ARTICLE

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

Debbie Gearner Thompson, MS, RN, CNS, PNP-BC,
& Anna Tielsch-Goddard, MSN, RN, CPNP-PC

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. (2013) ■, ■-■.

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

Debbie Gearner Thompson, Pediatric Nurse Practitioner, Perioperative Services, Children's Medical Center at Legacy, Plano, TX.

Anna Tielsch-Goddard, Pediatric Nurse Practitioner, Perioperative Services, Children's Medical Center at Legacy, Plano, TX.

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Correspondence: Debbie Gearner Thompson, MS, RN, CNS, PNP-BC, Perioperative Services, Children's Medical Center at Legacy, 7601 Preston Road, Plano, TX 75024; e-mail: debbie.thompson@childrens.com.

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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.

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).

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 (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

clinician for behavioral concerns, including aggression and combativeness.

REVIEW OF THE LITERATURE

A literature review was conducted before this quality improvement project was begun. A comprehensive search of accessible medical school library databases was conducted, including PubMed, Medline, Cinahl, and Ovid. The main search terms used were "perioperative process," "presurgical assessment," and "perioperative," with Boolean operators including "children," "child," "pediatric," and "pediatrics," as well as variations of "autism" diagnosis ("ASD," "autistic," "autism," and "PDD"). A secondary search of journal manuscripts that were not found in the primary search was also conducted for additional references. Limitations to the literature search were the various uses and definitions of the severity of terms "autistic," "autism," and "ASD." Only studies available in English were explored. Results were not restricted by date because scant information is available on this topic. Information from the literature review was used to develop a practice protocol aimed at gathering information from the family prior to the child's arrival, managing the child upon arrival and during presurgical assessment, and providing environmental and emotional support for the child and family throughout the surgical experience.

A retrospective chart review study from a hospital database in Australia demonstrated 87 occasions for 59 autistic children who required day surgery over a period of 4 years (van der Walt & Moran, 2001). Part of the hospital's routine program for children with autism was to provide additional support for the family through early communication before the scheduled procedure. A preoperative phone call was made to all patients with a script for nurses to follow, which included what to expect the day of surgery. The nurse asked the parent general questions to assess the degree of autism severity and developmental level of the patient and then collected additional information, such as the child's likes and dislikes, any specific phobias, favorite objects, and social circumstances at home. Use of oral midazolam was effective for children with mild autism, and oral ketamine was used for children with moderate and severe autism. Comparison of both oral midazolam and ketamine showed no significant postoperative recovery and hospital discharge times. The authors of this study believed that earlier communication with the patient's family and flexibility in the admission process better prepared the patient for the preoperative process (van der Walt & Moran, 2001).

A case report discussing induction of anesthesia in combative autistic children that was written by anesthesiologists emphasized that successful management includes discussing options with the caregivers prior to the day of surgery (Christiansen & Chambers, 2005). These management options should be documented in the patient's chart. Play therapy or a preoperative visit to the facility was also recommended. Distraction with music, television, a DVD, or favorite toys is suggested (Christiansen & Chambers, 2005).

In a case study of a 28-year-old nonverbal autistic man who was undergoing surgery for recurrent metastatic germ cell testicular cancer, recommendations for the most optimal care environment were provided based on experiences of staff involved in this case (Dell et al., 2008). Authors stressed that staff must rely on caregivers to interpret the patient's needs to the staff, especially if the patient uses alternative forms of communication. The nursing staff aimed to provide a predictable, consistent, familiar, low-stimulus environment for this patient every time he was admitted to the hospital. His parents brought favorite videos, pictures, and stuffed animals from home for him. Providers were asked to remove laboratory coats before entering this patient's room because they were a source of agitation. The patient's likes and dislikes were kept on his bedside chart for perusal by nursing and medical staff. Upon discharge, the staff consulted with case managers and the discharge planner to meet this patient's specific needs for home care. The patient's mother was involved in all discharge planning and medical care plans (Dell et al., 2008).

Published recommendations from a pediatric otorhinolaryngology group who frequently performed ear/nose/throat surgeries on autistic children again emphasized communication with the family prior to the day of surgery (Seid, Sherman, & Seid, 1997). They recommend asking parents about the child's likes and dislikes and assessing if the child is particularly sensitive to blinking lights or noises or if he or she has specific fears. Additional recommendations include minimizing the amount of time the child and the caregiver are separated and possibly using a quieter isolation room preoperatively if possible (Seid et al., 1997).

