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Perioperative and anesthesia guidelines for children with autism: A nationwide survey from Sweden

Abstract

Objective: The overall aim of this study was to describe the current set of guidelines for the preparation and care for children with Autism spectrum disorder (ASD) in the perioperative setting across Sweden and explore the content of these guidelines in detail. Method: An online questionnaire was distributed to the chairpersons of all anesthesia departments (n= 68) and pediatric departments (n= 38) throughout Sweden. Follow-up phone calls were made to those departments that did not return the questionnaire. The presence of guidelines was analyzed via descriptive statistics. These guidelines and comments on routines used in these departments were analyzed inspired by conventional content analysis. Results: Seven out of the 68 anesthesia departments and none out of the 38 pediatric departments across Sweden have guidelines for preparing and/or administering care to children with ASD within the perioperative setting. From the guidelines and routines used, 3 categories emerge: “lacking the necessary conditions,” “no extra considerations needed” and “care with specific consideration for children with ASD.” These 3 categories span a continuum in the care. In the first category, the anesthesia induction could result in the child with ASD being physically restrained. In the last category, the entire encounter with the health care service would be adapted to the specific needs of the child. Conclusion: There is a lack of evidence-based guidelines specifically designed to meet the needs of children with ASD in the preoperative period in Sweden. Further research is needed to understand if children with ASD would benefit from evidence-based guidelines.

Key Terms: Autism spectrum disorder, children with ASD, guidelines, preparation, anesthesia, perioperative settings

Background

Approximately 1% of all children in Sweden have been diagnosed with Autism Spectrum Disorder (ASD). Children with ASD tend to present with difficulties surrounding communication, social interaction and processing facial expressions (1, 2). These children are often inflexibly dependent on routines. This routine dependence can lead to extreme distress when the child is faced with even small changes in his or her immediate environment (3). Children with ASD often show abnormal responses to sensory stimuli, such as over- or under-reactivity to stimuli, particularly sound, touch, visual stimuli, pain, or the sensations of hot and cold (4, 5). Underscoring its significance, children with ASD frequently rely upon the healthcare system for examinations, treatments, and surgeries. Due to nature of the disorder these children often require anesthesia for procedures that other children can undertake without sedation or anesthesia, i.e. for dental care, x-rays, as well as other examinations and treatments (6-8).
Preoperative anxiety is common among typically developing children (9). This anxiety can lead to decreased cooperation during anesthesia induction and increased emergence delirium. Its presence can even exacerbate postoperative pain. Preoperative anxiety may result in negative postoperative behaviors, such as sleep disturbances, nightmares, separation anxiety, apathy, general anxiety, and withdrawal (10-13). Children with ASD frequently rely upon the health care system (6, 7); this frequency, in turn, places the children at particular risk for preoperative anxiety. Anesthesia inductions can become traumatic for children with ASD, and these inductions have even been shown to later exaggerate a child's anxiety at the bare sight of a hospital bed (14). Caring for all children who require anesthesia—whether typically developing or diagnosed with an disorder—is an inherent challenge, especially in creating confidence in both the child and the parents to decrease anxiety about the impending procedure. Children with ASD pose an even bigger challenge for the nurse tasked to provide the child with care (15-18).

Adding to these difficulties within the perioperative setting, the abnormal sensory reactions that are specific to children with ASD can make it difficult to interpret a child’s behavior. For instance, when a child with ASD visits the preoperative setting for a procedure requiring anesthesia, he or she may react unpredictably, diverging from expected responses to stimuli compared to those of typically developing children or those with other intellectual disabilities like Down syndrome (4, 19). Additionally, children with ASD often have difficulties with social interaction and understanding verbal and non-verbal communication, compared to children with other intellectual disabilities such as Down syndrome who are usually good communicators as well as highly social and engaging (19). For example, children with Down syndrome may exhibit limited verbal communication skills, but they usually demonstrate good non-verbal communication (19). Due to the problems children with ASD have with interpreting words, facial expressions, and other forms of non-verbal communication, establishing a rapport with the children becomes especially difficult (2, 3, 16). These difficulties can lead to higher risks of uncooperative behavior during anesthesia induction, making physical restraint more common among this group than among either typically developing children or children with other intellectual disabilities (15-18).

