

# Improving Management of Patients With Autism Spectrum Disorder Having Scheduled Surgery: Optimizing Practice

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## ABSTRACT

**Introduction:** Surgical preparation for children with autism spectrum disorders can be a challenge to perioperative staff because of the unique individual needs and behaviors in this population. Most children with autism function best in predictable, routine environments, and being in the hospital and other health care settings can create a stressful situation. This prospective, descriptive, quality improvement project was conducted to optimize best practices for perioperative staff and better individualize the plan of care for the autistic child and his or her family.

**Methods:** Forty-three patients with a diagnosis of autism or autistic spectrum disorder were seen over 6 months at a suburban pediatric hospital affiliated with a major urban pediatric hospital and had an upcoming scheduled surgery or

procedure requiring anesthesia. Caregivers were interviewed before and after surgery to collect information to better help their child cope with their hospital visit.

**Results:** In an evaluation of project outcomes, data were tabulated and summarized and interview data were qualitatively coded for emerging themes to improve the perioperative process for the child.

**Discussion:** Findings showed that staff members were able to recognize potential and actual stressors and help identify individual needs of surgical patients with autism. The families were pleased and appreciative of the individual attention and focus on their child's special needs. Investigators also found increased staff interest in optimizing the surgical experience for autistic children. *J Pediatr Health Care.* (2014) 28, 394-403.

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## KEY WORDS

Autism, autistic spectrum disorders, presurgical assessment, quality improvement, pediatric, perioperative process

Surgical preparation for children with autistic spectrum disorder (ASD) can be challenging because of the unique individual needs and behavioral differences for children with this diagnosis. Children with ASD may behave negatively in new situations and experience what is sometimes referred to as an "emotional meltdown" as a maladaptive coping mechanism to a new environment or event. Multiple characteristic behaviors observed in autistic patients influence their ability to cope with an elective surgical procedure, such as impaired social skills, communication challenges, restrictive interests, repetitive behaviors, sensory issues, poor problem-solving skills, and a high level of stress and

anxiety. Most children with autism find comfort in predictability and routine. Experienced parents and caregivers work hard to establish a routine with these children through a visual, predictable schedule and learn to advise the child if there is a possible change in the normal routine. Therefore establishing a sense of trust and security in the day surgery environment can be challenging. Hospitals and health care facilities include numerous triggers, such as people moving quickly, disruptive noises, and the need for the child to operate outside of his or her normal habits. Additionally, many children are fearful of health care environments and experience anxiety because of previous experiences with hospitals and health care personnel.

ASD involves qualitative impairments with regard to communication and social interactions, as well as repetitive and sometimes restrictive behaviors, interests, or activities (Golnik & Maccabee-Ryaboy, 2010). The fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-V) was released in 2013, with one of the most notable changes being the combination of “autistic disorder,” “Asperger disorder,” and “pervasive developmental disorder” into the broader label of ASD. The modification was made by the American Psychiatric Association (APA) to enable the provision of more reliable and valid diagnoses (Lohr & Tanguary, 2013). One change that has occurred in the DSM-V is the diagnosis of “Pervasive Developmental Disorder (PDD) Not Otherwise Specified,” which has been replaced by social communication disorder. Early identification of ASD is vital because interventional therapies are most effective during the preschool years (American Academy of Pediatrics [AAP], 2001; Golnik & Maccabee-Ryaboy, 2010). The AAP recommends that primary care providers utilize an ASD screening tool such as the Modified Checklist for Autism in Toddlers to screen patients at 18 and 24 months of age (Pinto-Martin et al., 2008). Symptoms and observable characteristics of ASD can be found in Box 1.

Autism has many medical comorbidities, and children with autism, global developmental delay, or intellectual disability should have genetic testing per AAP guidelines, which usually involves a high-resolution karyotype and a fragile-X DNA test (Johnson & Myers, 2007). Children with autism also have a 44% to 77% prevalence of having sleep disturbances, such as difficulty falling asleep (sleep latency) and difficulty staying asleep (sleep maintenance; Richdale, 1999). Approximately 50% of children with autism have gastrointestinal, nutritional, or feeding issues, including selective or obsessive eating, nonfunctional mealtime routines (such as foods on a plate not being allowed to touch each other), oral aversion, or sensory processing difficulties (Geraghty, Depasquale, & Lane, 2010; Golnik & Maccabee-Ryaboy, 2010). In some cases these problem eating behaviors cause a nutritional deficit

## BOX 1. Symptoms and characteristics of autism spectrum disorder

### Social Characteristics

- Difficulty with interpreting social cues (e.g., how to interact with others and understanding facial expressions or body language)
- Sudden or abrupt gestures
- Repetitive behaviors
- Single interest told in excess
- Lack of make believe or imitative play
- Lack of emotional or social reciprocity

### Communication Issues

- Nonverbal to limited vocabulary (varies by child)
- Echolalia (repeating phrases or words)
- Literal thinkers
- Struggles to understand the meaning of a conversation

### Sensory Issues

- Easily overwhelmed when combination of stimuli is too great
- Vestibular system gives sense of balance
- Hyposensitive or hypersensitive to sensations
- Modulation to balance sensory input

### Behaviors

- Fascination with a special interest
- Repetitive behaviors
- Easily overwhelmed or anxious
- Stereotypical and repetitive motor movements

### Executive Functioning

- Difficulty with complex concepts or multitasking
- Difficulty shifting attention and focusing on a new topic
- May attend to either facial movements or words but not both
- May follow visual instructions better than verbal instructions
- Poor nonverbal communication interpretation
- Persistent preoccupations with parts of objects

Data from Hudson, J. (2006).

(Geraghty et al., 2010). Epilepsy is more prevalent in children with autism, and electroencephalograph abnormalities are a frequent co-morbidity with ASD (Golnik & Maccabee-Ryaboy, 2010; Tielsch-Goddard, 2010). Children with autism often have significant psychiatric and behavioral issues, including inattention, hyperactivity, and impulsivity. They have a high incidence of the following co-morbidities: anxiety, obsessive-compulsive disorders, bipolar disorder, and depression (AAP, 2001; Bryson, Rogers, & Fombonne, 2003).

Medical management of the patient with autism is usually quite complex. Dietitians, psychologists, and occupational, speech, or feeding therapists may be involved because of gastrointestinal and feeding difficulties. A behavioral therapy program focusing on sleep disturbances and sleep hygiene sometimes must be utilized. Children with autism are often followed up by a psychiatrist, psychologist, or other mental health

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