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**The experiences of children with Autism Spectrum Disorder, their caregivers and health care providers during day procedure: a mixed methods study**

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**What is known about the topic?**

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Previous qualitative research was mostly concerned with the inpatient (rather than perioperative) care of children with disabilities. Others audited interventions introduced as quality improvement in the hospitals or surveyed the use of clinical practice guidelines in hospitals.

### **What this study adds?**

This study is a qualitative research of the experiences of children with Autism Spectrum Disorder, their caregivers and healthcare providers during day procedures in two major pediatric hospitals in Melbourne, Australia. These hospitals have been trying to use the best practices. This study explores the seemingly minor but important details that are generally missed and not reported before.

### **Abstract**

*Background:* Autism Spectrum Disorder (ASD) is now diagnosed in more than 1% of children in Australia and USA. Children with ASD may have additional health care needs, require more specialised services for their health care, or experience more difficulties during hospital attendance. Customised care for these children may assist in decreasing potentially challenging behaviours during hospitalization. The purpose of this study was to explore the experiences of children with ASD and their caregivers during attendance for day procedures in two hospitals in Melbourne, Australia. Further, the perceptions of their health care providers were explored.

*Method:* Twenty-nine participants, including 14 health care providers and 15 caregivers of children with ASD, were interviewed within 72 hours of their day procedure attendance at the Royal Children's Hospital (RCH) and the Royal Dental Hospital (RDH) in Melbourne, Australia. Interviews were recorded digitally, then transcribed and coded. Mixed quantitative and qualitative methods (content analysis) were used.

*Results:* Hospital attendance was often stressful. Participants identified a number of facilitating factors including good communication, clear explanations, and friendly attitudes of staff. Flexibility and individualised care of patients (such as avoiding unnecessary blood pressure measurements, and not changing into hospital gowns) were valued. Supportive aids (such as tablet computers or special interest objects), use of social stories, and giving premedication were all considered helpful. Perceived barriers to care included prolonged waiting times for operation date as well as waiting on the day of operation, lack of private space, lack of non-invasive equipment such as cutaneous infrared thermometers, poor communication and inadequate training of staff about ASD.

*Conclusion:* Providing optimal care for children with ASD requires a multifaceted approach that may require changes to hospital work flow, staff training, better use of aids (such as tablet computers and social stories), and premedication. Good communication and flexibility are key areas of importance.

### **Introduction**

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder with symptoms that are typically diagnosed in childhood. The Diagnostic and Statistical Manual Edition 5 (DSM5) defines ASD as a persistent deficit in social interaction and social communication across multiple contexts, and restricted, repetitive pattern of behaviours, interests or activities.<sup>1</sup> The prevalence of ASD has been reported as

1.5-2.5% in Australia <sup>2</sup> and 1.7% in 11 sites surveyed by the Autism and Developmental Disabilities Monitoring Network in the United States<sup>3</sup>. Boys are four times more likely to be identified with ASD than girls.<sup>3</sup> Around 55% of individuals with ASD have associated intellectual disability (i.e. IQ<70) <sup>4</sup> and up to 70% are diagnosed with other mental health disorders <sup>5</sup>, including diagnoses such as Attention Deficit Hyperactivity Disorder (ADHD)<sup>5,6</sup>, anxiety<sup>5-9</sup>, oppositional defiant and conduct disorders.<sup>5</sup> ASD is also associated with epilepsy in 22% of individuals<sup>10</sup>, and sensory processing disorder in 42-80%. <sup>11</sup> A Danish population based study found increased hospital contact for children with ASD almost regardless of the cause of hospital presentation.<sup>12</sup> The difficulties encountered during hospital visits have been documented in case reports and series.<sup>13-21</sup>

Anxiety associated with hospital admission is well-known in children.<sup>22</sup> Individuals with ASD are at higher risk of anxiety.<sup>5,6</sup> However, research into the perioperative management of children often excluded children with ASD in the past.<sup>23, 24</sup>

The aim of this study was to explore the experiences of children with ASD who underwent a day surgery procedure. We wanted to gain insight and understand the perspective of caregivers as they reflected on their journey through the health system at 2 major providers of health care in Melbourne, Australia. In addition, we studied the experiences of the hospital staff involved in the children's care.

## **Methods**

### *Ethical consideration*

This study was conducted in accordance with the Helsinki Declaration and was approved by the Ethics Committees of both Royal Children's Hospital (RCH) and Royal Dental Hospital (RDH). Informed written consent was obtained from all staff interviewed and participant caregivers of the children. It was not possible to obtain assent from children due to their developmental differences.

### *Participants*

We approached the caregivers of children with ASD. The children were scheduled for an elective day surgery procedure at the RCH and RDH in Melbourne, Australia during July to December 2015. RCH is a tertiary paediatric referral centre. RDH is a secondary level hospital that has expertise in dental care of children with disability.

Caregivers of children with ASD were provided with information about the study at the time when their consent was obtained. The consent was obtained on the day of surgery, after the child had been admitted to the hospital. In Australia, patients are usually only seen by an anesthesiologist on the day of admission, unless they have complex comorbidities and have been to a Pre-Admission Clinic at an earlier date. The children at RDH in our study had been health assessed via a mailed Health Questionnaire and a nurse led pre-operative telephone assessment. The children at RCH were known to the hospital from previous admissions. All caregivers who were approached agreed to be part of the study. Three families were subsequently excluded from the study due to inability to make contact with them post-operatively within 72 hours of the date of the procedure.

