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REPORTS OF ORIGINAL INVESTIGATIONS

Enhanced perioperative management of children with autism: a pilot study

Optimisation de la prise en charge périopératoire des enfants atteints d'autisme : une étude pilote

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Abstract

Purpose *When children with autism spectrum disorder (ASD) are in hospital, difficulties with socialization, communication, and behaviour can be exacerbated. The purpose of this study was to establish feasibility of an enhanced perioperative care pathway.*

Methods *Utilizing parental and provider feedback, a protocol including environment modification, anxiolysis plans, specialized order sets, and child life specialist (CLS) support was developed over a nine-month period. Autism severity scores (ASS), communication styles, triggers, and previous experiences were used to create individualized care plans in the preoperative clinic. Emotion and sedation scores in the same day surgery unit, at anesthesia induction, and in the postanesthesia care unit were recorded. Acceptance was obtained from nurses, anesthesiologists, and parents. Feasibility criteria included the recruitment rate, adherence to protocol, data collection, and patient follow-up.*

Results *Eighteen patients were enrolled in this pilot study. All feasibility criteria including recruitment, adherence to study protocol (97%), and follow-up (94%) were met. Fifteen (83%) patients were nonverbal and minimally interactive (ASS = 3). Common triggers were loud noises (78%), crowds (78%), and bright lights (56%). After implementation of the protocol, 15 (83%) of the anesthetic inductions were described as excellent. Ten different premedication plans were used. Parents described the personalized plan, anxiolysis medication, and CLS support as advantageous. All (100%) nurses, anesthesiologists, and parents felt the program should continue.*

Conclusion *We showed that a multidisciplinary perioperative care plan for children with severe ASD was feasible and 100% accepted at our institution. The individual nature of anxiolysis plans was considered a strength of the protocol.*

Résumé

Objectif *Lorsque des enfants souffrant d'un trouble du spectre de l'autisme (TSA) sont à l'hôpital, leurs difficultés en matière de socialisation, de communication et de comportement peuvent être exacerbées. L'objectif de cette étude était d'établir la faisabilité d'un plan d'intervention périopératoire optimisé.*

Méthode *En nous fondant sur les commentaires des parents et des professionnels des soins de santé, un protocole comprenant des modifications de l'environnement, des plans de gestion de l'anxiété, des ensembles d'ordonnances spécialisés et le soutien d'un spécialiste de l'enfance a été mis au point sur une période de neuf mois. Les scores de sévérité de l'autisme (SSA), les styles de communication, les déclencheurs et les expériences passées ont été utilisés afin de créer des plans d'intervention personnalisés en clinique préopératoire. Les scores d'émotion et de sédation ont été enregistrés à l'unité de chirurgie d'un jour, à l'induction de l'anesthésie et en salle de réveil. L'accord sur le plan d'intervention a été obtenu du personnel*

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infirmier, des anesthésiologistes et des parents. Les critères de faisabilité comprenaient le taux de recrutement, l'observance du protocole, la collecte de données et le suivi des patients.

Résultats *Dix-huit patients ont été recrutés dans cette étude pilote. Tous les critères de faisabilité, y compris le recrutement, l'observance du protocole (97 %) et le suivi (94 %), ont été respectés. Quinze (83%) patients étaient non verbaux et minimalement interactifs (SSA = 3). Les déclencheurs fréquents étaient les bruits forts (78 %), les foules (78 %), et les lumières vives (56 %). Après la mise en œuvre du protocole, 15 (83 %) des inductions anesthésiques ont été décrites comme excellentes. Dix plans de prémédication différents ont été utilisés. Les parents ont estimé que le plan d'intervention personnalisé, la médication anxiolytique et le soutien du spécialiste de l'enfance étaient bénéfiques. Tous les intervenants (100 %, c'est-à-dire personnel infirmier, anesthésiologistes et parents) étaient d'avis que le programme devrait se poursuivre.*

Conclusion *Nous avons démontré qu'un plan d'intervention périopératoire multidisciplinaire spécialement conçu pour les enfants souffrant de TSA sévère était faisable et accepté à 100 % dans notre institution. La nature personnalisée des plans de gestion de l'anxiété a été considérée comme l'une des forces du protocole.*

