Improving Communication Between Health Care Providers, Families, and Children with Autism Spectrum Disorder: The Linked Program

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Purpose: *To provide easy-to-use tools and skills to decrease stress in the perioperative period for families and their children with autism spectrum disorder (ASD).*
Design: *Evidence-based practice project.*
Methods: *After literature review, a perioperative assessment and management program was developed to guide and individualize the care of pediatric patients with ASD. The program was piloted on a convenience sample of 31 pediatric patients diagnosed with ASD.*
Findings: *Most patients were back to their baseline behavior according to their families or caregivers within 120 minutes of the procedure (n = 29, 93.5%), with two needing more than 24 hours (6.5%).*
Conclusions: *The Linked Program has enabled staff to be effective in meeting the perioperative needs of families and their children with ASD. Families have expressed great appreciation that they are able to share their knowledge of what their children need.*

Keywords: *autism spectrum disorder, pediatric, perioperative, communication tools, family.*

AUTISM IS A NEURODEVELOPMENTAL disorder that affects the social communication capabilities of a person and the way he or she perceives his or her surroundings. Autism may present early in life with communication delays or difficulties, with the inability to cope with stress, and having fixed interests or repetitive behaviors. The 2013 Diagnostic and Statistical Manual of Mental Disorders changed the classification to combine autism, Asperger syndrome, and pervasive developmental disorder into autism spectrum disorder (ASD).[1]

The Linked Program was created by a multidisciplinary team to address the challenges children on the autism spectrum face when going through medical procedures. Our team consisted of registered nurses, anesthesia providers, developmental psychologists, child life specialists, registration, surgery schedulers, and support services.

One in 68 children in the United States has been diagnosed with ASD, or 1 in 59 children in North Carolina.[2] Children with ASD differ greatly in the degree of their difficulties with behavior, communication, and need for support. The perioperative

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environment is very challenging with crowds, loud noises, and often a degree of inflexibility in the system, all potential stressors for the child with ASD. Identifying these children early and initiating a plan of care to limit identified and potential stressors improves patient outcomes and family satisfaction and reduces health care team stress. The Linked Program, an evidence-based program, was born out of families of children with ASD expressing anxiety surrounding surgery and staff's request for increased detailed knowledge on how to best help them.

Knowledge of how children with ASD communicate, how they react to different stimuli, and what previous difficulties they have had in the health care system helps the health care team to alleviate or lessen known stressors and promote family-centered care. Family-centered care is defined as "the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among patients, families, and providers that recognize the importance of the family in the patient's life."[3]

PICO Statement

A PICO question was developed in an effort to guide an evidence search and subsequent project development. The PICO components were as follows:

- Population: A pediatric patient with ASD undergoing an outpatient surgical procedure
- Intervention: A preoperative assessment tool and individualized perioperative plan of care
- Control: Standard care
- Outcome: Perceived perioperative stress and overall perioperative experience

The final PICO question for the project was as follows: In children with ASD, what is the effect of a preoperative assessment tool and individualized multidisciplinary, patient- and family-centered care, as compared with previous perioperative experiences, on perceived perioperative stress and overall perioperative experience?

Evidence Review

A focused evidence review was conducted using the Cumulative Index of Nursing and Allied Health Literature database, as well as by reaching out to other facilities through our child life specialist program for resources. Search terms included ASD and perioperative care of ASD. Several common themes were evident and included the need for evaluation of preoperative sedation with changes if necessary,[4,5] inclusion of the child's caregiver in the plan of care, use of alternative methods to communicate,[1,4-7] avoiding long waits in waiting rooms and scheduling the surgery earlier in the day,[4,5] encouraging bringing comfort items for child,[5,7] communicating the plan of care with the entire health care team,[1,7] expediting the removal of monitors and intravenous lines after surgery, and discharge with fewer moves to multiple areas.[6] A qualitative study of caregivers providing care to children with ASD undergoing outpatient surgery showed that individualizing the plan of care to address coping skills, behaviors, and special needs had a significant impact on reducing patient stressors and improving satisfaction with care.[7]

Sehnert[6] provided an overview of literature pertaining to the prehospital, preoperative evaluation and preparation, and postoperative care of pediatric patients with ASD. The author particularly focused on the Special Kids Treatment and Referral Center program initiated by child life providers at the Children's Medical Center at Winthrop-University Hospital in Mineola, NY.[8] Recommendations from this program include the following ones:

1. Creating a database for future health care experiences and use of role play and story boards/videos for improving communication,
2. Implementation of fast-tracking admission and discharge processes,
3. Keeping sensory load as low as possible through use of private rooms,
4. Caregiver at bedside as much as possible, and
5. Removal of lines and monitors quickly.