Health care providers who were involved in the care of the children were also interviewed. To select health care professionals we followed the patient journey from admission to discharge, and interviewed at least one representative from each staff group involved in the patient's care.

The health care provider interviewees included: admission clerk, admission nurses, anesthesiology nurses and technicians, anesthesiologists, anesthesiology resident, Post Anaesthesia Care Unit (PACU) nurses, and play therapist.

#### *Data collection*

Data were collected by means of semi-structured interviews. All interviews were conducted by the first author (NT). Interviews were recorded either face-to-face in the hospital or by telephone within three days of the child's surgery. The interviews were digitally recorded on two devices (mobile telephone, iPhone-5<sup>R</sup>, and tablet device, iPad<sup>R</sup>) and were later de-identified and transcribed. The introductory question for caregivers was "could you tell me about your child's anesthetic?" In addition, the patient files were consulted, and information about the child's anesthetic, type of premedication, side effects, and other relevant information were recorded.

#### *Mixed method*

A mixed method<sup>25</sup> was used to provide a better understanding of the experience of caregivers and staff. The design is a concurrent nested design with one data collection phase, during which a predominant qualitative study embeds the quantitative method. The qualitative section is in response to open-ended questions about the experiences of the caregivers and the staff, and the quantitative aspects were obtained by using close-ended questions about preparation and premedications and consulting the files of patients.

#### *Qualitative methods*

Deductive content analysis (CA) was used in order to identify, analyse and report patterns within the data, and to interpret them. CA can be applied across a range of epistemological approaches, and provides flexibility and theoretical freedom.<sup>26,27</sup> The content analysis was deductive because it was informed by our literature search on studies of caregivers of children with ASD in other settings.

The research steps were: recording the interviews; transcribing, using a transcribing service that typed the recordings; familiarisation with the data; checking for accuracy; immersing in the data and repeated active reading; developing initial codes; organising the data into groups and developing categories based on codes; reviewing the categories to see if they form a coherent pattern and if they reflect the data set. The study continued until saturation of themes, that is, no new information or theme was found. Two researchers (NT and GH) independently analysed the data. NT and GH independently read the transcripts multiple times, initially for an overview of the data set and then immersing themselves in the detail, independently identifying and coding the data into groups and categories for the various themes emerging from the data. NT and GH later met on multiple occasions and discussed their findings, further organising the data into categories and identifying the themes within, and generating conceptual maps. We used Standard for Reporting Qualitative Research (SRQR) to improve the reporting requirement.<sup>28</sup>

NT and GH are anesthesiologists with more than 10 years experience working at the RDH with children with ASD and their caregivers. The involvement of NT and GH with this project has broadened their understanding of the needs of children with ASD and has changed their anesthesiology practise. A thematic network (figure 1) shows the relationship between the quantitative data, qualitative data and the themes.

## Results

Fifteen caregivers of children with ASD and 14 health care providers were interviewed. The children who underwent a day surgery procedure ranged in age from 4-16 years old, with 11 children aged less than 12 years old. Eight children were reported by their caregivers to have severe ASD, based on their level of function and language skills, and a further 7 children to have mild to moderate ASD. Seven children were reported to have challenging behavioral issues, most commonly with aggressive behaviour towards siblings and parents. Four children were taking one regular medication: clonidine, risperidone, melatonin or methylphenidate. All interviews were conducted in person except for two caregivers, where telephone interviews were used.

### **Facilitative strategies**

Investigators identified 4 themes based on participants (caregivers and staff) responses (see Figure 2). The 4 themes were: communication and attitudes; individualised care within the hospital care framework; use of supports; premedication.

#### *Good communication, clear explanations and friendly attitude:*

Caregivers were generally appreciative if the staff had good communication with the child and demonstrated attitudes of being positive, compassionate, caring and understanding towards the child. They wanted their child to be treated like other children and to be spoken to in a “normal way”, not patronised and not ignored. These included: phone calls from hospital nurses the day before the operation, explanation on the day of the steps and processes to be undertaken, and communication about any delays.

*“They spoke to him in a very normal way. They didn't appear to be worried that he may not understand or not respond or do things as quickly as they wanted to. I actually found the experience was fantastic and the staff were very good in the way they managed someone like L. who has special needs”. (Caregiver of 13 years old)*

*“(the hospital) has a system established of preoperative phone calls now to ascertain the degree of autism the child has and how the child is best managed when they come to hospital. We give information to the parents on what will happen and what to expect, and we also ask the parents to suggest ways to help manage the child.” (Anesthesiologist)*

*"The best way is to communicate with the parents because they live with the child, so will best know how to deal with the child." (Anesthesiology technician)*

Clear explanations/ friendly attitude

*"The hospital was great. Everyone was explaining things. They were talking to him. He takes in some of the things but not everything that's why someone else has to be there like myself or my wife just so we take it all in. But as long as he is talked to and explained that this (is) what's going to happen. He's really good. ... (staff were) brilliant, really caring and understanding all the way through. I heard them explaining the same thing at least four or five times, it was great because everyone was on the same page and everyone knew what was going to happen." (Caregiver of 16 years old)*

*"Everyone is really cooperative and knows what to do, compared to adult hospitals that just carry on and aren't so kid friendly." (Anesthesiology resident)*

*Individualised care within the hospital care framework:*

Health care behaviours that were creative and flexible in response to each individual child were described by caregivers and staff. Examples given by caregivers (table 3) included: having both parents present in the operating room (OR) for induction, rather than only one parent as per protocol; not taking observations such as temperature or blood pressure if it caused distress to the child; allowing into the OR special objects desired by the child; not removing items of clothing or changing into hospital gowns; using premedication and awaiting its effects before applying topical local anaesthetic cream; trying different ways of giving premedication;

Staff also emphasised the importance of individualised care, adapted to a particular child's needs.