Autism spectrum disorder (ASD) is diagnosed in 1 in 68 children in North America.[1] Children with autism may have difficulties with sensory processing and language communication skills, and may require strict adherence to routines or stereotypic behaviours. Abnormal sensory processing is present in 40–80% of children with ASD.[2] Prolonged preoperative fasting times and the wide array of sensory insults present in the operating room (OR) environment (e.g., fluorescent lights, crying children, pungent volatile anesthetics) can be problematic in this population and lead to traumatic inductions, postoperative agitation, aggression, and flight behaviour. Children with ASD often have better visual versus verbal communication skills and may have difficulty interpreting social cues.[3] In a parental survey in 2013, Kopecky found only 23% of children expressed their needs verbally.[4] Concomitant medical issues, psychologic concerns (hyperactivity, obsessive-compulsive behaviours, tics), and intellectual disability may further complicate behavioural challenges.[4] Because of fundamental differences in communication style, healthcare providers often feel ill-equipped to communicate with a child with ASD and feel they would benefit from further training.[5,6] This combination of factors results in high perioperative stress for children, parents, and healthcare providers. Lindberg *et al.* surveyed 12 parents of children with ASD, many of whom described their perioperative experience as "disgraceful", "unspeakable suffering", and a "hopeless struggle".[7]

Despite its prevalence, children with ASD are historically an underserviced group of individuals. Rainey and van der Walt proposed an integrated preoperative management program for children with ASD that focused on early identification and collection of detailed information regarding specific triggers.[8] Anesthesia-related protocols previously focused on sedating combative behaviour, but behaviourally informed interventions are improving clinical outcomes.[9] Individualized plans that minimize known stressors have been shown to decrease non-compliance at induction from 50% to 17%, without the use of premedication.[10] A systematic review by Koski *et al.* stressed the importance of individualized care when designing a protocol to minimize stress in children with ASD. Three main themes emerged relating to the development of a perioperative care pathway: 1) collaborating with the caregiver to inform management; 2) developing a process for communicating information from caregiver to staff; and 3) modifying the perioperative environment based on patient-specific needs.[11]

With these considerations in mind, we developed a multidisciplinary care plan for children with severe ASD including both environmental modification and individualized anxiolysis to improve the perioperative experience (Figure). Herein, we describe its development and assess the feasibility of continuing the program.

Methods

Study design

We conducted a pilot trial of pediatric patients with severe ASD scheduled for surgery at a single-centre Canadian tertiary care pediatric hospital over a nine-month period from March 1 2016 to November 25 2016. Over the course of the study period, changes to the protocol were made based on parental feedback. This pilot study was conducted after local Research Ethics Board approval (Hamilton Integrated Research Ethics Board #15-168) and was reported in line with the CONSORT (Consolidated Standards of Reporting Trials) guidelines.[12]

Participants

Patients were enrolled from the preoperative clinic at the discretion of the pediatric anesthesiologist. All pediatric