Further training for anesthesia and nursing teams in caring for patients with ASD was also recommended.[6,8] These recommendations are further supported in Shah's[4] overview of ASD and perioperative management, which recommended

1. Early identification of these patients to allow for planning and early visits and consultation
2. Scheduling patients first to prevent stress from waiting and starvation

3. Use of medical play, electronic devices, music, or rewards to distract and decrease stress
4. Use of various premedications individualized for the patient's level of autism and
5. Use of communication techniques such as videos or story boards.

Methods

Design, Sample, and Setting

Based on available evidence, the team undertook a comprehensive evidence-based practice project to design and implement the Linked ASD Perioperative Pilot Program. To analyze the care processes, we recruited input from surgeon office schedulers, outpatient clinic managers, surgery center registration, developmental psychologists, pediatricians, anesthesia providers, child life specialists, family support center staff, certified nurse anesthetists, and registered nurses in the preoperative and postoperative areas. A program of evidence-based interventions was designed to span preparation in outpatient clinics and registration and the care in the surgical center. The program was shared with the staff affected by lunch-and-learn educational sessions; psychologist, pediatric, and outpatient surgery center staff meetings; as well as the hospital's system wide-shared governance council meeting. The program information was shared via development of a power point learning module available in our electronic learning system and a Linked Program poster. The program was implemented at an outpatient surgical center affiliated with a large health care system in the southeastern United States. This center provided care for 10,500 patients in 2017: 32% were pediatric (0-18 years old). Patients were excluded from the project if they were older than 18 years.

Implementation Strategies

Implementation strategies were coordinated among anesthesia providers, preassessment nurses, child life specialists, and preoperative, postoperative, and operating room nursing staff.

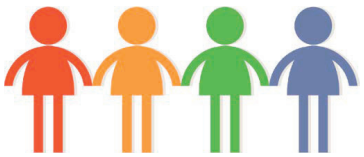
PREPARATION. Perioperative planning and care of patients with ASD and their family begin long before the actual day of surgery.

- Communication with our most frequent pediatric surgeons' offices addresses the need to schedule children with ASD early in the day to decrease stress from not being able to eat.[4,5]
- Surgery schedulers also make a note in the electronic medical record tracking board details section when the child has ASD or other special needs to alert the nursing staff.
- Preassessment nursing staff call the caregivers of the patients a few days before surgery to review and update their history and instruct them on preparation for surgery. Our anesthesiology protocols allow for the continuation of medications for anxiety with clear liquids no later than 2 hours before arrival at the surgery center.
    - The Linked Program is shared with caregivers of children with ASD, and the Linked Flyer (Figure 1) and All About Me Passport (Figure 2) are given to them. If they do not have an email, we give the Linked Flyer and All About Me Passport to them at registration on the day of surgery.
- The ASD Functional Scale comes from the 2013 Diagnostic and Statistical Manual of Mental Disorders update and helps to assess for amount of support the patient and family may need, as well as potential for behavioral problems such as aggression. The ASD Functional Scale levels[9,10] are used to determine if an anesthesia provider needs to evaluate for behavioral concerns and whether the patient needs to have surgery at the main medical center (Table 1).
- Early medical play visits with child life specialists are encouraged to decrease stress.[4,6]
- Families are also encouraged to bring comfort items such as a favorite toy, blanket, or electronic device on the day of surgery.[5,7]

PREOPERATIVE. Priorities on the day of surgery include facilitating registration, getting the patient and family to a private room, and individualizing the plan of care.

Figure 1. Linked flyer. © 2019 Mission Health, all rights reserved. Used with permission. This figure is available in color online at www.jopan.org.