Research has shown that preparing both the child and the environment to suit the child’s needs may decrease anxiety in children with ASD (17, 20). Other researchers have found that general knowledge about autism by practitioners (as well as knowing the specific child with ASD) in advance of the procedure can enhance the possibility for a calm anesthesia induction, thus relieving (or at least mitigating) any suffering for the child (17, 21, 22). Routinely, parents have reported frustration with the healthcare system for its lack of proper routines, and the lack of understanding about the impact of the disorder or its effects on their children’s behavior (17, 23, 24). A child with ASD has communications problems including difficulty reading social cues and understanding symbols. This makes it hard to interact with the child without specific knowledge about the disorder or, more importantly, its particular manifestation within the child. In addition, the abnormal, unpredictable sensory reactions in children with ASD add to the nursing staff’s difficulties in interpreting the child’s reactions and providing resultantly tailored care. These difficulties can heighten the risk that physical restraint will be employed for anesthesia induction among this specific group of children compared to other children (15-18).
Therefore, establishing guidelines for the care of children with ASD could increase the probability for creating a non-threatening and adaptive environment for treating this particular group of patients.

The overall aim of this study was to describe the current set of guidelines for the preparation and care for children with ASD in the perioperative setting across Sweden as well as explore the content of these guidelines in detail.

**METHOD**

**Sampling and participants**

An online questionnaire was distributed to the chairpersons of all anesthesiology departments (n= 68) and pediatric departments (n= 38) throughout Sweden. In total, 106 questionnaires were sent out. The chairpersons received instructions to forward the questionnaire to the appropriate person within his or her department, if he or she did not readily possess the applicable information. Two reminders were sent by email. Departments that did not respond to the questionnaire received a follow-up phone call to ensure that all information would be obtained. From the anesthesia departments, 24 questionnaires were returned by mail, and 44 follow-up phone calls were made. From the pediatric departments, 18 questionnaires were returned by mail and 20 follow-up phone calls were made. In total, 64 phone calls were made. The internal drop-out rate was 10 (10.6%). In all, 96 completed questionnaires were analyzed within this study: 60 from anesthesia departments and 36 from pediatric departments.

Ultimately, 8 anesthesia departments were unable to participate beyond completing the initial questionnaire, because they did not anesthetize children (or, more relevantly, children with autism spectrum disorder (ASD) and, thus, had little information of relevance. Similarly, one pediatric department did not provide surgical care for children, and another department did not care for children with ASD (36) (Table 1).

<table>
<thead>
<tr>
<th>Type of Department</th>
<th>Caring for children with ASD requiring anesthesia</th>
<th>Not caring for children with ASD requiring anesthesia</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Anesthesia Department</strong></td>
<td>60</td>
<td>8</td>
<td>68</td>
</tr>
<tr>
<td><strong>Pediatric Department</strong></td>
<td>36</td>
<td>2</td>
<td>38</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>96</td>
<td>10</td>
<td>106</td>
</tr>
</tbody>
</table>
Data collection

The questionnaire consisted of nine questions, including a field for comments from those to whom it was sent. Three of the questions gleaned demographic information, that is, data about the hospital, the department, and the number of children (as well as children with ASD) for whom the department administered care. Five of the questions were specifically concerned with the administration of anesthesia to children with ASD. The response format for these questions was in the form of “yes or no.” The questionnaire included the following questions: (Table 2)