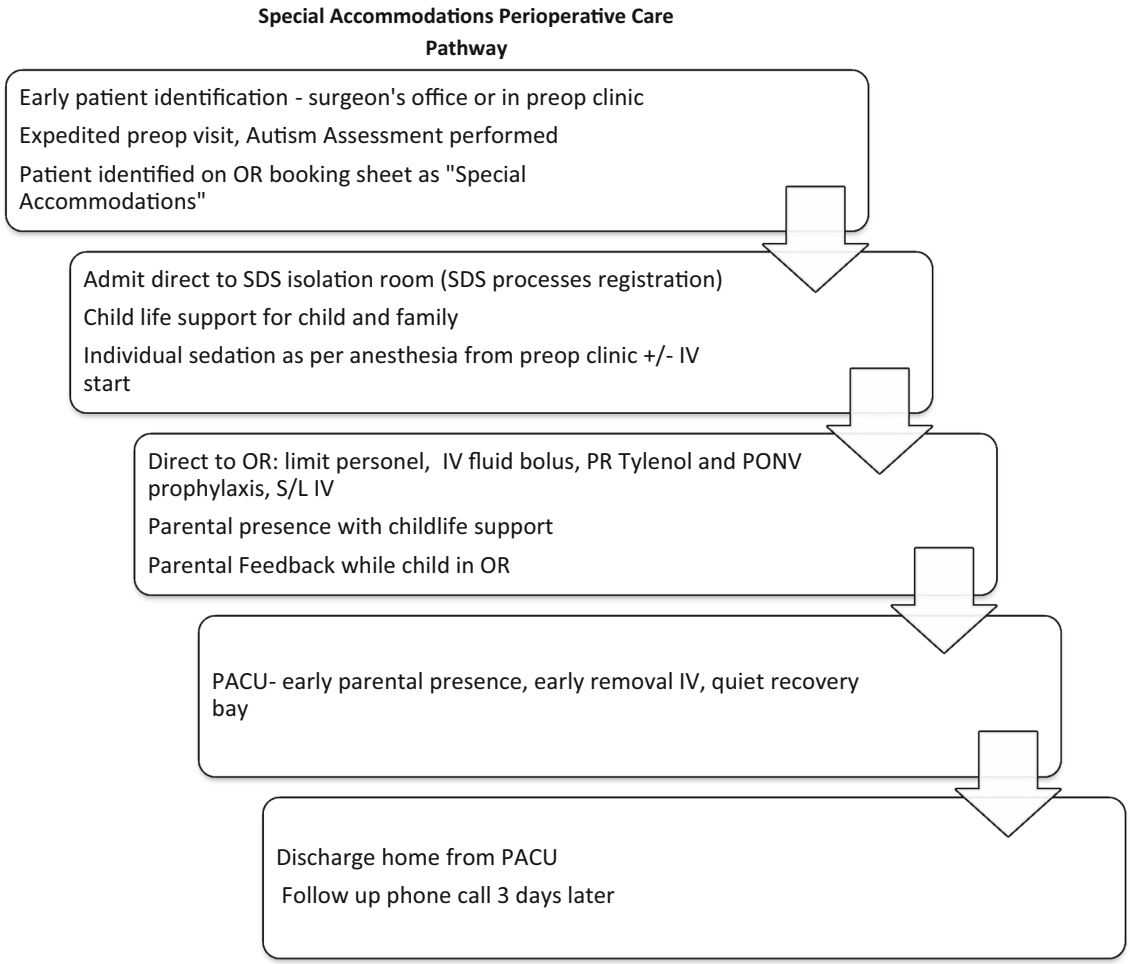

Figure Special accommodations care pathway flow diagram at start of pilot trial. IV = intravenous; preop = preoperative; OR = operating room; PACU = postanesthesia care unit; PR = per rectum; PONV = postoperative nausea and vomiting; SDS = same day surgery; S/L = saline lock

patients are seen preoperatively at our institution. Any child aged three to 17 yr with symptoms of severe ASD was eligible; nevertheless, patients that were nonverbal, had a history of traumatic inductions, or exhibited inability to cope during the preoperative appointment were prioritized. Only patients with procedures (dental, urology, otolaryngology, orthopedic) booked in the main OR were included, as procedures in outpatient areas are covered by a separate sedation service. Children < three years of age were not included because there is usually no formal diagnosis of ASD at this age.[13] Consent was obtained from caregivers at the time of enrollment by a research assistant after being approached by the child life specialist (CLS).

Study protocol

A psychosocial assessment including both observation and parental feedback was completed preoperatively by the CLS (eAppendix 1, available as Electronic Supplementary Material [ESM]). Patients were assessed using a four-level ASS developed by Hudson to communicate level of severity (eAppendix 1, available as ESM).[14] Nevertheless, severity scores were re-coded and reported using the more recent three-level scale described in the *Diagnostic and Statistical Manual of Mental Disorders, 5th Edition*.[15] Along with information regarding specific triggers and the anticipated level of sedation required, the pediatric anesthesiologist in the preoperative clinic would develop a "*Special Accommodations protocol*" with the family including pre-procedure individualized anxiolysis medication and environment modification. A specialized order set (eAppendix 2, available as ESM) outlined options for medication including midazolam (0.25 $mg \cdot kg^{-1}$ or 0.5 $mg \cdot kg^{-1}$) and/or ketamine (3 $mg \cdot kg^{-1}$ or 6 $mg \cdot kg^{-1}$) with the medications to be given orally or intramuscularly (individually or in combination). Routine anti-sialagogues were not used. Medication doses were based on previous studies that examined optimal doses for anesthetic premedication in children with ASD.[16-19] Patients were to

be booked as the first case of the day and identified on the main OR list as "*special accommodations*". The *npo* times were not altered from institutional policy. Wait times in the preoperative clinic were minimized for patients with ASD. Surgeons were asked to identify patients with severe ASD when booking clinic appointments.