- Early identification of a child with ASD helps the team to expedite registration if needed to decrease stress from busy waiting rooms and bright lights.[4-7] The availability of a quiet room while waiting, as well as support from child life specialists, is essential in reducing stress before surgery.
- Families may complete consents and paperwork ahead of time or after getting to a private room.
- The child life specialists provide therapeutic play and support during procedures and have been instrumental in designing the story board (Figure 3) used to improve



ALL ABOUT ME PASSPORT

Please let us know how we can best take care of your family member by filling out this passport.

Nickname? _____ Who is primary caregiver? _____ How does your child communicate best?

- ☐ Verbal ☐ Electronics
- ☐ Story/picture
- ☐ Other _____

What activities does your child need help with?

- ☐ Eating ☐ Bathing
- ☐ Walking ☐ Dressing
- ☐ Other _____

What comfort items may calm your child?

- ☐ Stuffed animal ☐ Wearing own clothes
- ☐ Dark room ☐ Music
- ☐ Particular Toys ☐ Caregiver
- ☐ Other _____

What upsets your child?

- ☐ A lot of people ☐ Bright lights
- ☐ Changing clothes ☐ Covers
- ☐ Medications ☐ Needles
- ☐ Other _____

Does your child have sensory problems?

- ☐ Touch ☐ Noise
- ☐ Visual ☐ Smells
- ☐ Tastes ☐ Light
- ☐ Other _____

What sensory input/stimulation is helpful for your child?

- ☐ Weighted blanket
- ☐ Storyboards
- ☐ Light
- ☐ Electronics
- ☐ Other _____

Is your Child extremely interested in a particular object/subject?

_____

What does your child use to drink:

- ☐ Sippy cup
- ☐ Glass
- ☐ Bottle

How can we tell when your child is uncomfortable?

- ☐ Crying
- ☐ Withdrawal
- ☐ Repetitive motions
- ☐ Other _____

Any previous medical experiences to share?

_____

_____

Patient Sticker Here

For questions or concerns, please call the Linked program at (828) 213-0740.

NURS041-121217

MISSION HEALTH

Figure 2. "All About Me" passport. © 2019 Mission Health, all rights reserved. Used with permission. This figure is available in color online at www.jopan.org.

communication for the child, who is a visual learner. Parents are encouraged to create their own story, taking into consideration their child's needs and fears.[1,4-7]

- The All About Me Passport is printed, placed in front of the chart, and shared among all surgical staff before their interaction with the patient. A Linked magnet (Figure 4) is applied to the patient's doorway to highlight the need for a team communication or approach.
- The anesthesia team assesses the need for particular sedation medications before surgery.[4,5] Individualizing the plan of care for children with ASD may mean allowing them to stay in their own clothes, turning off lights, having one staff member address them at a time, or allowing them to hide under a blanket until surgery.

INTRAOPERATIVE. Oral midazolam is routinely given to our pediatric patients with ASD before surgery to reduce stress. Our anesthesia protocols do not allow for liquids up to 2 hours before arrival at the surgery center. Alternative methods of

Table 1. ASD Functional Scale[9,10]

Level	Criteria
Level 1 (high functioning; Asperger Syndrome, Autism, unspecified type)	• May live/work independently • Normal or above intelligence • Normal communication but may have robotic tone, hard to find words • Few behavioral issues: may be interested in single topic, repetitive motions • Socially atypical: may struggle with eye contact, hard to interpret body language

Level 2 (Autism, Rett syndrome, childhood disintegrated disorder, unspecified type)	• May live and work with assistance
	• Normal or below mental functioning
	• Difficulty communicating: may prefer signs or technological devices
	• Behavioral issues:
	  • Oversensitive or undersensitive to sights, sounds, and stimulation
	  • Resists changes, displays behaviors such as rocking, hand flapping, and spinning in circles
	• Socially aloof: hard to start communication, aware of others in room

Level 3 (Autism, Rett syndrome, childhood disintegrated disorder)	• Do not live independently
	• Degree of mental retardation: self-care difficulties
	• Lack of language
	• Severe behavioral issues:
	  • Repetitive or atypical behaviors
	  • Frustration may lead to anger and aggression
	• Socially unreachable

premedication have included nasal fentanyl and intramuscular ketamine. Communication of the Passport information to the anesthesia team is crucial for them to be able to lessen potential stressors such as lights and noise during induction. To support recovery and a quick return home after surgery, antiemetics and pain medications are administered, as well as intravenous fluids to replace fluid deficits.[1,5] Most patients receive antiemetics and pain medications, but we do have pediatric surgeries where there is no intravenous catheter (ie, myringotomies) and nasal fentanyl would be used to prevent pain if needed.