Table 2. The questions in the questionnaire

<table>
<thead>
<tr>
<th>Question numbers</th>
<th>Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Do you administer anesthesia to (or sedate) children for investigations, treatments, or surgeries within your department?</td>
</tr>
<tr>
<td>2.</td>
<td>If yes, how many children are anesthetized or sedated within your department per month?</td>
</tr>
<tr>
<td>3.</td>
<td>Do you provide anesthesia to (or sedate) children with ASD for investigations, treatments, or surgeries within your department?</td>
</tr>
<tr>
<td>4.</td>
<td>If yes, how many children with ASD are anesthetized or sedated within your department per month?</td>
</tr>
<tr>
<td>5.</td>
<td>Do you have any guidelines for the preparation of children with ASD before their anesthesia induction or sedation?</td>
</tr>
<tr>
<td>6.</td>
<td>Do you have any guidelines regarding how to care for children with ASD when they come to your department for anesthesia or sedation?</td>
</tr>
<tr>
<td>7.</td>
<td>Do you have a specific person responsible for administering care to children with ASD? If yes, please attach the name and email address of the individual tasked with providing this care.</td>
</tr>
<tr>
<td>8.</td>
<td>Comments:</td>
</tr>
<tr>
<td>9.</td>
<td>For which department, do you work? Please provide the name of the hospital and the department.</td>
</tr>
</tbody>
</table>

Analysis

Descriptive statistics were utilized to analyze the portions of the questionnaire with quantitative data. An analysis largely influenced by traditional content analyses was used in dissecting the comments made by the departments in describing their provision of care to children with ASD, either with or without guidelines. Two guidelines were received from their respective departments as complete documents. The rest of the analyzed text consisted of guideline descriptions, provided in the questionnaires’ “comments” field. Data about the existence of guidelines were subsequently compiled through descriptive statistics. The number of children with ASD receiving care was not available from the
departments, as departmental statistics are based upon the procedure performed, not the diagnosed disability of the child receiving treatment.

As noted, analyses involving the comments, both descriptions of guidelines and routines, from the departments were inspired by conventional content analysis, drawn from Hsieh (25). First, the guidelines and comments were repeatedly read in their entirety to obtain a sense of these comments as a whole. Subsequently, words which captured the texts’ key concept(s) were highlighted with different colors representing these different concepts. Codes were then drawn from the highlighted text. These codes were grouped into subcategories, and these subcategories were then assembled into larger, encompassing categories (Figure 1). Two of the researchers, independent of one another, examined the subcategories as well as the broader categories. Through discussion, these researchers reached a consensus. These subcategories and categories underwent further discussion in the larger research group, which resulted in a negotiated consensus regarding the subcategories, categories, and the delineations of each. These negotiations were of particular importance given the backgrounds of the respective authors. The first author, as a nurse anesthetist, had a preexisting understanding of the perioperative context; meanwhile, the other researchers possessed knowledge about children with disabilities but not the perioperative context itself.

![Figure 1. Example of the analytic process from “meaning unit” to “category”](image)

**Ethical considerations**

According to Swedish law (2003:460) and 12 § bylaw (2003:615)) ethical approval from an ethics board is unnecessary for research that is not aimed to physically or psychologically affect involved subjects, or which poses a clear physical or psychological risk to harm the subject (26). The survey executed within this study was appraised to neither affect nor harm anyone, physically or psychologically.

**RESULT**

The existence and distribution of guidelines
Sixty of the anesthesia departments performed pediatric surgery on children with autism spectrum disorder (ASD). Of these sixty departments, six affirmed they had specific guidelines for children with ASD. One department responded that it had guidelines for patients with special needs (of which children with ASD were included) (11.6%). However, only two departments submitted an actual copy of their respective guidelines. The other five departments explained their guidelines in the “comments” field of the questionnaire. The lone guideline for persons with special needs consisted of a single overall question posed during a preoperative phone call, inquiring about the need(s) of the patient. Three of the 60 departments were located in a children’s hospital (Table 3). Of the 36 pediatric departments, none had specific guidelines for children with ASD (Table 3).

<table>
<thead>
<tr>
<th>Type of Department</th>
<th>With Guidelines</th>
<th>Without Guidelines</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anesthesia Department</td>
<td>7</td>
<td>50</td>
<td>57</td>
</tr>
<tr>
<td>Pediatric Anesthesia Department</td>
<td>0</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Pediatric Departments</td>
<td>0</td>
<td>36</td>
<td>36</td>
</tr>
<tr>
<td>Total</td>
<td>7</td>
<td>89</td>
<td>96</td>
</tr>
</tbody>
</table>