On the day of surgery, patients had an expedited preoperative course. Normally, patients are admitted 1.5 hr prior to surgery and have multiple transitions—i.e., admission office, same day surgery (SDS) intake, and group preoperative holding area (with multiple children and families). Children with special accommodations were admitted 1 hr prior to their procedure directly to a private quiet room away from non-sedated children. They were attended by a CLS and SDS nurse. Patients were not required to change clothes or have routine vitals done. Anxiolysis medication was administered in the clear fluid of choice of the child by a parent or the SDS nurse. Intravenous (IV) access was obtained as sedation levels allowed or based on the child's individualized plan. An IV was avoided if there was a history of traumatic IV starts.

The number of personnel in the OR was kept to a minimum (signs were placed on the OR doors indicating nonessential personnel should keep out) and room lights were dimmed during the anesthetic induction. The CLS and parents accompanied the patient to the OR; parental presence is routine at our institution. Intraoperative management was at the discretion of one of the four pediatric anesthesiologists involved in the study. Parents were debriefed post-induction by the CLS.

Postoperatively, patients were admitted to a quiet recovery bay with dimmed lights. A specialized order set (eAppendix 3, available as ESM) was used by the postanesthesia care unit (PACU) nurses to guide monitoring, early IV removal, and direct discharge to home from the PACU as soon as the patient met usual discharge criteria (a score of 18–20 based on a modified postanesthesia discharge scoring scale).[20] Familiar toys, parental presence, and individual coping strategies (e.g., music, weighted blankets, and service animals) were utilized on emergence as per the child's plan.

Feasibility was the primary outcome; in addition, whether the interventions were perceived as disruptive or helpful were also recorded. The patient's activity level/emotional state were documented at arrival to the SDS, at induction, and in the PACU according to scales derived by Gutstein *et al*.[21] These scores have been used and validated in studies investigating pediatric premedication using midazolam and ketamine in non-ASD children.[22-25] They have not been validated for children with ASD. Of note, there is no premedication or perioperative anxiety score validated for the ASD population. Compliance with anxiolysis medication, time between sedation and admission to the OR, quality of anesthetic induction, presence of emergence agitation, nausea/vomiting, and time to discharge were also recorded.

Formal feedback and post-intervention comments were collected from parents, SDS nursing staff, and anesthesia and PACU nursing staff. Parents were asked to compare this experience with previous OR experiences using a paper questionnaire filled out while the child was in the OR. Parents were asked specifically what interventions were helpful during their stay, what could have been improved, whether the child had difficulties during their stay, and what was done.

Outcomes

The primary outcome was the feasibility of a perioperative protocol for children with ASD. Feasibility was defined as the ability to enroll ten patients with ASD over a six-month period, greater than 90% adherence to the study protocol, and 90% follow-up with caregiver/parent feedback. Secondary outcomes included emotion and sedation scores pre- and post-anxiolysis medication and the quality of anesthetic induction. Parental satisfaction was used both to gauge the efficacy of the intervention and to make modifications to the protocol. The written comments from the parents' completed feedback forms (eAppendix 4, available as ESM) were analyzed using established qualitative thematic analysis; two authors (L.B., A.W.) individually reviewed and inductively coded all of the written comments to identify meaningful feedback.[26,27] Related codes were amalgamated under common categories and organized in table form to identify recurring thematic patterns. They compared their analyses to ensure the thematic categories comprehensively captured all of the data and resolved discrepancies through discussion.