POSTOPERATIVE. Priorities in the postanesthesia care unit (PACU) include emergence support, participation of the caregiver at the bedside, minimizing light and noise, and early discharge instructions.

- After getting report from an anesthesia provider, the PACU nurse gets the child's caregiver to the bedside before he or she awakens.
- Lights and noise are kept to a minimum.
- Providing discharge instructions before the patient's waking allows time for the caregiver to process the information and ask questions.
- Upon waking, the child's electrocardiography leads and blood pressure cuff are removed, keeping only the oxygen saturation probe. Removing the child's intravenous catheter as soon as possible helps to alleviate stress and is encouraged if the child is stable and further needs for intravenous fluids or pain medications are not foreseen.[6]
- Discharge is done once the child meets the surgeon's discharge criteria as well as anesthesia discharge criteria. Discharge from the PACU is encouraged if possible to avoid transitioning to the step-down discharge unit because it is typically more crowded and loud. We have used private observation rooms in the step-down unit if the PACU is getting too stimulating for the child.

Figure 3. Story boards. Small pictures with Velcro backings allow for family to individualize preoperative instruction. This figure is available in color online at www.jopan.org.

FOLLOW-UP. We routinely call patients or their families the day after surgery to evaluate any postoperative problems with pain, nausea, surgical site drainage, circulation issues, or fever. Before discharge, we add the Linked Program follow-up form to our routine call back sheet. If there were any issues while at the surgery center, the discharging nurse makes a note for the follow-up. Linked Program follow-up (Figure 5) is conducted at the same time to evaluate how long patients took to return to their baseline behavior and inquiring about their health care experience. The All About Me Passport is sent to our medical records department to scan into the child's chart for future encounters.

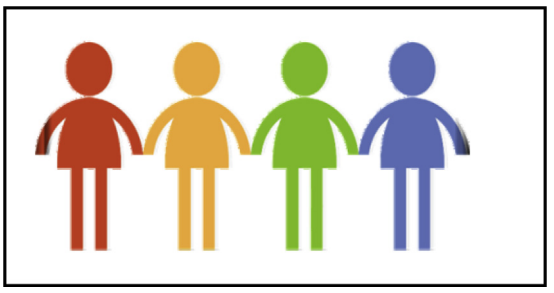


Figure 4. Postoperative follow-up. This figure is available in color online at www.jopan.org.

Program Evaluation

Data were collected only by the project lead to reduce potential bias and variability and to improve reliability of the interview process. Data collection included time from arrival to the recovery room until surgery center discharge, the time it took the patient to get back to baseline behavior according to family or caregivers, and feedback about the health care experience. The evaluation of time from postanesthesia care unit arrival time to surgery center discharge was not performed because baseline data were not gathered before our pilot interventions. Eleven families were excluded from final evaluation because we were unable to reach them by phone after several attempts.

Findings

The final convenience sample of program participants consisted of 31 pediatric, postoperative patients, 27 males (87%) and 4 females (12.9%) aged from 20 months to 18 years with a mean of 8.2 years. There were 3 patients older than 18 years (aged 21, 23, and 41 years) with whom we used the Passport and protocol, but anyone older than 18 years was excluded from the analysis. Diagnostic codes of the sample were dental (n = 19, 61.3%); ear, nose, and throat, (n = 11, 35.5%); and plastics (n = 1, 3.2%).

Most patients were back to their baseline behavior, according to their families or caregivers, within 120 minutes (n = 29, 93.5%) of the procedure, with two needing more than 24 hours (6.5%) (Figure 6). One of the two patients needing more time to recover had drainage tubes, which were difficult to adjust to, and in the other case, the child was newly diagnosed with ASD at age 5 years and had not gotten any behavioral therapy or treatment before the procedure.