Table 3: Distribution of guidelines among the departments

Most of the departments cared for children with ASD in the same fashion as all children. There was no consideration taken whether the child had a disability of any sort or not. The category Care with specific consideration for children with ASD mainly came from the departments’ expressed guidelines. However, the contributing subcategories also came from departments without written guidelines (Table 4).
Table 4: Distribution of departments with and without guidelines in each one of the categories and subcategory

<table>
<thead>
<tr>
<th>Categories</th>
<th>Subcategories</th>
<th>Anesthesia departments with guidelines (n= 7)</th>
<th>Anesthesia departments without guidelines, but some routines (n= 53)</th>
<th>Pediatric departments without guidelines (n= 36)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lacking the necessary conditions</td>
<td>Identified by chance</td>
<td>0</td>
<td>6</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>Parent-initiated contact</td>
<td>0</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Limited time</td>
<td>0</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>Use of physical restraint</td>
<td>0</td>
<td>4</td>
<td>0</td>
</tr>
<tr>
<td>No extra considerations needed</td>
<td>The same preparation as all children</td>
<td>0</td>
<td>9</td>
<td>11</td>
</tr>
<tr>
<td></td>
<td>The same premedication as all children</td>
<td>0</td>
<td>21</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>The same staff as all children</td>
<td>0</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Care with specific consideration for children with ASD</td>
<td>Structured identification</td>
<td>3</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>Healthcare center-initiated contact</td>
<td>3</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>Parental Participation</td>
<td>5</td>
<td>7</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Adapted preparation</td>
<td>6</td>
<td>7</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Special and experienced staff</td>
<td>4</td>
<td>11</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>Information transfer</td>
<td>2</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>Adapted premedication</td>
<td>2</td>
<td>10</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Cooperation between staff</td>
<td>0</td>
<td>0</td>
<td>2</td>
</tr>
</tbody>
</table>

Description of utilized routines and guidelines

Three categories and fourteen subcategories emerged from the qualitative analyses of the guidelines in hard copy, and the guidelines and routines supplied by the departments as
comments. The three categories were as follows: “lacking the necessary conditions,” “no extra consideration needed,” and “care with consideration for children with ASD.”

**Category 1: Lacking the necessary conditions**

The content of this category described working in an environment wherein the staff did not have the time or requisite structure in place to sufficiently prepare a child with ASD. The subcategories within this category came exclusively from the anesthesia departments.

**Identifying** a child could result by chance (The subcategories, agreed upon by the researchers, are expressly identified herein by bolded text. The type of department is marked with (A) for anesthesia and (P) for pediatric department after the statement).

“Two days a week, there are open preoperative visits for all children. Then these children can be found” (A). In actuality, a child with ASD would only be identified, however, if the parents chose to attend such a visit and the staff also recognized the disability of the child. In some departments, all children were seen by an anesthesiologist days before surgery and could, resultantly, be identified as a child with ASD when applicable. This information would then be transferred to the operation schedule one day in advance.

In some cases, the child with ASD would only be identified if the parent initiated the contact. “It is up to the parent to get in touch with the department and inform that they have a child with special needs and tell how they want it done” (A).

**Limited time** represented one obstacle when caring for these children with ASD. Either there was insufficient time to collect information when the child arrived for treatment or the preoperative visits were canceled altogether (due to limited time). “Trying to take the parent aside and ask [about the child when they meet them for the procedure] (A). Limited time could also be the reason for the choice of sedative premedication.

“Sufenta® nasally has been used, but it is extremely rare, because the children become so drowsy, postoperatively, and take up a space for too long” (A).

A lack of the necessary conditions to prepare the child with ASD sometimes led to the use of physical restraint of the child for anesthesia induction. “If it doesn’t work, you use mask induction against the resistance of the child to, in essence, ‘run over them’” (A).