Statistical analysis

The descriptive summary of patient demographics, prognostics, and surgical information was reported as count (%) for categorical variables and mean (standard deviation [SD]) for continuous variables. The sample size was based on the prediction of two to four severely autistic patients presenting to the OR per month. A sample size of ten patients allowed data to be collected over a period of approximately six months while still being representative of the larger population study.[28]

Results

Over a nine-month period, 18 patients completed the Special Accommodations program, which included modifications from the preoperative clinic to discharge home from PACU on the day of surgery. There were no cancellations, despite 15 (83%) ASS level 3 patients (i.e., nonverbal and minimally interactive) taking part. Many of these children had a history of traumatic experiences in the hospital, and 11 (72%) had a history of combative or aggressive behaviour. Age ranged from three to 16 yr with a mean (SD) age of 8 (3.5) years. The most common reported triggers were loud noises and crowds (78%), and bright lights (56%). Over half (67%) of patients underwent dental procedures. The mean (SD) sedation time preoperatively was 38.6 (15.7) min, mean (SD) procedure duration was 81 (43) min and mean (SD) PACU stay to discharge home was 93 (37) min (Table 1). One patient had an unanticipated postoperative admission for more extensive orthopedic surgery.

All feasibility criteria were met including recruitment of two patients/month, 97% adherence to the study protocol, 95% data acquisition, and 94% patient follow-up (Table 2).

Ten different anxiolysis medication combinations were used (Table 3). A combination of midazolam and ketamine was utilized in 11 (60%) of the cases. Fifteen (94%) of the inductions were described as very good or excellent by the anesthesiologist managing the case whether via inhalational (61%) or IV (39%) induction (Table 4). Sedation increased from a mean (SD) score of 4.2 (0.9) pre-sedation to 2.7 (0.9) at induction, following administration of premedication. Emotion scores decreased from a mean (SD) of 1.9 (0.9) to 1.3 (0.5) at induction.

Parental feedback identified several positive elements of the program (Table 5). Ten parents (55%) commented on the benefit of the personalized approach/sedation plans and

Table 1 Patient characteristics of Special Accommodations program participants

Demographics	Descriptive statistic (n = 18)
Age (yr); mean (SD)	8.1 (3.5)
Weight (kg); median (min, max)	28.8 (11.1, 100.0)
Gender (male); n (%)	16 (89)
Autism severity*; n (%)	
Severity Level 3 (requires very substantial support)	15 (83)
Severity Level 2 (requires substantial support)	1 (6)
Severity Level 1 (requires support)	0 (0)
Missing	2
Sensory dislikes/triggers; n (%)	
1. Crowds	14 (78)
2. Loud noises	14 (78)
3. Bright lights	10 (56)
4. Touch	9 (50)
5. Smell	3 (17)
6. Other	3 (17)
History of aggressive/combative behaviour; n (%)	11(73)
Missing	3
Type of surgery; n (%)	
Dental	12 (67)
Otolaryngology	3 (17)
Urology	2 (11)
Orthopedic	1 (6)
Time from admission to surgery (sedation time - 8am surgery only); mean (SD)	38.6 (15.7)
Duration of procedure; mean (min,max; SD)	81.3 (15, 208; 43)
Time from PACU to discharge; mean (min, max; SD)	93.4 (54,180; 37)

*Autism Severity Scores were initially recorded on a four-level scale developed by Hudson (2006).[14] These have been re-coded as per the three-level scale outlined in the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition.[15] PACU = postanesthesia care unit; SD = standard deviation

Table 2 Assessment of feasibility objectives

Feasibility objective	Feasibility criteria	Result	Conclusion
Recruitment rate	10 patients per 6 months (1.67 patients/month)	18 patients recruited over 9 months (2 patients/month)	Feasible
Adherence to study protocol: • Individualized plan created, order set filled • Admission to SDS with supports • Move directly to OR • PACU/ direct discharge home	Minimum 90% of adherence check points	104/107 adherence check points (97%) 17/18 individualized plans documented 18/18 order set completed 18/18 admitted to SDS with supports (quiet room, CLS) 16/17 accepted premedication if planned 18/18 completed surgery 17/18 discharged home (1 unanticipated admission)	Feasible
Parental consent rate* Consent rate $= \frac{\#\text{consented}}{\#\text{approached}}$		18/18 (100%)	Feasible
Ability to collect data	> 90% fields collected	1,180/1,246 (94.7%) More than 90% of fields collected contained information that was not considered missing	Feasible
Follow-up rate	At least 80% of parents provided follow-up feedback	17/18 (94%) – More than 80% of parents provided at least some information during the follow-up period	Feasible

