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Management of children with Autism Spectrum Disorder (ASD) in anesthesia and radiographic contexts

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Abstract

Objective: As a primary objective, this study purports to develop guidelines to better care for children with Autism Spectrum Disorder (ASD), particularly regarding these children's preparation for anesthesia and radiologic procedures

Method: Using a Delphi method with an online distribution of questionnaire, guidelines for caring for children with ASD were created. Twenty-one participants were included in the expert panel. These participants were working with children with ASD in several anesthesia and radiology departments in Sweden. A list of items was created from a previous survey and the literature. In the first round the items with <60% agreement were discarded. Items were merged and a new list was created. Two more similar rounds were performed. In the last 2 rounds 21 participants responded and 80% agreement was considered to be consensus.

Results: The final guidelines consisted of 14 items and a checklist of 16 factors. The 5 areas covered by the items and the checklist were: Planning involving parents/guardians, Features in the environment, Use of time, Communication and The health care professionals. The organization was important in making it possible for the health care professional to care for the individual child according to the child's needs. It was important to involve the parents/guardians in order to obtain knowledge about the functioning of the child.

Conclusion: A caring encounter involving a child with ASD in the anesthesia and radiology contexts requires advance planning, catered specifically to the individual needs of each child. In order to accomplish this, general knowledge regarding ASD as well as ASD's particular manifestation in the child entrusted to their care, is required from the health care workers. The organization needs to have structures in place to facilitate this process.

keywords: Autism, anesthesia, care, children, guidelines, radiology

Background

Children with Autism Spectrum Disorder (ASD) often have difficulty interpreting both verbal and nonverbal cues, generally impeding effective communication. These children are largely dependent on routine and sensitive to even minor modifications within their environments (1). Furthermore, children with ASD commonly experience atypical sensory reactions—for example, both overreacting to sound and underreacting to pain (2). The precise manifestation of autism among children with ASD can vary significantly from child to child; as such, these children fall along a spectrum from “high functioning” (according to diagnostic criteria) to “low functioning,” often with added cognitive disabilities. Despite the variance of characteristics among children with ASD, healthcare visits may represent a consistent source of anxiety for any child with ASD. The behavior that results from this anxiety can become a significant strain on the child, his or her parents, and even the Health Care Professionals (HCPs) caring for the child (3-5).

In Sweden, the prevalence of ASD is approximately 1% among the general population (6). Children with ASD utilize the healthcare system more frequently than typically developing children (7-9). Radiographic examinations, in addition to other treatments and surgeries, comprise these visits. Furthermore, these children may also require anesthesia, even for procedures that typically developing children routinely undergo without it, like dental examinations. Given their frequent visits to healthcare settings, these children need to receive care and treatment in accordance with their specific needs (8, 9). In healthcare departments that are highly dependent on technology, such as the departments for radiology and anesthesia, the limited knowledge about the general needs of children with ASD—as well as the lack of initiative in acquiring knowledge about the individual needs of a child with ASD—remain persistent problems (5, 10, 11).

For parents of children with ASD, navigating the complexities of the healthcare system often constitutes an inherently stressful experience (12, 13). Healthcare departments’ unfamiliarity or misconceptions regarding the individualized needs of children with ASD compounds this stress. Many parents feel poorly understood when they visit medical settings with their child. These parents find that the HCPs do not understand the complexities of ASD, nor do they know how to functionally adapt to a child’s precise needs (3-5, 12, 14).

Consequently, HCPs’ lack of knowledge regarding ASD poses a significant obstacle to smooth, functional cooperation between the HCPs and the child (3-5, 12, 15, 16). HCPs who are prepared and knowledgeable about a specific child’s communication needs—and approach the child accordingly—greatly facilitate the success of healthcare encounters involving children with ASD. Preparing the child and parents in advance of the healthcare encounter serves a similarly integral role. To this end, the departments need to maintain time management and provide a space where sensory stimuli can be reduced to minimize the child’s discomfort as necessary (5, 10). Effective understanding within medical encounters is based upon free-flowing communication where parents can convey information about the child’s specific needs; such communication can only be established when parents feel their voices are heard in dialogue with the HCPs (14). Thus, a positive medical experience is predicated upon meeting with HCPs who are actively interested in the parents’ expertise and involve parental insights into the healthcare planning for the child. Ultimately, a positive health care encounter between the parent, child, and HCPs requires that the HCPs understand the particular needs of each child with ASD. (4, 5, 10, 14). If a child with ASD receives medical attention without proper consideration for his or her specific needs or diagnosis, the result can be wrought with complications, potentially resulting in the child being subjected to physical restraint for a procedure (3). Consequently, HCPs require more knowledge and training

in caring for children with ASD, both to address the complexities of children's diagnosis and to facilitate a more positive healthcare encounter (4, 5, 17, 18).