**Category 2: No extra considerations needed**

The subcategories listed within this broader category came from both the anesthesia and pediatric departments. The underlying reasoning behind these subcategories emanated from the fact that children with ASD did not need any other preparation or treatment than typically developed children; rather, these departments emphasized that all children, regardless of disability, would receive good pre-operative preparation and treatment. There are citations from both anesthesia departments (A) and pediatric departments (P).
Both anesthesia and pediatric departments described that children with ASD received the same treatment as the other typically developing children; consequently, children with ASD received the **same preparation as all children**. Children with ASD were invited to the preoperative visits with all other children, and, similarly, these children with ASD were seen by an anesthesiologist, like all other children. "*All children are invited to come for a group preoperative visit*" (A) Receiving the same preparation as typically developing children also meant that children with ASD were seen like any other child and given care to the best of the staff’s ability. "*We prepare all children as good as possible. We show and explain*" (A). "*We do not believe anything specific is required for these children [with ASD]*" (P).

The routines pertaining to sedative premedication were **the same premedication as for all children**, regardless of disability. "*Premedication for all children is Midazolam® or Clonidin®*” (A). The majority of departments used Midazolam® as the preferred sedative premedication (when any medication was used at all). Many departments mentioned Clonidin® as the drug of choice, but it still was not used as expected.

Furthermore, **the same staff as all children** provided care to children with ASD as well. Some departments had a special group working with children in general. "*A special team interested in children in general*” (A). "*One learns gradually, and all the nurses are pediatric nurses*” (P). "*After a day of education, we became aware of the need of specific guidelines*” (P).

### Category 3: Care with specific consideration for children with ASD

The core concept that permeated the existing guidelines involved making an individualized care plan for the child, taking into consideration the specific needs of a child with ASD. Creating this plan included collaboration with the parents to gather knowledge about the child to better facilitate preparation and resultant care. The plan, among other elements, included a decision about whether or not to use sedatives. In crafting the plan, the particular environment and staff members’ knowledge about ASD (or familiarity with the individual child) were taken into account. To facilitate this aspect, a structure was in place to alert the department that a child with ASD had been scheduled for a procedure.

A **structured identification** of the child with ASD was sent to the department by a referral letter or written operation notification, alerting the operating clinic that a child with ASD was due for anesthesia. Via this referral letter, information could be disseminated to the appropriate staff in time for the necessary preparations. "*The surgeon, dentist, or equivalent writes a referral letter to the nurse anesthetist in charge of these children*” (A).

The **healthcare center initiated contact** with the parents, via either mail or telephone. The aim of this contact was to gather knowledge regarding the specific needs of the child, such as the child’s specific interests and particular difficulties the child as well as soliciting the parents’ involvement in the child’s care.
Parental participation was identified as particularly important in relaying information to the nurse and/or personnel about the child with ASD. In such instances, the parent and nurse would collaboratively craft a plan. “We usually ask the parents what works best for their children” (P). “Ask the parents how they think it should be” (A).

To meet the child’s needs, an adapted preparation was tailored to each child, preoperatively. The child had a calm space where he or she could wait without being disturbed. Extra time was also provided to minimize the child’s stress. “In our routines, we offer a preoperative dialogue where we gather information and an individual plan is created together with parents, the surgeon, and the [anesthesia] staff” (A). “Sometimes we send photos home to the children; other times a preoperative visit is needed” (P).

Special and experienced staff members worked with the children with ASD. The precise number of staff members involved in this provision of care was limited, but some nurses had experience working with children with ASD (and preferably, also possessed specific education regarding the disability in general). The nurse designated to take care of the child was specifically familiarized with him or her (as well as his or her particular needs). “A nurse anesthetist with education on ASD who is to anesthetize the child is booked (at least 2 weeks ahead of anesthesia). This nurse anesthetist meets the child and the parents... At the visit, they go through the plan for the care of the child” (A). “There is one specific nurse caring for these children [with ASD]” (P). The familiarization of the nurse anesthetist to the child could be established by photo and/or a preoperative visit with the child. Pictures, suitable for the child, were used to facilitate communication with the child. If the child came for several procedures requiring anesthesia, the same nurse anesthetist took care of the child whenever possible.

If the same nurse was not available, information transfer from the previous visit was employed to ensure that the nurse caring for the child knew the care plan from the child’s previous visit. “At the visit, they go through the plan for the care of the child the day of surgery, and the plan is documented in the computerized documentation system” (A).