*"What I do is I always give a choice. Do they want inhalational induction or an IV induction? I let them choose. It's the only thing they have any control over and I think that actually makes it ... when they come to see me we've already agreed on what we're going to do. It's very straightforward. A lot of people don't like doing inhalational inductions. They don't feel happy not being able to have an IV in place at the start. " (Anesthesiologist)*

Flexibility with the time that a child is kept in PACU was mentioned.

*"I think they do benefit from going home sooner rather than later and sometimes they (the nurses) keep them to make sure they have a drink or whatever. Well, I don't think that's necessary. I think you do what you can to get them out as quickly as possible." (Anesthesiologist)*

*Use of supports:*

Supports, including tablet computers, special interests and special interest objects, and social story were valued by caregivers and staff. Play therapists were considered to be helpful by caregivers and staff, but were not always available.

*Use of tablet computers:* Nine caregivers specifically mentioned that they brought their hand held tablet computer to the hospital, and described how they used it to assist the child.

One caregiver reported that the child took his hand held tablet computer into the OR, and that he was still holding the device post-induction. Caregivers also successfully used the devices to distract the children while waiting on the day of surgery. One caregiver described how their child used an electronic communication device that helped the child communicate with others; by pointing it at pictures, the associated words were announced by the device.

One anesthesiologist reported using a tablet computer with children who were cooperative but anxious. The computer was used to distract the children, and was reported as helpful for both intravenous and inhalational inductions.

*“if you have a child that is cooperative but anxious, the other thing is a lot of these kids love their iPads<sup>R</sup> and their games, some of these kids would be quite happy with IV induction if they keep playing their game, so I think keep playing their game and not to take the iPad<sup>R</sup> from them, ... put them to sleep with a mask or put a drip (IV) in if they are playing because the repetitive nature of the game (distracts them) , so ...find out what game they like playing and that way they hardly notice the induction” (Anesthesiologist)*

Tablet devices were also successfully used for post-operative management.

- *“After the operation I think he felt a lot of pain but he was calm and he played with his iPad<sup>R</sup> and he didn't cry at all.” (Caregiver of 11 years old)*

*Use of special interests and special interest objects:* Caregivers mentioned the use of special interests and special interest objects as being helpful in managing their child peri-operatively. For 1 child, hospitals and health had become the subject of his special interest. Now he loved coming to hospital, to his mother's great surprise: *“When he was younger, couldn't get him through the door of the doctors.”* (Caregiver of 13 years old)

Another child liked building blocks as his special interest objects, and playing with these helped him to stay calm while waiting for the surgery.

Staff also mentioned the utility of special objects.

*“we advise that they bring their special blanket, iPads<sup>R</sup>, music, videos. It makes them feel more at home, more at ease. We always tell Mom bring anything. Even cups, even medication cups. We always tell parents, because we had a case where the child would not drink anything except from their special cup, and we had a hard time giving him premed.” (Anesthesiology nurse)*

*Use of social story:* A social story can be defined as a story that explains a social situation and outlines the expected and appropriate responses to social cues.<sup>29</sup> With regard to social story, 3 schools of thought, 1 supportive and 2 alternative, were identified among caregivers:

Most caregivers considered social story to be beneficial in reducing anxiety and potentially leading to better cooperation. There were 2 caregivers who had made their own social story for the day procedure

surgery visit, and did so regularly for any stressful event. Others tried to talk with the child about the operation and prepare their child as best they could, without formally preparing a social story. Alternative views were also expressed. One view was that the more information given to the child prior to hospital, the higher the level of anxiety. The other view was that severely affected children with ASD could not comprehend a social story.

These differing viewpoints may suggest an individualised approach to use of a social story is appropriate.

*Play therapists:* Play therapists were valued by staff for assisting with distracting the children whilst waiting for the procedure, managing challenging behaviours, and preparing the children for anaesthesia induction.

- *“I just met him in the waiting room and he was trying to run out the door, so we came in here (area away from the waiting room), did some play with the doll. We have a doll that, if we have time, we play with it. Just really helped him, and practising with the mask..” (Play therapist)*

*Premedication:*

Twelve of 15 patients (80%) had premedication: midazolam alone (5), midazolam with ketamine (2), clonidine alone (1), clonidine with midazolam (1), ketamine (2), combination of temazepam, clonidine and ketamine (1). The child who had the combination of 3 different premedications was taking risperidone for his behavioural problems at school. All children took their premedication with 2 exceptions: 1 child spat out midazolam and was given ketamine 5 mg/kg orally, and another child had refused oral midazolam, so intranasal midazolam was administered.

Most caregivers and staff believed that premedication was useful and necessary. However, caregivers knew little about the different types of premedication and what had been used. The bitter taste of a pre-medication was occasionally mentioned by caregivers.

Staff reported that sometimes the caregivers were concerned about potential adverse effects of premedications.