Frequently, when a child is scheduled for a medical procedure, HCPs will initiate contact with the parents. However, this contact is generally one-sided, rarely involving the transfer of information about a child's specific needs from the parents to the HCPs. Rather, the information pertains exclusively to the details of the procedure itself, unilaterally relayed from HCPs to the parents (10, 11, 14, 19). In order to successfully mitigate the anxiety of a child with ASD in anesthesia or radiology departments, HCPs should engage in a dialogue with the parents, prior to the planned procedure; this open communication would allow HCPs to obtain information about the particular needs of the child instead of merely conveying information (5, 19, 20).

Standard preparation and care for children with ASD in traditional medical settings often results in challenges for the HCPs, which can create unnecessary anxiety in the child. This anxiety, in turn, may manifest as challenging behavior (14, 16, 17, 21). The interpretation of this behavior—particularly, its cause—can differ markedly between parents and HCPs. For example, Johnson et al. (2014) illustrated the varying interpretation between parents and HCPs regarding the child's behavior. In the study, the mothers, who arguably know their child most intimately, interpreted the child's challenging behavior as a reaction to the environment: an attempt by the child to self-calm to address anxiety or express frustrations about not being understood. HCPs, by contrast, generally interpreted the same behaviors as emanating from the child for reasons exclusive to the child. To elaborate, the HCPs interpreted these behaviors as self-stimulation (the child's repetition of physical movements or sounds) or as a reflection of the child's aggression, i.e. attention-seeking behavior with the risk of self-injury or harm to others. To adequately address these challenging behaviors (and create congruence in their respective interpretations), both parents and HCPs have advocated for the use of cooperative strategies, such as advance preparation, coordinated distraction for the child during procedures, and teamwork between the parents and the HCPs (22).

Although their perspectives would be invaluable, it is difficult to directly gain the perspectives of children with cognitive disabilities from the children themselves in research (23). Thus, a proxy is used to approximate the child's voice: the parents as spokespersons for their children. This approach has an existing basis in care for children with ASD, given that involving parents within decision-making is already a critical component of family-centered care (24).

Structured guidelines, particularly guidelines that incorporate and rely upon a checklist, are helpful in managing the child's healthcare encounter. These guidelines can greatly help in the creation and implementation of a structured plan for each child, tailored to his or her particular needs. Within these guidelines, a checklist should be employed in order to elicit the precise variables particular to the child—for example, his or her likes and dislikes, or levels of sensitivity to sound and light. (16, 20, 25). Both parents and HCPs express a desire for accessible, intuitive structured care plans to improve the care of children with ASD in health care settings (5).

As a primary objective, this study purports to develop guidelines to better care for children with ASD, particularly regarding these children's preparation for anesthesia and radiologic procedures.

Methods

This study relied upon a modified Delphi method. This interactive forecasting method can be visualized as a structured communication process among a group of individuals when dealing with complex problems (26, 27). The method's chief objective is to reach a consensus through the aforementioned structured communication process. At the behest of the U.S. Air Force at the start of the Cold War, the Delphi method was developed for forecasting purposes and has since been widely adopted across multiple fields (27). In particular, the Delphi method is now heavily utilized in health care settings to create standards and principles by which to guide practices within medical environments, underscoring its relevance in the present study (26).