Another difficulty that arises in this patient population is the refusal to drink the premedication prior to a procedure, along with potential agitation and combativeness. Most children receive midazolam (Versed) in the presurgical setting to calm and relax them and prevent them from remembering their separation from their parents. Use of physical restraints and forced intramuscular injections with patients who have limited communication abilities can be extremely traumatic and is not always advantageous (Shah, Apuya, Gopalakrishnan, & Martin, 2009). In a case report of a 16-year-old boy with severe autism who was scheduled for dental rehabilitation with use of a general anesthetic, Shah and colleagues (2009) found that mixing oral ketamine and midazolam with the beverage Dr. Pepper to mask the taste of the drugs increased the acceptability of the medication. The pH of Dr. Pepper (2.5) is close to that of midazolam (3.3) and ketamine (3.5), therefore providing stability to the drug mixture.

These providers concluded that disguising the premedication drugs by adding them to a palatable but compatible beverage eases administration of these medications in uncooperative patients (Shah et al., 2009).

Recommended care guidelines highlight the importance of individualized treatment plans for children with autism in the perioperative settings (Nelson & Amplo, 2009). Because children with autism often get stressed in a new environment, desensitization to the hospital is recommended with a visit prior to the day of surgery. Play therapy with a thermometer, stethoscope, and other medical tools is sometimes useful. Because consistency is important for these patients, having the same nurse provide both preoperative and postoperative care can be beneficial. The parents should be instructed to bring a favorite toy or movie with them to the hospital. Caregivers should be consulted if the patient uses alternative forms of communication, such as a picture chart or rudimentary signing. Special attention should be given to possible hypersensitivity to external stimuli such as the intravenous line, bandages, sheets, gown, or any other medical devices. The standard practice in dealing with this concern is to explain clearly and simply what is going to occur and alert the patient before touching him or her. The authors report that although these practices should be utilized with any patient, this is especially true with any patient who is autistic (Nelson & Amplo, 2009).

The Autism Institute provides special instructions for parents whose child might need a surgical procedure and anesthetic. This organization emphasizes that a preoperative visit or phone call is important to ensure a better experience for the child (Rankin, 2009). The Autism Institute provides a parent handout for parents on the background of different types of anesthetic agents and what is entailed in most preoperative processes.

METHODS

The purpose of this project was to collect information from families of children with a diagnosis on the autism spectrum to develop an individualized plan of care and evaluate possible improvement in the surgical experience. A need to improve the presurgical and perioperative process was recognized by advanced practice nursing staff. It was determined that obtaining additional information preoperatively on behavioral issues related to children with autism might improve the quality of care these patients receive during the surgical experience. Once materials were developed, a panel of experts consisting of two parents of autistic children (a previous patient and an operating room [OR] registered nurse who was the parent of an autistic child), a child life specialist working in the presurgical area, and an elementary school teacher with experience with autistic children reviewed the materials and provided feedback regarding the project.

Institutional Review Board Review

The Evidence Based Practice and Research Council reviewed the study and determined in October 2010 that the study met criteria for exempt approval from the Institutional Review Board (IRB) in accordance with hospital policies and the council charter. The IRB proposal was submitted in January 2011 and was reviewed by an IRB panel member in accordance with the guidelines for exempt approval. The IRB determined that the proposed project met the criteria as a quality improvement activity and did not meet the criteria for regulated human research requiring IRB approval. Key factors in this decision included the project's design to effect a process change while all groups involved received the standard of care and the fact that the project did not involve withholding any aspect of the standard of care, seek to test interventions or treatments, or involve research grants, funding, or sponsorship.