ASC Autism Pilot Program Evaluation

How long was recovery from phase I (PACU) until discharge? _____

How long did it take for your child to return to their baseline? _____

Any feedback about healthcare experience? _____

Please save these evaluations for Pilot group to review: Folder in Stepdown

Not part of medical record

Patient sticker

Figure 5. Linked program management. © 2019 Mission Health, all rights reserved. Used with permission. This figure is available in color online at www.jopan.org.

Table 2 provides a summary of feedback gathered from family or caregivers, showing predominately positive outcomes. A strength, weakness, opportunity, and threat analysis, which provides a map for institutions to predict how a project may be affected by internal or external factors, was also conducted (Table 3).

Discussion

The qualitative findings of this project are consistent with those of previous studies and recommendations, showing positive perioperative outcomes for children with ASD when individualizing their plan of care and addressing coping skills, behaviors and

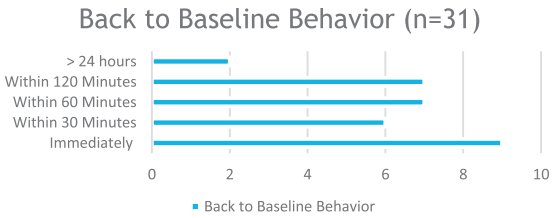


Figure 6. Time to baseline. This figure is available in color online at www.jopan.org.

special needs.[1,4-7] The project helped to identify these children with ASD earlier in the perioperative continuum, improved communication between health care team members, and highlighted the importance of listening to the family or caregivers to learn how best to care for their child. The All About Me Passport was essential in identifying the particular needs and previous experiences that may impact the current perioperative experience. Communication with the children was fostered with story boards, iPads, or other devices brought in with the child.

Previous literature did not address the knowledge or educational needs of the health care staff in caring for the child with ASD. This project was born from health care staff stress in not knowing how

Table 2. Qualitative Family Feedback

Pt came home, slept for 2 hours and now back to normal. Everything was great, staff was understanding and attentive
It has been great. This is the easiest it has ever been. Liquid versed in preop with IV in OR was HUGE for him. Thanks!
Did great-very high functioning Autism
Mother said everything went great and nothing could have been done differently to improve his experience
Pt tolerated experience well
Forgot to ask-Use of MARTI for explaining medications in Spanish-family needed instructions gone over several times
No feedback
Positive experience, discharged from PACU
Drinking from sippy cup: using pacifier
It was a great experience
She woke up very pleasant and cooperative. Mom very happy with experience
"You guys did great, excellent, fantastic care!"
They took good care of him
Thank you for your care
You all did a great job with him
He is doing well
Ate well and taking fluids well. The staff were amazing
You guys were absolutely wonderful. He was just very tired and tearful but came home and has been sleeping since
Mom was very happy with experience
PACU was little over stimulating with lighting and putting on the pj's. Mom was extremely happy with the experience
You all were awesome!
Super happy with the care. Pt is taking soup and not having pain.
Everyone was very attentive. Would have liked nickname used more. The form was very helpful
Protocol not followed: pt taken to SDDU then saw mother, IV removed, given tylenol and discharge instructions. Use of protocol would have been helpful
Very grateful when they left. Accompanied by Dad for initial induction
Everything was great
He's not wanting to eat, taking fluids ok, just very tired
So far so good
Might have needed more pain medicine in recovery, she was pulling at her lip and trying to touch her site where tooth taken out
He's doing fine, a bit more quiet but ok
He's doing fine. You all did a great job with him
Very traumatic for patient's mother as child agitated and growling in recovery with subsequent angry tantrums at home since surgery (more than he usually has) Referred to Anesthesiologist and behavioral specialist for ASD support. No current ASD treatments with OT/Behaviorists.

Note. MARTI (My Accessible Real-time Trusted Interpreter) system is a video and audio wireless connection to a skilled, medical interpreter. SDDU, same day discharge unit.