Participants

Participants were identified in a nationwide survey, administered in anesthesia departments and radiology departments; these departments identified members with knowledge and experience regarding children with ASD. This survey was intended to elicit the existence of guidelines regarding care for children with ASD (10). Contact was also made with representatives of the Swedish Autism Association and the Swedish Society of Radiographers. In total, 30 experts were identified. Specifically, these 30 experts were selected from among HCPs specifically working with children with ASD in the medical contexts of anesthesia and radiology. Four of these experts had significant others diagnosed with ASD. Expert researchers in ASD were also included, as well as a member of the Swedish Autism Association. The respondent experts' answers to questionnaires (not including the expert researchers) were analyzed using the Delphi method. Application of the Delphi method contained three questionnaires for the experts. Nineteen experts answered the first questionnaire. Two of the 19 experts returned a response where the sender's identity was inadvertently hidden. Because these responses could have come from four possible experts, the second questionnaire was sent to all four. All four responded to this second round of questions, resulting in two experts being added to the study. Ultimately, 21 experts responded to this second questionnaire. All experts involved in the study possessed ample experience working with children with ASD. (For the demographic data regarding the participants, see Table 1.)

Table 1. Demographic data of the experts

Demographic aspects	Number (n)
Nurse Anesthetist	n =14
Radiographer	n =5
Other profession	n =2
Female	n =20
Male	n =1
Age (m)	m = 54 year; range (38-67)
Working experience	m= 30 year; range (14-43)
Significant other diagnosed with ASD	n=4

M=mean

Development of Guidelines in Anesthesia and Radiology Contexts

Use of a modified Delphi method allowed for creation of the guidelines. These guidelines were created in four steps, which include three questionnaires. The first step involved creating a list of items that could be used as guidelines in anesthesia and radiology-related contexts. The second, third, and fourth steps consisted of three individual questionnaires, which were emailed to the aforementioned group of experts to develop the guidelines. See Figure 1.

Creation of the questionnaires relied upon the communication tool esMaker®. All communication was conducted through separate emails to each individual participant, thereby ensuring confidentiality between various participants.

Figure 1. Flowchart of the process in creating the guidelines

The First Round

This study's first step involved a review of the literature surrounding the management of children with ASD in the perioperative and radiologic contexts. An investigation into the existence and present usage of guidelines regarding children with ASD in anesthesia, pediatric, and radiology departments throughout Sweden followed this literature review. These surveys asked respondents to attach their guidelines (when present), and they also encouraged respondents to comment on their own routines involving children with ASD, even in the absence of written guidelines within their department (10, 11).

Subsequently, a list of items was collectively distilled from the existing guidelines, respondent experts' comments regarding care for children with ASD in their respective departments, and information from the original literature review. These items led to the creation of a multi-part

questionnaire. The questionnaire began with six demographic questions about the respondent. The questionnaire then continued onto a collection of 72 items in total for the respondents' review—71 separate items plus 1 checklist consisting of 15 different factors about the child's particular manifestation of ASD. The respondent experts were then asked whether each item should constitute a part of general guidelines regarding children with ASD and instructed to answer with a "yes" or "no." They received further instruction to insert or email comments to the researcher, as necessary. The questionnaire, containing the full list of items, was then emailed to all 30 respondent experts via esMaker®. Respondents received a reminder email one week after the initial questionnaire. Nineteen of the experts responded. The results from this first round were sorted, and items that received more than 60% agreement (i.e., 60%+ "yes" answers among respondents) were used to develop a draft of guidelines, alongside the respondent's relevant comments. The remaining items were merged, resulting in a list of 22 items (excluding the checklist). The 15-factor checklist was extended to 20 factors, following experts' comments. Items which did not achieve 60%+ agreement were discarded. See Table 2.

Round	Total items	Items <60% agree	Items with 60-80% agreement	Items with 80-100% agreement	Number of items to rephrase	Number of merged items
One	71 + 15 from checklist	17	19	50	-	45
Two	22 + 20 from checklist		1	41	12	15
Three	16 + 17 from checklist		2 + 1 from checklist	30		

Table 2. Summary of the agreement results of the Delphi rounds

The Second Round

The second questionnaire consisted of 22 items, and the checklist was increased from 15 to 20 factors. In evaluating these items with respect to a set of guidelines, the experts were presented with three answers from which to choose: "(1) To be included," "(2) To be rephrased," "(3) Not to be included." After each item, a space was provided for comments at the expert's discretion. This second questionnaire was then emailed to all 21 experts who had submitted responses to the first questionnaire. All 21 of these experts responded. A final draft of guidelines was subsequently drawn from respondent experts' answers and commentary. Items which received more than 80% agreement for the "To be included" answer were incorporated into the final draft of guidelines. Items with suggestions for rephrasing were also rephrased.