*“Sometimes the parents refuse to give their child the premed... they are worried about toxins.. (Anaesthesiology nurse)*

Staff reported that parental refusal to accept an oral pre-medication sometimes led to trauma at induction for the child.

*“(The child’s) mother (who had refused to allow oral pre-med) came in and she was quite hysterical... shouting a few times. He (the child) leapt off the trolley, went into a corner. I grabbed him. Restrained him and the anaesthesiologist got the ketamine dart (intramuscular injection) and stuck it in his upper thigh... He fell asleep. So I picked him up and put him on the trolley” (Anaesthesiology nurse)*

Although premedication use was overall considered positive, the traumatic experience of administering it by means of physical restraint or intra-nasally was reported as negative in nature by both caregivers and



staff. One child had intranasal midazolam administered by nursing staff while two security guards restrained the child. The caregiver's comments speak to poor communication about how the pre-medication was to be administered, as the caregiver was unsure about what was happening.

*"The only thing that freaked me out a little bit is when I realised there were two nurses and then two big guys came in. I thought oh my God what are you going to do to my Grandson. I was a little bit protective but I didn't say anything. They just pinned him down and put this thing up his nose and the next thing you know he was as good as gold"* (Caregiver of 10 years old)

Anesthesiologists differed widely in their opinions about what type and dose of pre-medication to use. Whilst some said they would never use intramuscular ketamine, others pointed out the utility of intramuscular injections in children who refused oral pre-medications. Some anesthesiologists had experience in prescribing oral pre-medication to be used at home on the day of surgery. Some anesthesiologists had administered pre-medication in the carpark of the hospital for children with ASD refusing to get out of the car.

### **Barriers to care**

Four overarching themes were identified with respect to barriers to care: limitations of staff awareness of special needs; lack of suitable equipment; lack of suitable environment; waiting time.

*Limitations of staff awareness of special needs :*

*Rigidity of protocol:* Both staff and caregivers said that rigid adherence to protocol could cause behavioral deterioration in children with ASD. For example, insistence on performing routine observations could lead to considerable behavioural distress in the child.

*"There was 1 nurse before and after the procedure (who) was very persistent, not just insistent, but persistent in taking his temperature... she was manhandling him and actually restraining him to stick the digital thermometer in his ear. And that made him very agitated and very upset where he actually started self-harming and hitting himself on the head. In the second one after the operation I actually said to her that was enough because he was getting very upset, we were getting very upset..."* (Caregiver of 6 years old)

*"The child would be screaming and the anesthesiologist was angry with us because we had not done saturation (monitoring in PACU). I said because it's not possible. Then he mentioned something about not using the right technique. I spoke to (the director of anesthesiology) (asking) "Is there any correct technique as to how to approach an autistic child?" He said "None, you just have to play it by ear and see how it goes." So for me there is no right or wrong approach, you just have to deal with it as you go along."* (PACU nurse)

*Lack of formal training:* Staff, particularly nurses and anesthesiologists, highlighted that they had not received formal training in dealing with children with ASD.

One anesthesiologist suggested that care for patients with ASD should be limited to anesthesiologists who have undergone further training in the area.

*"I think the main problem is not everybody is aware of how to treat autistic children... Perhaps we should not roster people who find it stressful on pediatric lists, who can't handle autistic children, because often it's very stressful for the anesthesiologists and all the staff and for the parents as well. Maybe we should have anesthesiologists who are designated as competent or ..... specialising in autistic children. That may be a subspecialty in anesthesiology..."(Anesthesiologist)*

Nurses described situations in which anesthesiologists appeared unfamiliar in dealing with children with ASD.

One caregiver stated that they travelled a long distance to RDH because staff at centres closer to home did not have the training or competence to look after their non-verbal child with ASD.

*Lack of explanation to patients and caregivers:* Some caregivers stated that there had been a lack of explanation about why a premedication was being given and how it was to be administered.

*Lack of suitable equipment :*

Although vital signs observations are important, when they cause undue distress to the child various modifications may be required, such as taking temperature with cutaneous infrared thermometer instead of tympanic thermometer. Staff reported that use of a tympanic thermometer had caused distress to many children with ASD, in particular children with sensory sensitivities. However, the PACU at one of the hospitals had only one cutaneous infrared thermometer.

Other equipment that a PACU nurse found useful was a patient bed that lowers to the ground. The nurse had hurt her back trying to stop a large autistic child jumping off the usual type of patient bed. The staff perceived a lack of budget for any change in equipment as a reality of the public hospital system.

*Lack of suitable environment:*

Lack of dimmable lights was mentioned by staff, who reported dimming of lights could be calming for children with ASD while waiting for their procedure, and also in PACU. Lack of a private waiting area was mentioned by staff, in that children with ASD could find it difficult to wait in an area where there are other children. Lack of private and quiet space in PACU was reported as a problem by caregivers and staff at one hospital, where there is no designated private room in the PACU. One caregiver reported that the noise of crying children triggered challenging behaviour in PACU.