* Patients were screened beforehand to see if they fit the study population before being approached

CLS = child life specialist; OR = operating room; PACU = postanesthesia care unit; SDS = same day surgery

Table 3 Premedication plans used to facilitate either intravenous placement or transition to operating room and inhalational induction

Planned premedication (*po*, unless stated)	Rescue dose	*n*
None		1
Midazolam 0.5 mg	–	2
Midazolam 0.25 mg·kg^{-1} + ketamine 3 mg·kg^{-1}	–	4
	Ketamine 3 mg·kg^{-1} *po*	1
Midazolam 0.5 mg·kg^{-1} + ketamine 1 mg·kg^{-1}	–	1
Midazolam 0.5 mg·kg^{-1} + ketamine 3 mg·kg^{-1}	–	4
	Ketamine 3 mg·kg^{-1} *po*	1
Midazolam 0.5 mg·kg^{-1} + ketamine 6 mg·kg^{-1}	–	1
Ketamine 3 mg·kg^{-1}	Ketamine 1 mg·kg^{-1} IM	1
	Ketamine 3 mg·kg^{-1} *po*	1
Ketamine 2 mg·kg^{-1} IM	–	1

IM = intramuscular; *po* = per os

eight parents (44%) commented on the presence of CLS workers. The use of preoperative anxiolysis medication (33%), parental presence at induction and emergence (33%), decreased wait times (28%), the patience displayed by healthcare providers (27%), and the use of a quiet room (28%) were also noted as strengths of the program by parents.

Feedback from healthcare providers was also very positive (Table 6). With 100% acceptability, healthcare providers (SDS, OR, PACU, and anesthesiologists) felt that the program should continue. Perceived strengths of the program included its multidisciplinary structure, the use of preoperative anxiolysis medications, and its family-centred approach. One of the issues raised was the increased nurse:patient ratio that was required in PACU for the Special Accommodations program patients. Early feedback also included comments about the need for early identification of patients requiring special accommodations.

Table 4 Descriptive characteristics of intraoperative special accommodations

Characteristics	*n* (%)
Inhalational *vs* IV induction	
Inhalation induction	11 (61)
IV induction	7 (39)
Quality of anesthetic induction	
1. Poor (afraid, combative, crying)	0
2. Fair (moderate fear, not easily calmed)	1 (6)
3. Good (slight fear, easily calmed)	5 (28)
4. Excellent (unafraid, cooperative)	10 (56)
Missing	2
Sedation scores in SDS *(prior to premedication if applicable)*	
1. Barely arousable, needs shaking/shouting to arouse	0
2. Asleep, eyes closed, arouses easy	1 (6)
3. Sleepy: eyes open but less active and responsive	2 (11)
4. Awake	7 (39)
5. Agitated	8 (44)
Sedation score at induction	
1. Barely arousable, needs shaking/shouting to arouse	2 (11)
2. Asleep, eyes closed, arouses easy	3 (17)
3. Sleepy: eyes open but less active and responsive	10 (56)
4. Awake	3 (17)
5. Agitated	0
Emotion score in SDS *(prior to premedication if applicable)*	
1. Calm	5 (31)
2. Apprehensive/tentative behaviour/withdrawn	9 (56)
3. Crying	0
4. Thrashing/crying with arm, leg movement/resistance	2 (13)
Missing	2
Emotion score at induction	
1. Calm	12 (66.7)
2. Apprehensive/tentative behaviour/withdrawn	6 (33.3)
3. Crying	0
4. Thrashing/crying with arm, leg movement/resistance	0
Complications - post sedation	
Nausea/vomiting	2 (11)
Increased secretions	1 (6)
Aggressive behaviour on emergence	1 (6)
Additional preoperative anxiolysis medication required	4 (22)

IV = intravenous; SDS = same day surgery

Discussion

This pilot trial shows that an individualized perioperative care plan using a multidisciplinary team is feasible at our institution to improve the perioperative experience for children with ASD. The concept of individualized sedation planning is not novel; nevertheless, only recently have a small number of Canadian institutions (predominantly at tertiary pediatric hospitals) adapted this approach into a formalized process. In 2017, Swartz *et al*. reported perioperative care plans for children with ASD, resulting in 90% overall cooperation at induction of anesthesia with preoperative sedation administered to only 38% of the entire cohort (50% in the severe group).[29] One benefit of our protocol identified by parents was the presence of the CLS. The addition of a CLS helped to focus coping strategies for the child and parent and ensure individualized plans were carried out. Some of these plans included service animals in the SDS holding area, mobilizing with supervision while waiting for the OR, removing siblings and/or other additional personnel from the patient's room, acting as a liaison between healthcare providers and family, and providing distraction.