Following comments from the experts, 15 of the items were merged. Twelve of the items were also rephrased, resulting in a total of sixteen items (Figure 1). The item consisting of 20 factors was extracted from the guidelines as a separate checklist. Five of the factors on this checklist were merged, and six factors were rephrased, resulting in sixteen factors in total (Table 2).

The Third Round

In the third and final questionnaire, the experts could indicate whether an item should be included in the guidelines with a “yes” or “no”. Per usual, the questionnaire featured an area for experts to comment on the items at their own discretion.

All 21 expert respondents were sent the third questionnaire. They received a reminder email two weeks after being sent the third questionnaire. Nineteen experts responded. After receiving a second reminder, two additional experts submitted their answers, resulting in a total of 21 responses.

All items receiving less than 80% agreement (i.e., “yes” responses) were removed from the guidelines. Two items fell beneath this threshold and were discarded. Eight of the items received a full 100% consensus for inclusion. The remaining items received one (or occasionally two) “no” responses. The same procedure and 80% threshold for inclusion was applied to the separate checklist, resulting in one factor falling beneath the threshold and being removed.

Ethical Considerations

Under Swedish law, the Ethical Review Act, which governs research involving humans (2003:460), as well as Section 12 of the Regulation Concerning The Ethical Review Of Research Involving Humans (2003:615) collectively deem ethical approval from an ethics board unnecessary when the research does not involve a risk to subjects’ physical safety, psychological health, and/or personal integrity (28). As such, formal ethical review was not needed. Furthermore, the present study maintained the experts’ confidentiality by distributing the questionnaire in separate emails, ensuring one recipient per email.

Results

The study’s guidelines consisted of 14 items and a checklist of 16 factors. The guideline’s items were further divided into five areas: (1) planning that involved parents/guardians, (2) features in the environment, (3) use of time, (4) communication, and (5) health care professionals (HCPs).

In the first round, all items that failed to reach a consensus of 60% or more were discarded. Examples of these discarded items included: “[m]any persons can be involved in the encounter at the same time,” “children with ASD can be cared for in the same space as all other children,” and “there is no extra consideration needed when caring for children with ASD.” These items were all comments that came from departments without guidelines about how to care for children with ASD. Items were merged if they had the same content but were worded slightly differently. For example, “[t]he staff needs to use concrete/plain language” was merged with “the staff needs to adjust its language” and “the staff should not communicate unnecessarily.” These three items were condensed into the following: “[i]t is important that the staff uses plain language. Resultantly, the staff needs to adjust its language to the level of the child’s communication, refraining from use of symbolic language. For example: ‘Do X...’ instead of ‘can you do X?’ Staff should refrain from using phrases like ‘soon’ or similar abstract timestamps, only using a plain, concrete timestamp when speaking with the child.”

Following the second questionnaire, one item received less than 80% agreement among the respondent experts and was discarded. This item was “during preparation, it is important that the HCP encourages the child in an appropriate way.”

Following the third questionnaire, two items were removed from the list of guidelines. These items were “HCP is responsible for asking the parents/guardians (hereafter referenced as ‘parent’) if they need extra support in connection with their healthcare visit,” and “the HCP can preferably support the child in his or her use of self-calming or coping strategies.”

One factor from the separate checklist was discarded, which asked about “[h]ow the child shows confidence in someone.” The remaining factors in the checklist received between 0 to 3 “no” responses (with zero “no” responses being the most common). The final guidelines consisted of 14 items and a checklist comprised of 16 factors (Table 3).

Within this project, the guidelines for children with ASD were specifically developed for use in the anesthesia and radiology contexts.

Planning Involving Parents/Guardians

This area consisted of items: 1 to 6

The first step in successful interaction between the HCPs and a child with ASD is an informed department—particularly, a department informed of the fact that its scheduled patient is a child who has been diagnosed with ASD.

Upon receiving this information, it is the department’s responsibility to ensure routines are in place to accommodate a child with ASD. In particular, these routines should include contact with the parents to inform them of the procedure’s essential components; however, during this conversation, it is most important to glean information from the parents/guardians regarding the child’s precise needs. To ensure that all factors are covered, the checklist should be used within this conversation between HCPs and the parent(s). Here, a comprehensive plan should be crafted, encompassing both the child’s preparation and the entire plan for the child’s visit. This plan should include scheduling of a preparatory visit (as dependent on the child’s needs), premedication where needed, and the type of premedication (when relevant). Any changes to the plan must be handled with deliberation and care. These plans should be discussed and evaluated in conjunction with the parents to ensure that the resulting schedule is best adapted to the child’s needs. To this end, HCPs should always maintain the option of postponing the intended procedure as necessary, in order to accommodate the child’s scheduling needs and routines.