- *"My child was very distressed because he could hear the distressed screaming and crying of two children in particular... He started hitting himself, hitting us, hitting his arms very hard on the bed rail. So I actually asked the nurse..., could you please move us to a slightly quieter place, because this is going to escalate and become harder for us to manage his behavior and he will have a full blown melt down... He had slapped my husband right across the face because he was so upset. Finally I said, please can you do something. So she moved us into an isolation room... the behavior started coming down and he wasn't as distressed. So even if there was some sort of sound proofing, some sort of portable partition or something." (Caregiver of 6 years old)*

*Waiting time:*

Waiting time was an important issue mentioned by caregivers, both waiting for the procedure as well as waiting on the day of procedure. Prolonged waiting prior to receiving a date for an operation was a major complaint for some caregivers. Caregivers reported that 1 child had to wait for almost 2 years, another for 1 year, and 2 had to wait for several weeks with dental abscess and constant pain.

One caregiver recalled the difficulty of keeping their child still and co-operative for treatment at a dental office:

- *“We took him to our dentist at..(dental office) and it was literally a blind filling. We were trying to pin him down just to get that done. He was living on Nurofen<sup>R</sup> (Ibuprofen)... He's been living on Nurofen<sup>R</sup> since ... about seven weeks (ago)”.* (Caregiver of 8 years old)

Waiting on the day of the operation/procedure was also of concern, as children with ASD can have behavioural deterioration, agitation, and increasing distress when they become hungry and thirsty. It can also be stressful for other children and families to observe this distress.

- *“When you see them waiting around for hours, it starts to have an impact on their parents and families as well. It's quite exhausting for them. Not meaning to sound cold but (also) for the other people in the waiting room... if the autistic patients are distressed and unsettled (it is also difficult) for some of the other patients and families in the waiting room.”* (Admission clerk)

Staff mentioned the need to place children with ASD first on the operating room list if possible.

## Discussion

In our mixed methods study we identified a range of facilitatory factors and barriers for the optimal management of children with ASD having day surgery procedure. Some of the facilitating factors have been described in the literature. For example, individualised care plans have been shown to be helpful in the perioperative management of children with ASD.<sup>30</sup>

Similarly, early identification, specialist preadmission procedure and anesthesia plan has been described.<sup>15</sup> A quiet room in which the child waited pre-operatively, and scheduling that allowed the ASD child to be first on the operating room list had been successful strategies. These recommendations have been largely implemented at both RCH and RDH hospitals. However, a private and quiet space in the recovery room was not always available, and children with ASD were therefore exposed to the noises common to a busy children's hospital. Lack of flexibility in the nursing approach, for example taking non-urgent vital sign observations, was also of concern. This was compounded by the lack of availability of less invasive equipment.

One of the major concerns raised by caregivers was unacceptably long wait for the operation date. There is a relative shortage of dental services for children with ASD. Children with ASD may not be able to tolerate even a basic dental examination and require a general anaesthetic for examination as well as treatment. Greater availability of anaesthesia-based dental treatment is necessary in this group of children.

Waiting during admission processes and pre-operatively can trigger a range of behaviors in children with ASD that are particularly problematic in the peri-operative setting. The availability of creative check-in processes, quiet waiting areas, play therapists, and scheduling children with ASD first on the operating room list, are strategies that can decrease challenging behaviors.

Our participants highlighted the utility of using supportive objects. Use of personal computer or tablet devices was a dominant theme. Children used the devices for different purposes including communication and distraction. Such devices have the potential to be a useful tool peri-operatively, including as a distraction device at induction. Specific electronic media technologies have been shown to decrease anxiety in children with ASD having office-based awake dental procedures.<sup>31</sup> Other studies into the utility of tablet computers in children with ASD in the education setting, to decrease anxiety and help learning, have been promising.<sup>32</sup>

Our participants reported mixed views about the value of social story as a peri-operative coping mechanism. Social story has the potential to be a useful tool in perioperative setting, in particular if it includes coping skills training and modelling. The availability of social story resources to assist with pre-operative preparation of children with ASD seems to be a simple and inexpensive way of helping these children. Caregivers can then decide if it is appropriate for their child. Yet, social story was not routinely used at either hospital in our study. This is an area that needs further research and development, in particular with respect to what specific types of social story are most effective for children of different ages with ASD presenting for surgery. In keeping with the need for individualised care plans, as previously mentioned, caregivers could individually adapt social story templates provided by hospitals to assist their children with ASD. Use of computer-based tailored programs that are web based is gaining popularity for managing perioperative anxiety in children.<sup>33</sup> Similar web-based applications that uses simple language, capable of being adapted for individual children with ASD, could be an effective, cheap and accessible means of perioperative preparation with social stories.

The utility of premedications was highlighted by our participants. Internationally, the traditional premedication used in severe autism has been ketamine<sup>15-17, 20</sup> but it has many potential side effects. More recently, use of alpha 2 agonists has been described.<sup>34-36</sup> In our study, different combinations and different doses of premedication were used. This inconsistent use of premedication has been demonstrated previously.<sup>37</sup> It is worth noting that it is difficult to have a discussion about the best premedication for children with ASD in the absence of high quality evidence, such as that gained from randomised trials. The result is confusion for anesthesiologists, and varying use of different premedications. Often caregivers were not aware of what premedication had been used, currently or in the past, so it may be helpful to provide caregivers of children with ASD with information about what premedication was used, such that other anesthesiologists can refer to it in the future.

A lack of understanding and knowledge by health care providers about ASD is also described as a factor that interferes with patient access to appropriate services.<sup>38</sup> Caregivers and staff participants in our study

mentioned this lack of understanding and training. It would be helpful to develop learning resources for staff about the particular requirements of children with ASD in the peri-operative setting.

