



# Nurses' experiences of giving care to children with autism spectrum disorder within somatic emergency care

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## Abstract

**Aims:** To describe nurses' experiences of giving care to children with autism spectrum disorder in a paediatric emergency care unit and to explore how the nurses had obtained their knowledge of the subject.

**Background:** Within somatic paediatric care, nurses frequently encounter children with autism spectrum disorder. Many parents of these children report a lack of knowledge about the diagnosis and difficulties in encounters with somatic care. According to Patricia Benner's theory of learning, a skill is developed through education, tutoring and experience.

**Design:** A qualitative interview study.

**Method:** Semi-structured interviews were held with ten nurses during the spring of 2015. Data was analysed by content analysis to find categories and codes corresponding to the study's aims.

**Findings:** The findings present information regarding: 1) knowledge and experience; 2) the context in which the child finds itself, as well as an unsafe working environment for the nurses; 3) how the treatment and care of the child, among other things, is affected by information given by the parents about the diagnosis, and how the nurses feel in difficult situations; 4) interaction with the children, the parents and colleagues. The findings in this study mainly show the complexity in encounters with children with autism spectrum disorder and their parents and that nurses require further education. The nurses also give a number of suggestions for improvements that well concur with the literature.

**Conclusion:** To be able to care well for children with autism spectrum disorder, a combination of knowledge and experience is necessary.

**Keywords:** Children, Autism Spectrum Diagnosis, Emergency Care, Nursing, Interviews.

## Summary statement

### Why is this research needed?

- Children with an autism spectrum disorder have symptoms that vary greatly and, due to difficulties regarding communication, interaction with others can be complicated.
- Children with ASD experience stress when coming to an emergency care unit.
- Parents report healthcare personnel as lacking knowledge about the diagnosis.

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### **What are the key findings?**

- Insight to how nurses experience giving care to children with an autism spectrum disorder.
- More understanding of the complexity of encounters with these children and their families in an emergency care setting.
- Knowledge that parents are left with a great responsibility regarding interpretation of their child's symptoms.
- Information about how nurses gather information and knowledge about the subject.

### **How should the findings be used to influence policy/practice/research/education?**

- The nurses want and need more education about autism spectrum disorders.
- Examples for changes in routines and context given by nurses with experience should be taken into consideration.

### **Introduction**

Nurses within somatic paediatric care frequently encounter children with autism spectrum disorder. Problems with the care and assessment of these children often appear due to difficulties regarding communication. The children may experience the situation as stressful and this leads to further difficulties. Nurses frequently feel insecure in encounters with children with autism spectrum disorder when they cannot communicate and assess the child by its body language and behaviour. Some children with autism spectrum disorder react by acting out, leading to more insecurity. There is a need for research about nurses' experiences of children with autism spectrum disorder within somatic care.

### **Background**

Patricia Benner's theory of learning is built on the Dreyfus model that describes how a student passes through a number of stages during the process of developing a skill. A necessity for good development is a foundation of education, tutoring and experience. Benner was of the opinion that nursing can be learnt by interpretation of actions and conditions. Deep knowledge comes with tutoring by more experienced nurses. Benner's theory includes five stages from novice to expert. The novice lacks experience and needs tutoring to gain knowledge. The novice's behaviour is ruled by theoretical knowledge and regulations. During the stages, knowledge and experience increase and the nurse finally becomes an expert in the field. The expert nurse no longer needs to rely on analytical principles to be able to link together her own opinion with a suitable action. Regarding psychiatric patients who may not feel

or perceive events the same way as others do, the nurse needs to mediate between the patient and the normative culture within the healthcare system. The foundation of understanding psychiatric patients is openness and acceptance, which comes more quickly through repeated encounters with patients who have special needs [1,2].