Features of the Environment

This area consisted of item: 7.

Within the department conducting the procedure, there should be an environment that can accommodate children who are sensitive to sensory stimuli. This could, for instance, be a room with adjustable lighting and the capacity for noise reduction, if necessary. This environment should also be equipped with comforting items for the child. When feasible, parents should be encouraged to bring the child’s favorite toy or other items with which the child is familiar that can help reduce his or her anxiety.

Use of Time

This area consisted of items: 8 to 9.

When planning the child's procedures, time management should be carefully considered. The scheduling should effectively suit the routines of the child as well as the department. Time management with regard to departmental routines should strike a balance. Scheduling should be done to eliminate unexpected waiting time while concurrently allowing for enough time to avoid creating stress for the child or the HCPs involved in the procedure.

In the context of anesthesia, application can be problematic for a child with ASD who is highly dependent on routine. Proper application requires that a child must have been fasting before his or her visit. To accommodate this logistic, optimal scheduling would likely be in the morning. In the radiology department, where the child does not need to fast, scheduling can be more flexible and occur throughout the day. In this context, the key is choosing the best time for treatment that effectively minimizes interruption and delay.

Communication

This area consisted of items: 10 to 11.

Communication should be customized to the child, deliberately tailored to his or her means and style of communication. Given that children with ASD may have difficulty interpreting body language as well as verbal communication, the child should have access to a set of pictures realistically depicting the forthcoming procedure, providing the child with the opportunity to understand and anticipate the procedure's steps. This is especially pertinent for children who regularly rely upon images in their communication. A copy of these pictures should be presented to the child in advance of his or her visit.

Additional considerations should be given when communicating with the child. When giving instructions, HCPs should convey information simply and with specificity, refraining from use of any abstract cues. For example, instead of relying upon abstractions like "soon," the HCPs should say, "when the sand has fallen to the bottom of this hourglass, we will do this part of the procedure." A child with ASD may not understand abstract temporal concepts like "soon," potentially resulting in anxiety for the child.

Health Care Professionals (HCPs)

This area consisted of items: 12 to 14.

HCPs providing care for a child with ASD should possess the requisite knowledge about the disorder to effectively care for the child. Having broad knowledge of childcare or how to care for children in a general medical setting is not enough. Children with ASD can respond in behavioral extremes that are not demonstrated by typically developing children. For example, children with ASD can respond with extreme anxiety to even light touching, while others may not mind being held in a firm grip. Both responses would be highly unusual for a typically developing child. Additionally, continuity among the child's HCPs is important. A child with extreme sensitivity to

changes in his or her environment needs a familiar face, someone whom he or she readily recognizes or has familiarity with in the medical setting. Facilitating this familiarity can be accomplished through department visits, in advance of any treatment, where the child meets the HCP. Alternatively, a photo of the HCP can be sent to the child to gain familiarity with his or her face. This photo should accurately reflect the HCP's appearance in the appropriate medical setting, i.e., hospital attire rather than casual clothing. When the child ultimately arrives in the department, a limited number of personnel should be involved in the procedure—ideally, only the HCP caring for the child and necessary assistants. Of course, in the anesthesia context, additional HCPs can enter and be involved with the procedure while the child is anesthetized.

Table 3. Guidelines for Preparing Children with ASD before Anesthesia and/or Radiographic Examinations