#### *Limitations of this study*

This study explored the experiences of 15 caregivers of children with ASD and 14 staff in 2 hospitals in Melbourne, Australia. Some of the findings may be specific to a particular institution, or not specific only to children with ASD. However, most of systematic issues we identified appear to be generally relevant to hospitals dealing with children with ASD.

It may also be that our sample was not representative of children with ASD, given the high reported rate of behavioural challenges present in our group. However, a study of children with ASD aged less than eight years of age reported a 76% rate of tantrums, 61% aggression and 11% self-injurious behaviour<sup>40</sup>, not dissimilar to our sample.

Further, our data were collected in tertiary and secondary level hospitals. Our patient group may be different to children with ASD presenting to community surgery facilities. In addition, our patients were presenting for day surgery, and findings for patients presenting for multi-day admissions may vary. The consents of caregivers were obtained on admission to hospital, and this could have resulted in some bias compared with obtaining consent before admission or before leaving the hospital.

The experience of authors as anesthesiologists may also have influenced the perspectives taken and the interpretation of these findings.

#### **Conclusion**

Children with ASD require a multifaceted approach to provide optimal care. Identifying barriers to care and facilitating factors can help guide improvement in the care of these children. Further work is required to develop individualised supportive strategies for children with ASD presenting for surgery, such as the use of personal computer or tablet devices, special objects, and tailored social stories. The current heterogeneity in pre-medication of children with ASD awaits further research into optimal pre-medication selection and administration.

**MeSH:** Autism Spectrum Disorder, Child, Perioperative care, Care givers, Hospital staff, Attitudes

**Clinical trial registry URL:** RCH HREC REF. NO: 44118A, RDH: approval Number: 28

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#### **References**

1. American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorders, 5<sup>th</sup> ed. Arlington, VA: American Psychiatric Publishing, 2013.

2. Randall M, Scriberras E, Brignell A. Autism Spectrum Disorder: Presentation and prevalence in a nationally representative Australian sample. *Aust NZ J Psychiatry*. 2016;50:243-253.
3. Baio J, Wiggins L, Christensen DL, et al. Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2014. *MMWR Surveill Summ* 2018;67(No. SS-6):1–23.
4. Charman T, Pickles A, Chandler E. IQ in children with autism spectrum disorders: data from Special Needs and Autism Project (SNAP). *Psychol Med*. 2011;41:619-627.
5. Simonoff E, Pickles A, Charman T. Psychiatric disorders in children with autism spectrum disorders: prevalence, comorbidity, and associated factors in a population-derived sample. *J Am Acad Child Adolesc Psychiatry*. 2008;47:921-929.
6. Hofvander B, Delorme R, Chaste P, et al. Psychiatric and psychosocial problems in adults with normal-intelligence autism spectrum disorders. *BMC Psychiatry*. 2009; 9(35):1-9.
7. Gillott A, Standen PJ. Levels of anxiety and sources of stress in adults with autism. *J Intellect Disabil*. 2007;11:359-370.
8. Gillott A, Furniss F, Walter A. Anxiety in high-functioning children with autism. *Autism* 2001;5:277-286.
9. Vasa RA, Mazurek MO, Mahajan R, Bennet AE, Bernal MP. Assessment and treatment of anxiety in youth with autism spectrum disorder. *Pediatrics*. 2016;137(Suppl 2):S115-123.
10. Bolton PF, Carcani-Rathwell I, Hutton J, et al. Epilepsy in autism : features and correlates. *Br J Psychiatry*. 2011;198:289-294.
11. Heflin LJ, Alaimo DF. Students with autism spectrum disorders : effective instructional practices. Upper Saddle River, NJ: Pearson/Merrill Prentice Hall, 2007.
12. Atladóttir H, Schendel D, Lauritsen M. Patterns of contact with hospital for children with an autism spectrum disorder: a Danish register-based study. *J Autism Dev Disorder*. 2012;42:1717-1728.
13. Abraham E, Shah S, Parray, T. Combination of oral clonidine and midazolam as premedication when ketamine is not an option in an uncooperative autistic patient. *Internet J Anesthesiol*. 2009;24(1):1-4.
14. Rainey L, Van Der Walt JH. The anaesthetic management of autistic children. *Anaesth Intensive Care*. 1998;26:682-686.
15. Van Der Walt JH, Moran C. An audit of perioperative management of autistic children. *Paediatr Anaesth*. 2001;11(4):401-408.
16. Bachenberg KL. Oral ketamine for the management of combative autistic adult. *Anesthesiology*. 1998;89:549-550.
17. Shah S, Apuya J, Gopalakrishnan S, Martin T. Combination of oral ketamine and midazolam as a premedication for a severely autistic and combative patient. *JAnesth*. 2009;23:126-128.
18. Christiansen E, Chambers N. Induction of anesthesia in a combative child; management and issues. *Paediatr Anaesth*. 2005;15:421-425.