Participants and Recruitment of Subjects

This project took place at a suburban children's hospital, which is part of a larger pediatric hospital located in a major urban area in the southwest region of the United States. The surgical schedule at this facility is finalized 3 days before the date of surgery. When this patient schedule information became available, the pediatric nurse practitioners (PNPs) in charge of this project were able to review the charts to identify which patients qualified for the project. During standard presurgical assessment of every patient who is scheduled for an elective procedure (which includes dental work and medical procedures performed with use of an anesthetic), an extensive medical record review is conducted to evaluate each patient for potential risks for surgery. Patient information is obtained during a routine chart review by the PNPs prior to all elective procedures to ensure that information in the record is accurate and to flag any medical conditions or anesthesia risks that need to be identified prior to the surgical procedure. The exchange of medical information relative to the patient's medical care needs is a routine part of the perioperative process and standard of care at this hospital. During this routine chart review, patients who qualified for this project were noted. Patients with autism were identified during this chart review, and this information was recorded in a data log that was kept secure in the locked PNP office. Criteria for inclusion of subjects were broad; all patients who had a diagnosis of autism (or ASD) and were scheduled for elective surgical procedures in the outpatient surgery site were invited to participate via a phone call to the parent. Patients scheduled for elective surgical procedures at this hospital whose parents were not able to be contacted by phone before surgery were excluded from the project. The parents were called 2 to 3 days prior to the patient's scheduled procedure, and the purpose and background of the project were briefly described. Parents

were given the option to be interviewed using a presurgical telephone survey tool developed by the authors for this project. If the parents agreed to participate, these questions were reviewed with the family in a preoperative phone call. Their answers were entered into the electronic medical record so staff would have access to this information prior to the patient's arrival.

Procedures

A prospective chart review is performed for all patients prior to scheduled elective surgery to identify any health care needs or issues related to anesthesia. Patients with ASD were identified in the electronic medical record 3 days prior to the procedure (when normal chart review procedures take place). A data log was completed for unique identifiers obtained from the medical record without the use of protected health information and included the severity of autism, date of surgery, surgical procedure, and surgeon's name.

The severity of autism was rated on a scale from 1 to 4 based on autism developmental levels developed by Hudson (2006). It was believed that this grouping identified patient abilities and needs better than age and parent descriptors such as "mild" or "severe" autism. Level 1 describes a child who responds to his or her name and is aware of another person's presence or attends to the person speaking. Level 2 describes a child who interacts functionally with toys, has developed beginning language, is curious about his or her environment and demonstrates repetition in play and tasks. Level 3 describes a child who interacts with others, recognizes order and sequence, and is able to control his or her own behavior. The highest level of function, level 4, identifies a child who is curious to learn with detailed description, maintains control when provoked, verbalizes feelings, and understands rules and regulations.

Parents were called by one of the two project investigators. Verification of parental identify, the child's name, the type of procedure, and the diagnosis of autism or ASD was then obtained. If parents reported that their child did not have ASD, they were thanked for their time and the phone call was terminated. If the patient met inclusion criteria, investigators explained the background of the project with use of a written script to ensure uniform communication with all participants. Appendix 1 describes the preoperative phone call script and interview questions. Each phone call took approximately 5 to 10 minutes. Parents were also told that they would receive a follow-up phone call 2 to 3 days after their child's surgery to ask follow-up questions. Data collected during interviews were based on a review of the literature for beneficial information to know in order to help autistic children cope better with stressful events. For example, parents were asked if their child exhibits any common behaviors when he or she is having difficulty coping or that signal a potential stressful situation. Parents were also asked if a picture chart illustrating the steps of the perioperative process would be useful for the day of surgery. Information on cues prior to an emotional meltdown was also obtained, and parents were encouraged to bring a special toy, game, or music to comfort the child on the morning of the hospital visit. Parents were also asked if the child had any special interests, such as trains or blocks. If they specified a toy, character, or theme that the department had in the toy or movie chest for patients, every effort was made to have those items available for the patient on the morning of the procedure in the patient's preoperative room.

Information obtained from the presurgical phone call was printed and attached to the front of the patient's physical medical chart as part of a "Handoff Communication Tool" for patient arrival so the medical assistant and registered nurses (RNs) would have immediate access to this information. The preoperative and pediatric acute care unit RNs were also able to make additional notes on this communication handoff tool regarding specific behavioral or emotional difficulties in coping with the procedure.

A postoperative phone call was placed to the parent or guardian 2 to 3 days after the procedure to obtain additional feedback information regarding their child's surgical experience. This phone call took approximately 10 minutes. Parents were first asked if it was a convenient time to speak before a scripted phone call and interview took place. Verification of the patient's recent visit and surgery was confirmed with the interviewee. Additional questions were tailored to obtain information regarding the surgical experience and whether activities or interventions that occurred were helpful. The parent was also asked if he or she could identify opportunities for improvement of the surgical experience.