<p>Planning involving parents/guardians</p> <ol style="list-style-type: none"> 1. Prior to scheduling a procedure, the department must be clearly informed of the child's special needs and/or diagnosis. 2. When the department schedules a procedure, it should contact the child's parents/guardians to involve them in the planning. Oral and written information about the procedure should be given during the contact with the parent/guardian. 3. During the initial contact with the parents/guardians, the department should inquire about the child's special needs, according to the Checklist for child function. It is important to be sensitive and aware of the knowledge parents/guardians have regarding the specific needs of the child. 4. Where appropriate, the department should prepare a specific plan for relevant premedication. 5. The HCP tasked with caring for the child should coordinate with the parents/guardians and comprehensively plan for the entire visit (before, during, and after the procedure). Individual preparatory visits should be scheduled as needed. (See Checklist for the areas to be covered during coordination). 6. At the outset, it is important to work with the parent to create a clear, comprehensive structure for both the planning and execution of the procedure. It is also important to adhere to this structure. The structure for the procedure may be organized into smaller parts to help facilitate the child's understanding. (For example, the HCP may employ the aid of images regarding the procedure, which make it easier for the child to follow the process.) <p>Features of the Environment</p> <ol style="list-style-type: none"> 7. The department should provide an area that can accommodate children who are especially sensitive to sensory stimuli. This area, ideally a separate room, should have the capacity to adjust light, reduce sound, and minimize any other stimuli that may result in discomfort for the child. <p>Use of Time</p> <ol style="list-style-type: none"> 8. Departments should reduce waiting times by scheduling procedures in accordance with the needs of both the department and the child, particularly in departments that may run behind during the day and result in unnecessary waiting for the child. Scheduling should also accommodate the child's set routines. 9. To avoid stress for the child or HCPs, the department should allocate additional time in its scheduling as necessary and shrewdly coordinate the procedure around departmental needs. For instance, the department should schedule the administration of anesthesia in the morning, given that the child must fast beforehand. For radiographic examinations, scheduling can more generally accommodate the child and the department's needs. <p>Communication</p> <ol style="list-style-type: none"> 10. The department should have image support available for children who are accustomed to relying upon image support. This support should feature specific, realistic images of all stages of the procedure, and the images must follow the planned structure of the procedure. 11. HCPs should use language adapted to the child's level of communication. In general, they should use concrete language instead of symbolic language. For example, rather than using the word "soon" or other similar temporal abstractions, HCPs should use real-time indications—e.g., "when all the sand has fallen to the bottom of the hourglass, we will do [specific, concrete part of the procedure]." <p>Health Care Professionals (HCPs)</p> <ol style="list-style-type: none"> 12. The HCP tasked with caring for the child must possess knowledge/education about the practical implications of having autism. 13. The department should endeavor to maintain continuity among the HCPs working with the child. To this end, the HCP planning the procedure with the parent/guardian should also be the one who meets the child during the preparatory visit as well as the one administering care to the child during the procedure. 14. During the procedure itself, the department should only involve as few HCPs as is necessary.
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The Checklist

The checklist reveals many characteristics that are specific to the child. For example, it covers the child's communication pattern, how the child reacts to sensory stimuli, his or her special interests and likes/dislikes, sources of anxiety for the child, and strategies for calming the child when necessary. The checklist also describes how the child's anxiety manifests. In addition, the checklist addresses the specific, individualized environmental needs of the child as well as the child's potential cognitive impairments (Appendix I).

Discussion

Among the results, two components stand out with particular significance: the quality of the organization's structural conduciveness for children with ASD and the knowledge of the HCPs themselves in their encounters with the child. Foremost, the organization itself bears a responsibility to create a structure that allows for individual HCPs to establish a good caring encounter for a child with ASD. Additionally, the qualities of the HCPs themselves are critical within these encounters. The HCPs must jointly possess knowledge about ASD as well as the ability to apply and tailor this knowledge to the specific needs of the individual child.

Organizational Aspects

A critical tenet of successful care for a child with ASD involves alerting the involved parties in advance of the child's visit. This is an organizational issue between departments. This alert enables the HCPs to preemptively contact the child's parents and create a personalized plan for the forthcoming encounter (5, 10, 17, 20, 21). Nationwide surveys, however, have shown a recurrent failure in the healthcare system to properly identify children with ASD in advance of their visits (10, 11). When asked about this issue, parents suggested that there should be a notification (or similar "alert") in the child's medical chart about his or her ASD diagnosis; thus, when the child visits the emergency department, the parents would not be routinely tasked with providing this information (and its inherent complexities) to the treating HCP (4). For a planned procedure in the anesthesia or radiology departments, prior notification needs to reach the department as soon as the child is scheduled, thereby providing enough time to make a positive difference in the application of the child's treatment.