19. Tsang RW, Solow HL, Ananthanarayan C, Haley S. Daily general anaesthesia for radiotherapy in unco-operative patients: ingredients for successful management. *Clin Oncol (Royal Coll Radiol)*. 2001;13:416-421.
20. Petros AJ. Oral ketamine. Its use for mentally retarded adults requiring day care dental treatment. *Anaesthesia*. 1991;46:646-647.
21. Loo CY, Graham RM, Hughes CV. Behavior guidance in dental treatment of patients with autism spectrum disorder. *Int J of Paediatr Dent*. 2009;19:390-398.
22. Kain Z, Mayes LC, O'Connor T. Preoperative anxiety in children. Predictors and outcomes. *Arch Pediatr Adol Med*. 1996;150:1238-1245.
23. Bringuier S, Dadure C, Baux O, Dubois A, Picot MC. The perioperative validity of the visual analog anxiety scale in children: a discriminant and useful instrument in routine clinical practice to optimize postoperative pain management. *Anesth Analg*. 2009;109:737-744.
24. Wright KD, Eisner A, Stewart S, Finley GA. Measurement of preoperative anxiety in young children: self-report versus observer-rated. *J Psychopathol Behav Assess*. 2010;32:416-427.
25. Ostlund U, Kidd L, Wengstrom Y, Rowa-Dewar N. Combining qualitative and quantitative research within mixed method research designs: A methodological review. *Int Journal Nurs Stud*. 2011;48:369-383.
26. Vaismoradi M, Turunen H, Bondas T. Content analysis and thematic analysis: Implication for conducting a qualitative descriptive study. *Nurs Health Sci*. 2013;15:398-405.
27. Elo S, Kyngas H. The qualitative content analysis process. *J Adv Nurs*. 2008;62 (1):107-115.
28. Gray CA, Garand JD. Social stories: improving responses of students with autism with accurate social information. *Focus Autistic Behav*. 1993;9:1-10.
29. O'Brien BC, Harris IB, Beckman TJ, Reed DA. Standards for reporting qualitative research: a synthesis of recommendations. *Acad Med*. 2014;89:1-7.
30. Swartz JS, Amos AE, Brindas M, Girling LG. Benefits of an individualised perioperative plan for children with autism spectrum disorder. *Pediatr Anaesth*. 2017;27:856-862.
31. Isong I, Rao S, Holifield C. Addressing dental fear in children with autism spectrum disorders: a randomised controlled pilot study using electronic screen media. *Clin Pediatr*. 2014;53:230-237.
32. Clark MLE, Austin DW, Craike MJ. Professional and parental attitudes toward iPad application use in autism spectrum disorder. *Focus Autism Other Dev Disabl*, 2015; 30:pp.174-181.
33. Fortier M, Kain Z. Treating perioperative anxiety and pain in children: a tailored and innovative approach. *Paediatr Anaesth*. 2015;25:27-35.
34. Zub D, Berkenbosch JW, Tobias JD. Preliminary experience with oral dexmedetomidine for procedural and anesthetic premedication. *Paediatr Anaesth*. 2005;15:932-938.
35. Mehta UC, Patel I, Castello F. EEG sedation for children with autism. *J Dev Behav Pediatr*. 2004;25:102-104.

36. Lubisch N, Roskos R, Berkenbosch JW. Dexmedetomidine for procedural sedation in children with autism and other behavior disorders. *Pediatr Neurol*. 2009;41:88-94.
37. Thompson DG, Tielsch-Goddard A. Improving management of patients with autism spectrum disorder having scheduled surgery: optimising practice. *J Pediatr Health Care*. 2013;28:394-403.

Practises	Quotation
Both parents able to be present	<i>"Definitely with her Dad being here. Both of us. That was good...I think it made her more calm having both of us."</i> (Caregiver of 7 years old)

38. Wharton S, Hames A, Milner H. The accessibility of general NHS services for children with disabilities. *Child Care Health Dev*. 2005;31:275-282.
39. Kogan MD, Strickland BB, Blumberg SJ et al. A national profile of the health care experiences and family impact of autism spectrum disorder among children in the United States, 2005-2006. *Pediatrics*. 2008;122:e1149-e1158.
40. Horner RH, Carr EG, Strain PS. Problem behaviour interventions for young children with autism: a research synthesis. *J Autism Dev Disord*. 2002;32:423-446.