Adapted premedication was also employed by both anesthesia and pediatric departments. “We use sedating premedication if the child tolerates it” (P). “The strategies for sedating premedication should be made in consultation with the anesthesiologist. Clonidine® can be preferred” (A).

Cooperation between staff was a strategy claimed by the pediatric departments. “We have good cooperation with the anesthesia staff and other staff involved” (P). “Anxious children are transferred to the anesthesia department to have their IV line inserted” (P).

**DISCUSSION**

The major finding in this nationwide survey revealed a lack of structured guidelines in most of Swedish anesthesia and pediatric departments for preparing and subsequently caring for children with ASD in the perioperative setting. Furthermore, the qualitative data ultimately described a lack of necessary conditions to care for children with ASD.
Another view generally conveyed is that no extra considerations are needed for children with ASD in perioperative settings.

Children diagnosed with ASD are a diverse group with diverging needs, even between children with this diagnosis (27). However, the most common features of ASD, like difficulties interpreting verbal and non-verbal communication as well as tremendous dependence on routine, make a child with ASD more prone to extreme anxiety or of exhibiting challenging behaviors in an unknown or unfamiliar situation (28). The communication difficulties in children with ASD can often differ from the expected communication needs of children with other intellectual disabilities like Down syndrome; this makes it especially important that care for children with ASD is administered in a way suitable for their specific needs (19, 27). To this end, the abnormal reactions to sensory stimuli’s in children with ASD can make an act of kindness like a gentle touch, which many other children experience as enjoyable, feel extremely uncomfortable or even trigger challenging behaviors from the child (4, 27). This makes it difficult for the staff to provide good care in the absence of knowledge about the disorder and its precise manifestation in a specific child (16). Creating and implementing guidelines for the perioperative care of children with ASD would instill the staff with the requisite tools to effectively work with (and provide a higher quality of care to) these children with ASD.

As described by Lindberg (2012), the absence of a structured care plan for children with ASD can often lead to a frustrating experience for the child and the parents. They resultantly encounter a rigid healthcare system, wherein parents feel they are engaged in a hopeless struggle where no one listens (much less, addresses) their child’s particular needs within a hospital setting (17). Potential cooperation with the child could be ruined even before the nurse meets with the child due to, say, an excessive waiting time or a waiting room insufficiently adapted to the child’s needs. A lack of written guidelines implies that the way in which the child is treated depends primarily on the interests, attitudes, and knowledge of whomever happens to be working with these children in the hospital setting.

**Structured identification**, one of the findings in this study, appears as a key concept in providing good care for children with ASD in healthcare settings. This practice runs contrary to other departments within this study wherein children with ASD were largely identified by chance. If the nurses were unaware that a child to whom they would provide treatment had ASD, then their administered care did not matter in the context of the disorder. Put simply, when unaware to the child’s disability, the nurses did not have the chance to specifically prepare for the child. Previous research has revealed that the absence of any structure in place for preparation, the knowledge and the attitude of the nurse can only help a child with ASD to a limited extent (17, 24, 29, 30).

This study’s findings occasionally revealed special and experienced staff working with these children in certain departments. In some departments, nurses designated to work with children with ASD possessed both experience and knowledge about the disorder and its impacts. Previous research has underscored that the knowledge and the attitude of the nurses working with these children is of utmost importance (31).

Furthermore, continuity in the staff is one of the pillars in caring for these children to prevent challenging behavior (23). This study’s findings showed the opposite behavior in some departments, wherein the same staff as all children was adapted rather than maintaining continuity. These nurses were pediatric nurses, specifically skilled in working with children; resultantly, they did not appear to believe in the need for specific
guidelines for children with ASD. However, one department stated that after having a day of education about the disorder, they realized the need for specific guidelines for children with ASD in particular. In short, just because a nurse has experience working with typically developed children does not automatically imply that the nurse would have knowledge about children with ASD (3, 17, 22, 32). This study showed that parents often experienced meeting new people who lacked knowledge of the child or knowledge about his or her disorder. Bultas (2012) found that healthcare personnel often did not fully understand the precise impacts of the disorder on the child, nor did these personnel understand how the manifestations of ASD would affect the child’s hospital visit. In these instances, parents felt ignored by the staff, even regarding small requests that would serve to reduce the anxiety of their child (30). When only one or two nurses are dedicated to working with children with ASD, the administration of healthcare and adequate care provision can become vulnerable. A child scheduled for a procedure when that specific nurse is off-duty would intuitively receive care from a nurse lacking knowledge about the disorder or lack knowledge about the child’s particular needs.

