24</sup>. Some have suggested the use of specific premedications, such as oral midazolam for patients with mild cases of ASD and oral ketamine for patients with moderate-to-severe cases<sup>24</sup>. Clonidine is a viable alternative to midazolam, but has a slower onset of action<sup>25</sup>. It may be necessary to mask or alter the taste of the premedication to improve patient adherence. If possible, a patient with ASD should be booked as the first case of the day, and the premedication should be given in a quiet area to mitigate distractions. Moreover, parents and caregivers should be encouraged to bring items that provide comfort and stress support for patients with ASD, which may improve induction compliance<sup>26</sup>. After surgery, it is preferable to have the patient recover in a quiet, dimly lit room, and the caregiver should be immediately available to assist the nursing staff in the care of the patient. Restraints may be necessary if the patient exhibits emergence agitation or aggressive behavior. These and other perioperative considerations in patients with ASD remain an evolving area of medicine. There is no one-size-fits-all approach in the perioperative management of children with ASD. Consensusbased recommendations for sedation and analgesia in those with ASD are lacking.

#### Inpatient Considerations for Patients with ASD

Being hospitalized is stressful for any individual, but even more so for patients with ASD because of how anxious they may become in unfamiliar environments. Arranging the hospital room in such a way to make it feel less sterile and more familiar will help lessen the anxiety level of a patient with ASD during his or her hospital stay. Families should be encouraged to bring favorite items and things that the patient is attached to (e.g., preferred pillows, regular or weighted blankets, pajamas, picture frames and drawings, a service dog, etc.) to help him or her feel more at ease. Ambient scenting and music in the room may also solicit a calming effect in patients with ASD<sup>27</sup>.

Postoperative pain in patients with ASD should be managed effectively to reduce the likelihood of problematic behaviors like outbursts and aggression. Previous studies have reported that 64% of surgical pediatric patients experienced moderateto-severe pain, yet there is a paucity of research on the expression, the perception, and the assessment of pain in individuals with ASD<sup>28</sup>. Although reduced pain sensitivity in patients with ASD has been reported, there is evidence to suggest that these patients are not insensitive to pain<sup>29,30</sup>. While some highfunctioning individuals with ASD may be able to rate their own pain through self-reporting, others with ASD are unable to articulate or provide cues to the location of their pain. Given the idiosyncratic behaviors associated with ASD, observational pain assessment can be challenging and can lead to a misunderstanding of the patient's pain<sup>29</sup>. While most providers solicit parental feedback to ascertain the cause and severity of pain in patients with ASD, parents may underestimate their child's pain<sup>29,31</sup>. It is therefore helpful to use pain assessment tools (e.g., the Non-Communicating Children's Pain Checklist-Postoperative Version The Journal of Bone & Joint Surgery - JBJS.org Volume 100-A - Number 20 - October 17, 2018 PREPARING FOR AUTISTIC PATIENTS IN ORTHOPAEDIC SURGERY

[NCCPC–PV]), which can assist clinicians in identifying the source of pain in those with severe ASD. The NCCPC–PV is a validated observational pain assessment tool for measuring postoperative pain in patients with cognitive disabilities, and it has good psychometric properties when used with children who have severe intellectual disabilities<sup>32</sup>. Once the level of pain has been identified, appropriate pain management is crucial.

If a patient with ASD becomes uncontrollably aggressive during his or her hospital stay, a multidisciplinary approach may be needed to help manage the patient. For example, requesting the expertise of a pain specialist may help to ensure appropriate pain relief. It may also help to consult with a psychiatrist who can recommend specific medications (e.g., anxiolytics, antipsychotics) to help calm the patient down and to address comorbid diagnoses (ADHD, anxiety disorder, mood disorder, OCD, etc.) that may be exacerbating his or her behavior. A child life specialist can engage the patient in calming activities and distraction techniques that can help de-escalate the behavior. These considerations may contribute to a more manageable hospital stay for a patient with ASD.

#### **Post-Visit/Hospitalization Feedback**

It is recommended that orthopaedic surgery practices solicit feedback from the caregiver following an office visit or hospitalization. This can be accomplished by giving the caregiver a feedback questionnaire or by encouraging the caregiver to contact the physician's office staff to provide feedback about the health-care experience shortly after the clinic visit or hospital stay. Feedback regarding the length of the visit or hospital stay, the doctor-patient interaction, the support from the clinical or hospital staff, the appropriateness of the environment (i.e., the waiting room, the examination room, the hospital room), and specific accommodations can help identify effective strategies as well as gaps in care that can serve as a reference to improve subsequent visits. Gathering this type of information may help familiarize the office staff and providers with specific patient temperament patterns and help them to avoid the potential triggers that may have led to problematic behaviors for a particular patient, as well as assist them in avoiding possible issues with future patients with ASD.

#### Conclusions

In summary, the prevalence of autism in the United States has risen steadily for nearly 3 decades. Because of their atypical behaviors, managing patients with ASD can be challenging to members of the health-care team. Developing an individualized care plan with the input of the caregiver may help to facilitate a successful health-care interaction. Orthopaedic surgery practices should consider the importance of training staff and implementing clinical practice strategies and protocols to accommodate the needs of these vulnerable patients and their

#### TABLE I Key Recommendations for Patients with ASD

Outpatient considerations

Administer a registration questionnaire to allow caregivers the opportunity to discuss the patient's condition and behavioral coping techniques.

Prioritize appointments to avoid long waiting times and minimize exposure to the noisy environment of the waiting room.

Place patients in dimly lighted examination rooms away from the noisiest areas of the clinic, and limit the number of medical personnel who interact with these patients.

Do not keep the patient in the office longer than necessary.

Use simple, direct communication and positive reinforcement to improve cooperation and lessen possible tantrums or meltdowns. During a meltdown, talk to the patient calmly and allow him or her to take a short break from the examination, or end the clinic visit early to deescalate the behavior.

Perioperative considerations

For patients with co-occurring mitochondrial dysfunction: good hydration, minimal fasting, maintenance of normal blood glucose levels, avoidance of lactated Ringer solution (due to elevated blood lactate levels), minimization of orthopaedic tourniquet times, and maintenance of the acid-base balance help to reduce risks during anesthesia.

Consider the use of a sedative premedication (e.g., midazolam, ketamine) to facilitate the induction of anesthesia. The premedication may need to be given in a drink to mask or alter the taste of the drug.

After surgery, place the patient in a quiet, dimly lit room, and allow the caregiver immediate access to the patient.

Restraints may be necessary if the patient exhibits emergence agitation or aggressive behavior.

Inpatient considerations

Arrange the patient's hospital room to make it feel less sterile and more familiar.

Use pain assessment tools like the Non-Communicating Children's Pain Checklist–Postoperative Version (NCCPC–PV) to identify the severity and source of pain. Manage postoperative pain effectively.

Consider a multidisciplinary approach that includes a pain specialist, a psychiatrist, and a child life specialist to help manage the patient.

Post visit/hospitalization feedback

Administer a feedback questionnaire to identify effective strategies and gaps in care.

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| caregivers. The key recommendations for managing patients with ASD in an orthopaedic surgery practice are provided in Table I. ■ | <sup>1</sup> Orthopaedic Surgery PA Fellowship Program Director, Arrowhead<br>Orthopaedics, Colton, California<br><sup>2</sup> Developmental Behavioral Pediatrics, Kaiser Permanente, Fontana,<br>California |
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