Information obtained in the phone calls before and after surgery, as well as the hand-off communication sheet, was analyzed by the investigators. Data obtained in the interviews were sorted in categories of meaningful elements for emergent domains during data analysis. Staff interventions and patient responses were used to continue staff education on individualized patient needs during the perioperative process.

An initial introduction to the project was provided to the perioperative staff in a team meeting before the project was implemented. This meeting also included a PowerPoint presentation on general information about children with ASD, general principles of working with these children, and the project's goals and background. Providing details regarding the project prior to its implementation afforded the staff an understanding of the project design, goals, and the need for their input and assistance when they were assigned to a surgical patient with autism. Information obtained through this project was presented at the conclusion

FIGURE. Picture chart for use in the perioperative setting. This figure appears in color online at www.jpedhc.org.

of the project at a staff education meeting for all the perioperative nurses and support staff. Results also were summarized and presented in a poster presentation at the hospital's nursing week and research day for all hospital staff.

Picture Chart

A picture chart is sometimes introduced during therapy with autistic children and then incorporated into the child's routine at home. Visual aids are often used to support communication with autistic children. Studies and anecdotal evidence have shown that children with ASD are better able to process visual tools than verbal communication (Autism Speaks, 2013a, b; Bryson et al., 2003). Both Autism Speaks and the Autism Research Network support the use of picture charts for these purposes, and many commercial industries have created charts that can be purchased by parents of children with autism. Visual charts also can be downloaded for free online. A picture chart was created based on the perioperative process at this hospital (Figure). Parents were offered the opportunity to use one of these charts for their child on the day of surgery. The photo chart allows the patient to visually see the steps in the process and mark off steps that have occurred.

Potential Risks

The only potential risk identified was the inadvertent disclosure of personal medical information. However, special precautions were put in place to ensure maintenance of confidentiality. All telephone calls were conducted in a closed soundproof office, and all data recorded from phone calls were collected directly into the patient's electronic medical record, which was compliant with the Health Insurance Portability and Accountability Act. A data log of the patient's diagnosis and age, the date of the procedure, and the name of the surgeon or dentist was recorded and kept in a locked office file cabinet. No patient identifiers were used in the log, and no documents with patient identifiers were kept by the investigators. The communication sheet used by the PNP and other staff on the day of surgery was destroyed after the pertinent information was documented into the log or medical record. The information obtained by the PNP regarding

individual patient needs was documented in a progress note in the patient's electronic medical record to be used by staff during the current and future medical visits to optimize patient care.

Data Analysis

Data obtained in the interviews and patient care experience were sorted into categories of meaningful themes and emergent domains, including patient safety, care behaviors, staff knowledge regarding the special needs of autistic children, child and parent feelings, and experiences during their recent day surgery experience. Qualitative data coding was used to sort these themes. Coding was performed by one perioperative RN, one postanesthesia care unit (PACU) RN, and the two advanced practice RN investigators who first separately coded for themes and then compared results with one another. Parent and caregiver suggestions were also analyzed to document potential beneficial practices for the patient and opportunities for improvement. The investigators then discussed any cases in which data coding varied, areas of disagreement were discussed among research team members, and consensus was obtained.

RESULTS

After 6 months of data collection, 49 patients were enrolled, with data obtained for 43 patients who had the confirmed diagnosis of autism or who were on the autism spectrum. The patients ranged in age from 2 to 16 years, with a mean age of 7.5 years and a median age of 8.4 years. Forty-four percent of the patients were scheduled for a dental procedure; 16%, ear/nose/throat procedures; 16%, gastrointestinal procedures; 12%, eye procedures; and 5%, general surgery. Analysis of the severity of the patients' autism revealed that 21% were nonverbal with some awareness of surroundings, 21% were interactive with toys and had beginning language skills, 35% were able to interact with others and had skills to control behavior, and 23% were able to understand rules, verbalize feelings, and maintain behavioral control when provoked. Box 2 provides the details of patient ages in each developmental domain.