Our pilot trial targeted children with severe ASD and consequently many plans utilized anxiolytic premedication. The type of premedication varied widely from child to child and was determined by considerations such as taste sensitivity, compliance with oral medication, previous experience with pre-induction sedation, expected level of cooperation, and body mass index. Currently, there is insufficient evidence in the literature to support one medication over another, although some reviews have suggested using alpha-agonists with midazolam over ketamine because of the side effect profile.[3] At the time of this pilot study, dexmedetomidine was not available in our hospital.

Monitoring in the SDS was a concern at the onset of the pilot trial—no patients experienced desaturation or required supplemental oxygen. In fact, 20% required an additional dose of medication to achieve a suitable level of sedation. Arnold described intramuscular (IM) ketamine use in 85% of patients with ASD (not stratified by severity)[30]; 11% of individual plans utilized IM ketamine (one elective, one rescue) in our study. Although effective, routine use of IM medications can lead to increased anxiety with repeated visits and may not be a sustainable option.[18] Ketamine has been associated with emergence agitation and unwanted side effects, particularly increased secretions and nausea. Despite other studies citing no adverse effects of ketamine,[29] the two episodes of nausea observed in this pilot study were both after IM ketamine had been administered. Given the potentially unfavourable side effect profile of ketamine and longer recovery time at higher doses,[31] other medications, including dexmedetomidine, will be considered in future studies.[32,33]

In this pilot, anesthetic management was at the discretion of the anesthesia provider; nevertheless, variability in technique was minimized by limiting the number of providers. Patients were given 1–2 $\mu g \cdot kg^{-1}$ fentanyl at the beginning of the case and maintained on sevoflurane for the procedure. As is standard practice at our

Table 5 Themes from parental feedback regarding Special Accommodations protocol

Parental feedback theme	Exemplar quote	*n* (%)
Personalized approach	"(Staff) listened to suggestions, which is what made this our best experience ever!"	10 (55)
	"Wonderful to see that there is extra and different types of care given to children and families with special needs."	
	"This program is absolutely necessary for families and patients with special needs!! Thank you so much for the options—best experience so far"	
CLS (distraction, iPad, toys)	"(CLS) was encouraging and supportive—could not have done it without her!"	8 (44)
Preoperative sedation		6 (34)
Parental presence	"Playing a favourite show, letting him cuddle with mom were great strategies"	6 (34)
Decreased wait times		5 (28)
Patient staff	"Staff were professional and patient. Took the time necessary for our son to complete each step"	5 (28)
Quiet room		5 (28)

CLS = child life specialist

institution, ondansetron (0.1 $mg{\cdot}kg^{-1}$), dexamethasone (0.1 $mg{\cdot}kg^{-1}$), and Tylenol 40 $mg{\cdot}kg^{-1}$ *pr* were administered intraoperatively. Three patients required morphine (0.02–0.05 $mg{\cdot}kg^{-1}$) for procedures with expected postoperative pain—tonsillectomy (n = 2) and osteotomy (n = 1). As more concerns are raised about the potentially decreased oxidative capacity and impaired methylation in children with ASD,[34,35] the use of short-acting medications and avoidance of certain drugs including nitrous oxide, prolonged infusions of propofol, or adding B_{12} supplementation may be considered. Balancing the need for pre-induction sedation and attempting to minimize drug exposure in patients with ASD is complex; traumatic inductions have been associated with postoperative general anxiety, enuresis, night-time crying, and temper tantrums. These changes are usually transient but may persist for up to one year in some individuals.[36]