The criteria according to the Diagnostic and Statistical Manual of Mental Disorders-DSM-5 for diagnosing children with autism spectrum disorder (ASD) are limited ability of social communication and limited, repetitive behaviour. The severity of the symptoms must create needs for support in everyday life. The symptoms must have started in early childhood [3]. Children with more severe difficulties often receive their diagnosis earlier than children with minor symptoms [4]. The exact cause of ASD remains unknown; damage during foetal life is thought to be part of the cause, but much indicates that there are genetic factors as well. Early research stated that psychosocial reasons such as emotionally cold parents or neglect caused ASD; today these thoughts have been completely abandoned [5].

There are three core aspects regarding cognitive dysfunction that all play a central role in the understanding of ASD. They represent a non-functional development of theory of mind/cognitive empathy, central coherence, and executive functions [5,6].

The difficulties within the theory of mind are usually the reason why children with ASD are misunderstood and have problems functioning well in social situations. They do not understand body language and instead focus on the words spoken. Most children with a lesser degree of ASD will

interpret the words very literally [5,6].

Regarding central coherence; children with ASD struggle to understand their surroundings. They often focus on details and can have difficulties seeing the whole situation. The details take up focus and even though they do not affect the situation, they are found to be essential to the child [5,6]. Children with ASD usually have difficulties with sensory input such as smell, touch, sound and sight. A visit to the hospital includes a lot of sensory input in these categories, leading to feelings of distress [7].

Language is included within executive functions; automatization of the spoken language is difficult. The degree of difficulty varies from child to child [5,6]. Some children have difficulties expressing their feelings altogether and caregivers have to be very specific in their questions to the child. Parents report that the child's difficulties with communication increase in the high-stress hospital environment. Care providers are not always aware of the pictorial and graphic communication aids available that can be of great use. Being unprepared for procedures triggers the child's anxiety with the risk of more negative experiences [7,8].

Children with ASD have difficulties regarding communication and social interaction [5]. This may lead to feelings of anxiety when visiting a healthcare facility. The parents are often present to speak for their children. In cases of severe ASD it can be difficult even for the parents to assess how the child feels. Many parents report a great lack of knowledge with healthcare personnel regarding treatment and care for children with ASD [9]. Parents also call for improved education and increased inter-professional cooperation within somatic care [10]. To facilitate healthcare contacts; it is of great importance that nurses feel comfortable in the situation. This requires a profound knowledge. Today there is very little research about nurses' experiences of ASD within somatic care, even less so in emergency care.

## The Study

### Aims

The aims of this study were to describe nurses' experiences of giving care to children with autism spectrum disorder in a paediatric emergency care unit and to explore how they had gained their knowledge.

### Design

This was a qualitative interview study. The interviews were analysed using a model for qualitative content analysis by Graneheim and Lundman [11].

### Participants / Settings

The participants were chosen according to a purposeful sampling and were included if they fit the set criteria [12]. The inclusion criteria were being a nurse in the emergency care unit, a minimum of six months' experience of working at an emergency care unit for children and youth. The exclusion criterion was nurses who had children with ASD in the family. All nurses working day/evening were asked to participate. A desirable number of 8-12 participants were set.

The participants all worked at a large paediatric emergency care unit in a university hospital. In total there were about 50 nurses working in the emergency care unit, and four-five of them were present at all times. First a triage nurse met the child and the parents in order to get information about the child's symptoms. The triage nurse measured and recorded vital signs (pulse, oxygen saturation, breaths per minute, temperature) and had the authority to order basic blood tests, pain medication, inhalations and enemas.

### Data Collection

The interviews were performed March to April 2015, and took place in a secluded room at the emergency care unit in connection with the nurse's shift. The interviews lasted for 15-30 minutes. Four open-ended questions were prepared beforehand: 1. Have you ever taken care of a child with ASD? 2. Can you tell me about an encounter with a child with ASD? 3. Is there anything you would like to change regarding the care of children with ASD? 4. How have you obtained your knowledge about children with ASD?. In the interviews these questions were

complemented with probing questions – either to clarify a statement or to ask the nurses to further develop their answers. The interviews were recorded and transcribed verbatim.