Table 3. Program SWOT Analysis

Strengths
- Outpatient, smaller facility
- Use of child life specialists
- Multidisciplinary teamwork
- Health care team awareness of local and regional ASD support network
- Communication with families/caregivers before arrival for procedure
- Follow-up communication with families/caregivers

Weaknesses
- Small facility close to street
- Offsite security and social work
- Complex EMR with many differences between inpatient and outpatient facilities
- Large health system change takes time
- Rapid pace of procedures
- More than 130 providers perform surgery at outpatient surgery center
- Staff comfort with caring for special needs children
- Ability to reach families/caregivers for follow-up

Opportunities
- Outreach to other outpatient clinics, providers' offices
- Use of All About Me Passport and protocol for all patients
- Educational opportunities for health care team to learn about ASD

Threats
- Change resistance in large health care system
- EMR downtime inability to access All About Me Passport in patient history

EMR, electronic medical record; SWOT, strength, weakness, opportunity, and threat.

best to care for children with ASD. Outreach education was provided to our system's pediatric staff and providers. System Clinical Developmental Psychologists and the Family Support Network led efforts to educate staff and families/caregivers about local and regional support groups for children with ASD. After educational opportunities, staff have expressed a better understanding of ASD and how best to address the needs of these children and families or caregivers. Dental and ear, nose, and throat clinics were given access to the All About Me Passport to initiate the protocol before the day of surgery.

Limitations

The initiation of the Linked Protocol is dependent on reliable details from the families or caregivers. Families or caregivers may not share behavioral challenges with caregivers in advance, and this impedes identifying patients with level 3 ASD, those with the most behavioral deficits. There also may be undiagnosed ASD.

Our surgical center has limited space in the PACU with 8 bays and privacy curtains. The goal to discharge from the PACU was not always attainable if large patient volumes or the loud, bright atmosphere disturbed the child with ASD. Attempts were made to control for light and sound, but this was often difficult with the large volume of rapid surgeries. Discharging from the step-down unit where we had a private room was sometimes optimal.

The comfort level of the nurses in allowing families in recovery while the child had an airway was a barrier. Encouragement and communication have been essential in following evidence-based protocol. We also emphasized the importance of evaluating the necessity for PACU versus step-down unit depending on noise and patient volume. Linked Program education continues to be an ongoing process with reinforcement of protocols and sharing of outcomes. Communication between perioperative areas is a continuing challenge, needing reinforcement in use of protocol. A laminated copy of the Linked Logo was added to the patient's chart and placed on the PACU curtain to communicate that a child with ASD was coming through our areas.

Relevance to Perianesthesia Nursing

Perianesthesia nurses have a great opportunity to advocate for and support children with ASD and their families. Clear communication between health care personnel and the families through the perioperative process is vital to provide the best and most individualized care for the child. Having an alert for staff to know a child has ASD has improved our communication, and the All About Me Passport has been instrumental in helping staff get to know the needs and stressors particular to that child. Families were thrilled to be asked about their children's preferences and experiences. Children with ASD often have difficulty communicating their needs, especially when stressed with procedures. Having the All About Me Passport available for future encounters also gives the families the opportunity to not have to retell the story over and over again.

This project attempted to bridge the gap between families and the health care team caring for the child with ASD. Perianesthesia nurses have the opportunity to be patient advocates with their knowledge of ASD community resources. This study has shown how addressing a child's needs and procedural history can impact outcomes of future encounters.

Future Research

Additional research is needed to evaluate how the All About Me Passport may help with pediatric patients or even the adult population with disabilities. What is the importance of previous medical experiences on current experience? What are the effects of having a family caregiver active in care at induction of anesthesia? Research is needed also to evaluate health care staff knowledge before and after use of the Linked Protocol to evaluate stress and comfort levels in caring for patients with autism.

Conclusions

The All About Me Passport is a tool that helps identify special needs and procedural history issues for children with ASD. Its use has fostered better communication between families and caregivers and the health care team throughout the perioperative areas. Families have expressed great appreciation that they are able to share their knowledge of what their children need. The Linked Program has been effective in helping our health care staff be more aware of the challenges facing families and their children with ASD in the perioperative setting while giving them the tools and skills necessary to meet their needs.

Acknowledgments

The Linked ASD Program would not have been successful without the contributions of our multidisciplinary team including registered nurses, anesthesia providers, certified nurse anesthetists, surgical providers, child life specialists, and nurses. The authors thank them for all the difference they have made in the children's care!

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