The overwhelming feedback we received from healthcare workers was that this program should continue. These results support the work of Thompson and Tielsch-Goddard who found increased staff interest in optimizing the surgical experience for children with ASD and increased satisfaction when additional attention is given to minimizing stress for families in the perioperative period.[6] Consistency in staff members caring for a patient with ASD can be very beneficial.[9] In our system, the patient is seen by different staff at the preoperative visit, before the OR and postoperatively; this is a potential area for improvement in the future. The increased nurse:patient ratio both in SDS and PACU was identified by healthcare providers as a potential difficulty. Nurses will typically be assigned to at least two patients in SDS and in PACU (once patients are awake and responding to commands). Mean recovery time in the PACU was 95 min, at which point patients were discharged directly home. This was shorter than the combined PACU/SDS stay of approximately 150 min that most patients experience (most patients stay 40–60 min in PACU and 90 min in SDS before discharge home at our institution). As in other aspects of the protocol there appeared to be a learning curve with the last four patients being discharged from PACU in 60 min with an overall trend of decreasing recovery time. Although we cannot decrease the nursing ratio, we have been able to minimize the time it is required. Additionally, a very agitated patient with ASD will definitely require an increased nursing ratio. One patient did have an extended PACU stay because of an unanticipated admission (surgical cause) and unavailability of an inpatient bed, which resulted in the only incidence of combative behaviour. This highlighted the need for our protocol to include expedited inpatient transfers.

Parental feedback weighed heavily into our protocol design. Several suggestions were made during the pilot for further environment modification including visual communication boards, additional parent information specific for children with ASD, and the need for consistency across visits, which were implemented. Unfortunately, we were unable to complete reliable post-discharge home follow-up. Parental feedback was obtained post-induction while their child was in the OR. Although this was a reliable way to obtain feedback, information on postoperative behaviour changes, sleep disturbance, and postoperative nausea and vomiting after discharge was not collected. This is an important area for improvement in future studies.

The success of the protocol was assessed using feedback from parents and healthcare providers, and using sedation and emotional scales. The sedation and emotional scales were previously developed to assess effectiveness of

Table 6 Themes from healthcare provider feedback regarding Special Accommodations protocol

Healthcare provider feedback theme	Exemplar quote
Program should continue	"Amazing program, I hope we learn more about it and it becomes part of our practice" – *OR RN*
	"Very worthwhile - particularly for family and patient" – *PACU*
Multidisciplinary structure is important	"Appreciated the structure, communication, and support from all services. Everyone had the same plan and expectations" – *SDS RN*
	"…Great supports with AA, Dr. (anesthesiologist), sedation, child life worker" – *SDS RN*
Preoperative sedation can improve experience	"Absolutely helpful for patient, family, and healthcare team to have this preop sedation prior to the OR. Very seamless transition into the OR with the child sedated and IV in place" – *Anesthesia*
	"Excellent result from premedication. Seeing patient preop and day of surgery was night and day!" – *Anesthesia*
	"Helped patient adapt without undue distress; patient-centred, wonderful!" – *OR RN*
Helpful for families	"Overall beneficial to staff and patient. Quiet and calm on induction and emergence." - *Anesthesia*
	"I think this intervention is very beneficial to the patient as well as the family. It might delay OR time but it is less traumatic to the patient" – *OR RN*
Increased nursing ratio required in PACU	"A little challenging as nursing ratio 1:1" – *PACU*
	"1:1 nursing ratio for 60 min … woke up very calm and had no issues" – *PACU*

OR = operating room; PACU = postanesthesia care unit; RN = registered nurse; SDS = same day surgery

preanesthetic medication.[22,23,25] Future studies should more precisely capture the anxiety level of patients distinct from their level of sedation; this may require using a different scale. Patients with ASD are believed to have a higher incidence of anxiety; nevertheless, no anxiety scale is currently validated for autistic children.[37] As the larger study will include both severe and higher functioning patients with ASD, having feedback from the patients directly will be an important additional source of information.

This pilot study shows that a multidisciplinary perioperative care pathway that improves the perioperative experience for severely autistic children and their families is feasible at our institution, which previously did not utilize premedication, quiet rooms, or CLS. With 100% acceptability among healthcare providers, our Special Accommodations program, which features individualized planning, formalized communication between healthcare providers and parents, and discriminant use of premedication, has changed practice at our institution.

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