Furthermore, an individualized structured plan should be created for the child. This plan should be created in tandem with the parents. Given that all children are unique with varying needs, it is imperative to create a plan for the individual child, tailored to his or her needs. To this end, parental involvement is crucial, since parents almost universally know their child and his or her specific needs in detail (5, 12, 14). Previous research revealed that parents of children with ASD had experienced less shared decision-making with medical personnel than parents of children with other disabilities (29). Simultaneously, there is a need to better understand the communication difficulties of a child with ASD. In this regard, involvement of the parents in the caring encounter is integral. Furthermore, when the HCPs provided parents with the option of being involved in their child's treatment plan, these parents expressed gratitude, feeling warmly received by medical personnel (14). Ultimately, there is also a balancing act between HCPs involving parents in the child's care and, by contract, shifting responsibility for this care onto the parents (30). To this end, HCPs and parents must work together. For a child with ASD in the anesthesia and radiology contexts, the involvement of the parents in decision-making is essential if the care is to be provided with respect and dignity to the child (14).

The Caring Encounter

To maximize the likelihood of the child's cooperation, the HCP tasked with caring for the child should actually know the child. At the very least, the child should be familiar with the HCP. This can be accomplished through preoperative visits or, when this is not feasible, by sending a photo of the HCP to the child in advance of his or her visit, as suggested in Lindberg et al. (2012) (14). Continuity of the HCPs is also helpful in establishing a trusting relationship between the HCP and the child. The HCPs designated to the child should also possess the requisite knowledge and experience regarding ASD to work with these children, by Lindberg et al. (2012) (14, 16). Routinely, parents have expressed frustration about the HCP's general lack of knowledge about how to properly care for a child with ASD (3-5, 12, 14-16). By contrast, when the HCPs actually know about the disability and, more importantly, the specific child and his or her needs, the parents often feel that the entire procedure proceeds with greater calmness and efficiency (14). If the HCP working with the child possesses the requisite experience, knowledge, and compassion, a positive rapport can be created. However, if the HCP lacks these qualities, the child's care is fundamentally incapable of being properly patient-centered. This is hardly a surprise. In fact, Hodgetts et al. (2013) found that the personal qualities of the HCP are more important than the organization itself when it comes to providing positive care for children with ASD (30). However, in the anesthesia and radiology contexts, the organizational components are just as critical to positive care as enabling the HCP to work in a patient-centered manner through the trifecta of knowledge, experience, and compassion.

As described in Gimbler Berglund et al. (2016), HCPs require information about the child with ASD prior to his or her caring encounter in order to provide effective treatment. Without this necessary component, facilitating the necessary preparations for a smooth, accommodated procedure becomes virtually impossible, as the child's needs and parents' involvement are excluded (10).

Within the caring encounter, communication represents a nexus between the organization's preparedness to care for children with ASD and the particular qualities of the HCP. Given the inherent difficulties that can often accompany communicating with a child with ASD, HCPs should be familiar with the child's communication aptitude and method; the HCPs must adjust their communication accordingly. Bultas (2016) and Pratt (2012) emphasize the importance of straightforward communication with the child; these studies underscore the significance of using concrete words to convey information, rather than incorporating abstract language (16, 31). For example, if an HCP desires a specific task from the child, the child should not be asked to do so; instead, the child should simply be told to do something. If an HCP asks the child to complete a task, the child may think the HCP is asking if he or she *can* complete the task; the child will react and answer accordingly. For example, asking, "Can you sit here?" may produce a simple answer of "yes" from the child but the child may not sit where indicated. Thus, if the HCP desires the child to sit in a certain location, giving the child an imperative instruction to sit there in a clear, direct manner is ultimately more appropriate. The child will generally understand what is meant. Communication is, of course, different for each child, but difficulties in both verbal and nonverbal communication apply to virtually all children with ASD as a major tenet of the disorder itself.

Additionally, the use of visual symbols in the anesthesia and radiology departments can greatly improve communication as well as better facilitate the child's understanding of the procedure. Preferably, these symbols should be given to the child in advance, allowing for the child to

become familiar with them; these symbols should then be utilized during the procedure (5, 19, 21). Ensuring the presence and usage of appropriate visual symbols is an organizational responsibility.