In evaluating the patients' behavioral responses to patient care, a range of 1 to 2 behaviors were observed per child, with a mean and median of 1.0. Behavioral responses to provide comfort and support were almost doubled with a range of 1 to 3, a mean of 1.8, and a median of 2.0. Two primary domains of behavior were identified by RN and PNP review: behaviors resulting from anxiety and fear, and behaviors providing comfort, security, and reassurance. Box 3 describes the variety of behaviors that were observed and their frequency.

The staff observed patients for stress behaviors and recorded their occurrence and precipitating factors throughout the perioperative experience. Staff documented 10 occurrences of behavior difficulties that they believed exceeded that which occurred with the average patient. These occurrences included having vital signs taken preoperatively, having a mask placed on the face, moving to a bed in the OR, waking up from anesthesia with equipment such as monitors, intravenous tubing, or a blood pressure cuff attached, and noise in the PACU. In 8 of those 10 occurrences, the parents were at the bedside, and the other two instances occurred in the OR. Eight of 10 occurrences were resolved with intervention by staff or parents and resolution of the patient's stress response. Only 2 of 43 patients had an "emotional meltdown" without resolution; both occurred postoperatively with the parents present at the bedside. Box 3 defines the interventions needed to minimize an observed stress response. Primarily, these responses occurred during taking of vital signs or examination before surgery (45%) and as a result of environmental noise in the PACU after surgery (71%). The PACU is a large room with individual bed spaces divided by curtains. This environment proved to be the biggest challenge; in response, patients were moved to another bed space that was farther away from a crying child or noisy area, they were initially placed in a bed that was as far away from other patients as possible, or they

BOX 2. Age and developmental domain of patients

Level 1: Responds to name, is aware of another person's presence
- Preschool (4 children): ages 3, 4, 4, and 5 years
- School age (3 children): ages 10, 11, and 11 years
- Adolescent (2 adolescents): ages 13 and 14 years
- Average age: 8.3 years

Level 2: Interacts with toys, beginning language, repetition in play and tasks
- Preschool: None
- School age (5 children): ages 6, 7, 7, 11, 11, and 12 years
- Adolescent (3 adolescents): ages 14, 14, and 16 years
- Average age: 10.8 years

Level 3: Interacts with others, controls own behavior
- Preschool (6 children): ages 3, 3, 4, 5, 5, and 5 years
- School age (8 children): ages 6, 6, 6, 7, 7, 8, 9, and 10 years
- Adolescent (1 adolescent): age 16 years
- Average age: 6.7 years

Level 4: Maintains control, verbalizes feelings, understands rules and regulations
- Preschool (1 child): age 5 years
- School age (6 children): ages 6, 8, 9, 10, 10, and 11 years
- Adolescent (3 adolescents): ages 13, 13, and 13 years
- Average age: 9.8 years

BOX 3. Observed behaviors by occurrence and setting

Occurrence

Anxiety and Fear
- Avoidance (5)
- Communication (17)
- Motor behavior (7)
- Aggressive behavior (9)
- Injurious behavior (3)
- Agitation (4)

Comfort
- Reassurance (25)
- Distraction (29)
- Communication (9)
- Environmental control (6)
- Containment (4)
- Self-stimulation (4)

Setting

Presurgical Area
- Environment
- Limited examination/vital signs (45%)
- Containment
- Distraction
- Reassurance

Operating room[a]
- Reassurance

PACU
- Minimizing environmental noise (71%)
- Adapting length of monitoring/intravenous line use
- Reassurance

Postrecovery Area
- Adapting the length of time the patient has an intravenous line
- Communication/reassurance

[a]All patients are premedicated.

were placed in a private phase 2 postoperative room for recovery if patient stress from the environment was observed.

The postoperative phone call provided the opportunity to discuss the perioperative experience with the parent or primary caregiver and determine which actions were helpful and improved the experience, as well as actions or behaviors that would have been helpful but were not observed during the outpatient surgical visit. Twenty-four patient family members were successfully contacted after surgery (56%). Multiple phone calls were placed in an attempt to follow-up with the parents. No more than two phone messages were left on the family's voicemail system. All of the families contacted voiced positive responses to the care their child received. Parents stated that the individual focus "showed we cared," and families were "pleasantly surprised" because they had not received this individualized attention at other facilities. The parents were appreciative that the staff took time to listen and provide explanations at a level their child could understand and were sensitive to their child's sensory issues.

