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Guidance on Working With Adult and Pediatric Patients With Autism

Lisa Croke, Managing Editor

Autism spectrum disorder (ASD) is a neurodevelopmental disorder that is often characterized by difficulties with communication and socialization and sensory challenges.[1,2] The prevalence of ASD continues to increase; it was diagnosed in one in 150 children in 2000 and in one in 36 children in 2022.[3] Because of the challenges experienced by patients with ASD, along with the lack of training on ASD for health care personnel (HCP), these patients often have inadequate health care experiences, resulting in negative effects on their physical well-being and quality of life.[2] More effective care can be provided to patients with ASD when HCP familiarize themselves with the specific challenges (eg, communication, sensory) of this patient population.[2,4] Shelly Reyes, BSN, RN, CPN, charge nurse, Valley Children's Hospital, Madera, California, indicated that an important starting point for addressing the challenges experienced by patients with ASD is increasing HCP knowledge. "When the health care team understands why a child with ASD is having a hard time, they are more compassionate to make the accommodations needed to help that child through the hospital experience," she said. "That knowledge is what drives the compassion needed to go the extra mile for this special patient population."

Challenges

Patients with ASD tend to communicate atypically and have a wide range of communication styles and abilities, which can differ based on the method and delivery (eg, verbal versus written, in-person versus telephone), environment (eg, overstimulating), and patient's condition.[5] Patients may be fully verbal, minimally verbal, or nonverbal. Even patients who are fully verbal may have trouble describing symptoms or indicating discomfort or pain. Patients who are minimally verbal or nonverbal often communicate using such methods as grunts, groans, or repeated words or expressions to indicate discomfort. Patients with ASD also can have difficulty understanding what HCP are trying to communicate.[2] Some patients may be able to easily process HCP's verbal information, whereas others may have more difficulty. They can have difficulty understanding tone, facial expressions, or body language and processing information fast enough to answer questions or make decisions.[5] They often cannot read between the lines and can interpret things literally.[6]

Reyes indicated that one of the main challenges experienced by patients with ASD is sensory issues combined with the unfamiliarity of the health care environment. "The hospital can be scary for all children and even more so for a child with sensory issues," she said. "A hospital visit can include bright lights, beeping alarms, and new faces." Patients with ASD can have atypical sensory processing, which can take the form of greater or reduced sensitivity to sounds, lights, smells, touch, or taste. They can have difficulty processing information when there is a lot of background noise or they are simultaneously experiencing multiple sensations.[5] Underprocessing sensory information can trigger a need to touch, taste, or feel specific textures to decrease anxiety or other strong feelings, whereas overprocessing can trigger self-injurious behavior (eg, hitting) or result in them running away or being physically or verbally aggressive. Sensory issues can prevent patients from being comfortable enough to stay in a waiting room or being able to remember what was shared at their visit.[2] Stimming, or making repetitive body motions (eg, hand flapping, rocking, pacing) or noises, can be used as a coping mechanism.[5]

Best Practices

Reyes indicated that one challenge of the perioperative environment is the need to transition to different care areas. "You are not just going to one place, and everything is done there; instead, you have to go to registration, then to preop, then to the OR, then to recovery," she said. "There is so much movement that the second you get comfortable with one area, it changes." To help ensure that health care interactions with patients with ASD are as beneficial as possible, it will be important to address sensory challenges and communicate effectively.[6]

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Sensory Issues

It will be important to discuss with the patient or their support person how best to create a calm environment for them.[4] "Staff can make the hospital experience better for patients with ASD by allying with caregivers and creating a partnership with a shared goal of making it less stressful for the patient," Reyes noted. Examples of strategies that may be helpful include using natural or dim lighting, conducting the visit in a quiet room, limiting the number of involved HCP, and ensuring one person talks at a time.[5,6] It also can be helpful if the patient or their caregiver brings items that decrease or increase sensory stimuli, such as headphones, sunglasses, or sensory items (eg, stress balls). What will occur during the visit, including the anticipated length and possible delays, should be shared with the patient and their support person.[5]

Communication

Health care personnel should gain an understanding of each patient's communication needs and preferences from the patient or their support person. It can be helpful to also identify if they read, write, or use alternative communication approaches (eg, sign language, pictures, computer programs). The Autism Healthcare Accommodations Tool (*https://autismandhealth.org/?p=ahat*) can help with gaining insight into a patient's abilities. The communication method most effective for the patient should be used by HCP; this may require a change in typical methods.[5]



Before performing examinations or testing on patients with ASD, HCP should describe what will happen, show them the equipment and supplies that will be used, and share how long tests are likely to take. Image courtesy of FatCamera via Getty Images.