**Parental participation** (and instructions to involve the parents in the actual planning of the child’s care) was found in departments’ guidelines. In such circumstances, parents felt they were positively accommodated and “received by warm hands” when they had the opportunity to provide information about the child’s specific routines and needs to the treating nurses (17). However, this cannot be taken to an extreme; it is important to refrain from allocating full responsibility for the child’s care onto the parents, as this can be unnecessarily burdensome and unwanted (17, 33, 34). A good interaction between the nurse and the family has been shown to result in successful care for children with ASD (24).

Performing **care with specific consideration for children with ASD** (and relying upon the particular strengths and resources of the individual child) was employed in all guidelines. In essence, there are multiple means to administer a calm anesthesia induction. This would help to prevent noncompliant behavior from the child (17, 33, 34). Davignon et al. (2014) found that alterations in the organization and administration of healthcare services is essential for the successful care of children with ASD (24).

The findings illuminated that some departments employed the adaptive **use of physical restraint**. On occasion, the staff remained unaware of the child’s condition before meeting him or her. When staff members lacked sufficient knowledge about the child or his or her disorder, the use of physical restraint could result. Time limitations posed additional obstacle in providing care to children with ASD; a lack of cooperation on behalf of the child, due to his or her disability, could increase the risk that the anesthetist would rely upon physical restraint to complete the treatment in an efficient timeframe. Ultimately, the lack of preparation and even the lack knowledge among anesthetists about ASD can led to inadequate preparation of the child prior to the treatment, resulting in the use of physical restraint for the child’s anesthesia induction (17, 18, 23).

**Methodological considerations**

The questionnaire expressly used the word “guidelines.” However, although many of the departments did not have explicit guidelines, they did nonetheless have routines. From a methodological standpoint, this means that answers provided would not have explicit guidelines to which they would refer; however, routines nonetheless existed. While those routines could have been lost in the questionnaire, space was nonetheless provided for comments in the questionnaire, which called for extensive elaboration on how each
department worked with children with ASD. Another limitation of the study might be self-reporting. A chief of an anesthesia department may over-represent their policies on children with ASD, which may not be consistently implemented in reality in their hospital. In the process of analyzing these comments, the extensive discussions between the researchers to establish a negotiated agreement became a strength of the study. In addition, answers were gathered from all departments. Follow-up phone calls were made to those departments who did not return the questionnaire, which made the survey complete. The wording of the main question consisted of: “Do you have any guidelines for preparing children with ASD for anesthesia or sedation?” This may have excluded an answer describing any guidelines for children with other neurodevelopment disabilities. However, despite this question’s potential ambiguity, one department answered that it had common guidelines for persons with special needs (and inquired into these precise needs) which indicates that there were no guidelines for children with special needs in other departments.

CONCLUSION, CLINICAL IMPLICATIONS, AND FUTURE RESEARCH

Children with autism spectrum disorder (ASD) frequently rely upon the health care system for procedures requiring anesthesia. Due to this group’s difficulty with interpreting words, reading facial expressions, and engaging in non-verbal communication, children with ASD run a higher risk than other children at becoming uncooperative in the perioperative setting and anesthesia induction in particular. These children’s inflexible dependence on routines may result in challenging behavior when experiencing an unfamiliar environment wherein many, if not all, of their routines are disrupted. The resulting encounter could be traumatic for the child, especially as anesthesia induction with physical restraint becomes the department’s course of action. Most departments in Sweden currently lack a structure by which to administer care for children with ASD. Consequently, there is a lack of evidence-based guidelines specifically designed to meet the needs of children with ASD in the preoperative period in Sweden. There is a need for further research to understand whether children with ASD would benefit from specialized preoperative procedures to reduce known problems related to anxiety/pain or use of physical restraint in the preoperative period.
References