Implementing Guidelines

Developing guidelines is not enough to address the needs of children with ASD. The guidelines also need to be implemented. Barriers to implementing guidelines may exist within the organization itself, such as lack of education among the personnel, burdensome workloads, and complications in top-down or bottom-up implementation (32, 33). According to Bathsevani (2010), it is easier for HCPs to accept guidelines' implementation when the guidelines come from their colleagues rather than top-down within the organization. Implementation is also facilitated when a relevant problem has been identified in the department and the guidelines are perceived by HCPs as useful and beneficial for the patients. Having facilitators within the organization as well as a working team of experts across professions within the department can greatly facilitate successful implementation of the guidelines as well (34). A major barrier to the guideline's successful implementation could be the pervasive attitude that specific guidelines are unnecessary for children with ASD since all children allegedly receive care in accordance with individual needs within the context of person-centered care (10, 35). This misguided attitude can be countered with opportunities for education regarding ASD to ensure that the HCPs understand the difference between typical developing children and children with ASD (10).

One of this project's strengths is that expert HCPs working in anesthesia and radiology in several hospitals have contributed to the development of these guidelines. This range of experts increases the likelihood that the guidelines would be successfully implemented.

Methodological considerations

As one of its strengths, this study amalgamates the perspectives of expert participants across varying professions throughout several hospitals in Sweden. The majority of the participants were nurses, although they were working in different medical settings. However, it bears mentioning that the sex ratio of this study does not reflect the gender ratio of the Swedish healthcare system at-large; in Sweden, 19% of nurse anesthetists and 17% of radiographers are male (36). However, no male experts working with children with ASD were identified in the initial surveys for inclusion within this study. Nonetheless, all of the study the participants had ample experience in their professions. More importantly, they had lengthy experience with ASD and the accompanying knowledge of the disorder. One of the expert participants also served as a representative of an ASD-related organization. No parents were solicited to develop the guidelines, which can be perceived as a limitation in the present study. However, four of the HCPs mentioned in the demographic section of the first questionnaire that they also had significant others diagnosed with ASD. Resultantly these participants spoke from two perspectives, as a significant other and as a HCP. Another strength of the study is its utilization of the same participants in answering all three questionnaires. However, the fact that two additional participants were added in the second questionnaire might constitute a limitation. Another potential limitation is that the statistics from the previous questionnaire were not fed back to the participants following each round. However, the final questionnaire achieved consensus among the participants, even without the participants being aware of previous levels of agreement.

Conclusion, Clinical Implications, and Future Research

A caring encounter involving a child with ASD in the anesthesia and radiology contexts fundamentally requires meticulous advance planning, catered specifically to the individual needs of each child. When the child ultimately visits the anesthesia or the radiology departments, the environment should be adjusted to the child's particular needs. Concurrently, the HCPs require general knowledge regarding ASD as well as ASD's particular manifestation in the child entrusted to their care. In order to regularly accomplish these goals, guidelines must be in place and followed.

This study aimed to develop guidelines for the proper care and preparation of children with Autism Spectrum Disorder during anesthesia and radiology procedures. During the course of the study, it became readily evident that the guidelines developed specifically for anesthesia and radiology contexts could be appropriately applied in other healthcare settings. These guidelines have been developed by experts from both the anesthesia and radiology contexts, with one expert coming from a special interest group for ASD. However, to their credit, the guidelines are general enough to transcend the settings of anesthesia and radiology. Regardless of the healthcare setting, the needs of this particularly vulnerable group of children are recurrent wherever healthcare procedures are administrated. Nonetheless, the guidelines should still be locally applied to the particular department. With regard to future implications of this study, the next step involves a pretest and posttest intervention, applying the present guidelines in anesthesia and radiology contexts. The outcome measures will center on the level of anxiety experienced by the children with ASD. These children's anxiety will be determined by both observational and biological metrics, and both parents and nurses will serve as observers of the children's behavior.

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Appendix 1

Checklist for Information about the Child's Manifestation of ASD

- 1, How the child communicates (e.g. language, images, other)
-
- 2, The child's special interest(s)
-
- 3, What the child likes
-
- 4, What the child dislikes
-
- 5, What works to achieve cooperation when interacting with the child.....
-
- 6, What does not work to achieve cooperation when interacting with the child.....
-
- 7, What calms the child
-
- 8, What makes the child anxious
-
- 9, How the child shows anxiety.....
-
- 10, How the child responds to touch
-
- 11, What environmental factors make the child feel calm
-
- 12, How the child reacts to sound
-
- 13, How the child reacts to light
-
- 14, Other special needs of the child
-
- 15, The child's degree of cognitive impairment.....
-
- 16, What the child would like to bring from home