Individualized approaches can be used to acquire information regarding a patient's health concerns.[4] Patients with ASD often need language to be precise (eg, Does your side hurt?) rather than vague (eg, How do you feel?). Being specific, not using figures of speech, providing a list of symptoms from which to choose, and providing examples can generally be helpful.[5] Honesty will be paramount; for example, HCP should not say something will hurt for a second if it actually will be 10 seconds.[7] Visual aids, such as a body map or pictures of a procedure or task (eg, taking blood pressure), should be used when possible.[6,7] Patients should be provided time to respond to questions and process information.[5] Because patients typically only respond to questions, rather than volunteer information, it can be helpful for HCP to expand their line of questioning.[7]

Examination and Testing

Some accommodations and planning can help patients tolerate examinations and testing. Before performing either, HCP should describe what will happen, show the equipment and supplies that will be used, and describe how long tests are likely to take. It also can be helpful to do a "trial run" with the patient. The patient should be notified before being touched; permitted to sit, lie down, or lean on something, when possible; encouraged to select a signal to use to announce the need for a break; and routinely asked about their pain or discomfort. Blood tests should only be ordered when necessary, and orders should be grouped to minimize the number of draws. When performing a blood draw, numbing sprays or creams, anti-anxiety medications, and distractions may be beneficial.[5]

Pediatric-Specific Considerations

When obtaining a medical history, HCP should ask the parents about their child's needs and methods for alleviating stress; they also should address the child and include them in the conversation as much as possible. Parents should be encouraged to bring items from home that help with communication and relieve stress (eg, favorite toy). Personnel working with a child with limited verbal abilities can consider using simple visual aids (eg,

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storyboards). For inpatient stays, home routines (eg, bedtime) should be maintained and everyday items (eg, cups, toothpaste) should be brought from home for patient use.[8] Helpful approaches when performing procedures may include using distraction (eg, toy, video); bundling or streamlining care, especially when general anesthesia will be needed; and using anxiolytic medication (eg, oral midazolam or ketamine before IV insertion and anesthesia induction).[8] "It is important to have distraction items, such as bubbles, fidget toys, and squishy balls, at your disposal when performing procedures on children with autism," Reyes said. "These can make a process easier for the child to tolerate; for example, when taking blood pressure, a vibrating toy can be used to create different inputs of sensory."

In Practice

Reyes indicated that her facility developed a program called George's Pass to address the growing need to individualize and enhance surgical care for children with ASD and other special needs. "It is a high-level customer service program because we improve the perioperative experience and ease their stress by partnering with the whole family," she said. Children with ASD have their medical record and room door flagged to alert all HCP that accommodations may be needed. Parents are asked to provide their child's preferred methods of communication, sensory concerns, behavior triggers, and de-escalation strategies. To prepare for the day of surgery, a tour of the hospital is provided, along with practice items (eg, patient gown, mask) and a step-by-step guide of what to expect.

On the day of surgery, the family is greeted at security and sent directly to a private room with dimmed lights and lowered monitor volume. Distraction items, sensory regulators, noise-canceling headphones, and virtual reality devices are available in the preoperative area. Selected patients can "drive" a car, which is controlled by a nurse using a remote, into the OR. To help decrease anxiety and the need for sedation, parents are allowed to be present during induction of anesthesia. Postoperatively, patients are placed in a private and quiet room where parents are waiting.

Conclusion

As the prevalence of ASD continues to grow, it is important for HCP to be knowledgeable regarding the challenges of patients with ASD and how to best provide care. For those wanting to learn more, Reyes will be presenting an education session, "Compassionate and Personalized Care for the Autistic Special Needs Pediatric Patient," at the AORN Global Surgical Conference & Expo 2024.

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