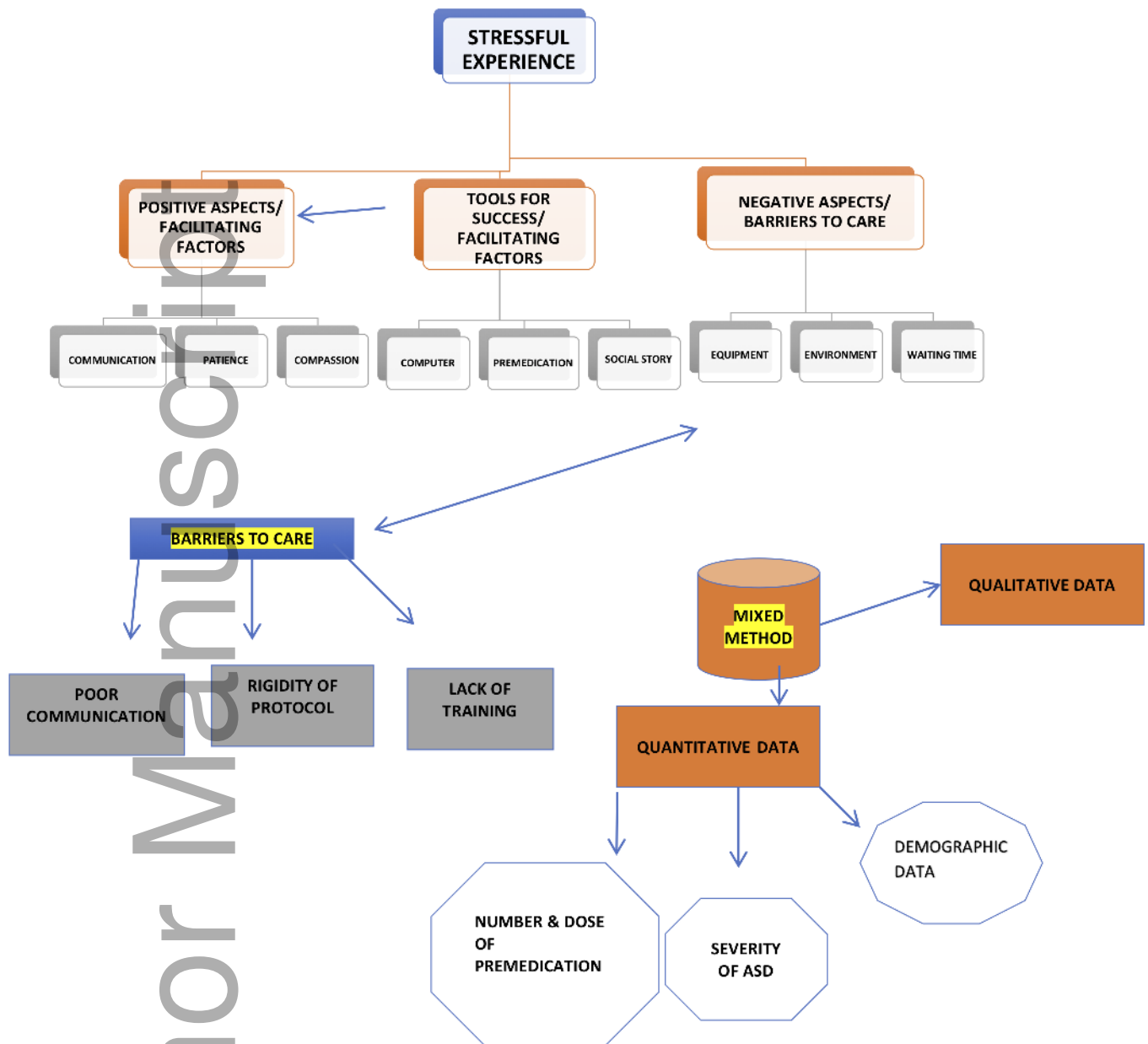
**Table 2: Quotation examples of flexible practises that improved the experiences**



Not doing non-urgent observations	<i>"They came in a couple of times to take her blood pressure and so forth she didn't want them to do it. They would say ok, that's ok, doesn't matter. Nothing was a real drama for them which was really great." (Caregiver of 12 years old)</i>
Allowing or offering special objects that were desired	<i>"She wanted keys. Those kinds of things to keep her a little bit calm." (Caregiver of 7 years old).</i> <i>"Things were offered to us constantly. Things like does he need anything to make him feel more comfortable like the TV or anything that would help him pass the time while he was waiting. I can't think of anything bad from yesterday ..."(Caregiver of 13 years old)</i>
Not insisting that child change out of their street clothes	<i>"She wanted her bracelets on. She wanted her shoes left on. It was good didn't make her get changed. I think that would have really upset her quite a bit." (Caregiver of 7 years old)</i>
Alternative approaches to taking premedication offered	<i>"I think in terms of trying to offer L. medication he obviously doesn't take it in a standard way. When he would not take it in a particular form the staff were very willing to try different ways to help him take the medication. I found that was very helpful.." (Caregiver of 13 years old)</i>
Offer of medication when needed	<i>"...They could see the he started stimming a little bit at one point with hand flapping ...said would you like us to give him some sedation before putting the AnGel<sup>®</sup> cream (local anaesthetic topical cream) so that will calm him down just that little bit more. I said that's brilliant,.. He was so calm" (Caregiver of 6 years old)</i>

Figure 1: Thematic map

Figure 2: Themes



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Facilitating factors
<ul style="list-style-type: none"> <li>• 1. Communication and attitudes <ul style="list-style-type: none"> <li>• Good communication</li> <li>• Clear explanations given</li> <li>• Friendly attitudes</li> </ul> </li> <li>• 2. Individualised care within the hospital care framework <ul style="list-style-type: none"> <li>• Flexibility with protocols</li> </ul> </li> <li>• 3. Use of supports <ul style="list-style-type: none"> <li>• Nalbed computer</li> <li>• Speech (nurse)</li> <li>• Social story</li> <li>• Play therapist</li> </ul> </li> <li>• 4. Personalisation</li> </ul>
Barriers to care
<ul style="list-style-type: none"> <li>• 1. Limitations of staff awareness of special needs <ul style="list-style-type: none"> <li>• Rigidity of protocol</li> <li>• Lack of formal training</li> <li>• Lack of explanation to patients and caregivers</li> </ul> </li> <li>• 2. Lack of suitable equipment <ul style="list-style-type: none"> <li>• Non-suasive thermometer</li> <li>• Beds that lower to ground level</li> </ul> </li> <li>• 3. Lack of suitable environment <ul style="list-style-type: none"> <li>• Quiet areas</li> <li>• Dimmable lights</li> </ul> </li> <li>• 4. Waiting time <ul style="list-style-type: none"> <li>• On the day of procedure</li> <li>• Missing for procedure date</li> </ul> </li> </ul>

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