Key findings from this study supported the importance of knowing details about the child's behavior and needs prior to the initial contact with the patient. Unfortunately, behavioral information or special needs are not always discussed when the families are contacted preoperatively to discuss arrival times, nothing by mouth status, and specific instructions that relate to the day surgery experience. Many children with autism and their families have specific unique methods of distraction or self-soothing. It is important that parents be offered and even encouraged to bring items for comfort, distraction, and stress support. Parents demonstrated appreciation for attention to their child's individual needs, and nurses verbalized increased satisfaction with taking care of patients with autism when additional attention is given to details that minimize the stress the patient and family experience during the perioperative period.

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The visual chart that was developed was used by parents and staff for the higher level functioning patients with mixed results. Although the chart helped the patient see what would happen next and the flow of the day through pictures, the parents and PNPs determined that it would be more useful to adapt it to show smaller portions of the process or only the major steps so it would not appear so overwhelming to the patient.

The recommendation to parents to bring a comforting toy or item from home as a support mechanism for the patient was particularly useful.

Limitations

Limitations to this project are recognized. When educating the nurse staff, a pretest and post-test could have been used to measure their baseline knowledge, as well as their understanding of the project and the unique needs of the patient with autism. The visual picture chart might have been more effective if it contained fewer pictures; for example, the chart could have only described the experience before the patient was premedicated with an amnesic sedative, thus minimizing the number of pictures. We also could

BOX 4. Presurgical checklist: individualizing care for the patient with autism

- Confirmation of autism spectrum disorder diagnosis
- Parent description of patient's abilities, response to verbal commands, behavior in new environments
- Techniques, toys, electronic devices, or other strategies that help calm the child
- Behaviors or cues when the patient is stressed
- Cues before a significant emotional meltdown
- Common behaviors the patient displays when working to cope with a stressful situation
- Behaviors the child portrays when having difficulty coping
- Sensitivity to touch, noise, bright lights, hospital linens/clothing
- Special interests of the patient
- Will the patient be able to wait in the registration area or surgical waiting area prior to his or her appointment? (If not, make special accommodations based on response)
- Encourage parents to bring a special toy, game, music, stuffed animal, blanket (regular or weighted) or other calming devices
- Confirm if the patient uses a special communication device, and if so have the parent bring it for the visit

have offered parents the option of bringing their own picture chart and incorporating perioperative pictures, if the family was already familiar with this form of communication.

SUMMARY

The medical setting can be challenging for autistic patients because it is unfamiliar, necessitates a change in routines, and includes unique environmental stressors. Recognition of special needs and better communication of individualized needs can have a significant impact on staff comfort, parent satisfaction, and the patient experience. Parents and caregivers know their child best and can quickly provide medical staff with specific details that can help create a successful experience (Box 4). The main project goal of identifying individual patient needs and responses to the stimuli for the autistic child to promote more adaptive coping was met. Advanced practice RN and RN staff more quickly recognized the cues to potential emotional meltdowns and altered their routines of obtaining vital signs and performing physical examinations to limit potential stressors for the patient. The recommendation to parents to bring a comforting toy or item from home as a support mechanism for the patient was particularly useful. A few parents of nonverbal children also brought electronic communicators used by the patient at home or school once they were encouraged to bring what child uses on a regular basis with them for the hospital visit. Nurses became more aware of similar needs of other special needs children who were not necessarily autistic but were developmentally delayed or had a different diagnosis.

This prospective patient care quality improvement project established a "best practice" for the patient with ASD and his or her family by identifying the importance of individualizing care to the unique needs of this population and recognizing adaptations that could safely alter the "routine" to make it a more comfortable and less stressful experience for the patient and family. Staff in other inpatient or outpatient settings can use the information learned from this project to examine the routines of their facility or clinic and determine opportunities for improvement to minimize the emotional stress and add to family satisfaction for their clients.

AREAS FOR FUTURE RESEARCH

Currently, research that specifically examines the child with autism in the elective surgical area is very limited. Most of the research to date has centered on specifics of anesthesia induction and pharmaceutical considerations for the combative autistic child. No studies have been performed that specifically focus on the nurse's role in helping the autistic child cope throughout the perioperative process and setting. The literature search also failed to reveal any evidence-based practice guidelines related to postoperative discharge planning for autistic patients. Research should continue to identify challenges associated with autism and how to best manage care of children with this diagnosis.

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