### **Ethical considerations**

The participants received verbal and written information regarding the aim of the study, possible risks and benefits, as well as information about their possibility to withdraw from participation at any time. They were asked to sign a written informed consent form with information regarding voluntary participation. The participating nurses were asked only to mention the age and gender of children, and to exclude information or characteristics that could reveal a child's identity. The participants are anonymous in the article, and personal data is protected by the Swedish Law of Privacy/Personal Data Act 1998:204 [13].

An approval regarding the implementation of the study was demanded by the hospital manager and the manager of the emergency care unit. No children were involved directly, and hospital personnel can participate in studies of this kind with the approval from the hospital manager. Theoretical research done in the context of higher education, with the aim of acquiring new knowledge and contributing to the development of routines does not need to require approval from an ethical committee [14].

### **Data analysis**

The first author performed the transcriptions of the interviews. The transcribed text was analysed using qualitative content analysis [11]. The transcribed text was read several times as a whole. Thereafter meaning units were identified, condensed and given a code (Table 1). The codes were sorted into categories and subcategories, which were identified during the analysis. According to the context of the categories two main domains were identified: resources and caregiving (Table 2). Creating categories is the core of a qualitative content analysis; no facts may be excluded due to not fitting into a category [11,15].

### **Rigour**

To reach trustworthiness, the first author transcribed the interviews, the analysis and the setting process is described in detail and quotes from the interviews are presented in the text. The coding and the analysis have been discussed between the authors [12].

### **Findings**

Ten nurses volunteered to participate. They were between 30 and 52 years old (median 39.1). They were all registered nurses; six had undergone further education to become paediatric specialist nurses. One participant was male. They had worked as nurses for between 3 and 24 years (median 10.7 years), and at the emergency care unit between 1 and 10 years (median 4.2 years). All the participants reported having encountered children with autism spectrum disorder in the emergency care unit, on average every two weeks.

### **Resources**

This domain discusses the psychological and physical resources that affect the nurses' working environment. The nurses discussed how they have obtained their knowledge about ASD while describing experiences gained from different encounters. Furthermore, they discussed how the work is affected by surroundings, and then offered thoughts of how to change them to improve the care.

### **Knowledge**

#### **Experience of autism spectrum diagnosis**

The nurses said that even if the children have the same diagnosis, it differs widely how they behave and how they want to be treated. Sometimes it can be difficult even for the parents who live with their children around the clock.

‘The mother doesn't have a handbook either... she also has a hard time approaching him’  
(Nurse 3, specialist)

#### **Knowledge acquisition**



Most of the nurses had received their knowledge through a combination of experience and from reading up on their own on the basis of personal interest. Most important was to have an interest and to draw lessons from experiences. The knowledge could also be completely self-acquired.

‘But one can feel, it’s like, [...], we get nothing [further training] of this, but we are supposed to handle it.’

(Nurse 1, registered)

Some participants said they had received very little theoretical knowledge during their initial or specialist training.

## Development

The majority of the participants wanted more knowledge about ASD as well as to receive training in how to interact with these children. It can be difficult to keep the knowledge updated without outside help as, for example, through lectures.

‘One doesn’t really have much knowledge, not me anyway, about these children – you mostly get a feeling for what is right.’

(Nurse 2, registered)

‘Maybe there are some really smart solutions that I have no idea about, because I don’t have that knowledge.’

(Nurse 10, specialist)

Some nurses were trying to set aside time for reflection about difficult situations, but this did not always happen. Instead, they talked very briefly in the hallway and just stated that the situation became a bit dramatic.

## Context

### Surroundings

The nurses reported that there could be many people involved in the care of these children, especially in acute situations. If the staff tried to remain calm, it could still work out well. The nurses

usually offered families a separate room directly in connection with the triage.

The triage area often felt cluttered and unorganized and children with ASD may feel better if they were there for as short a time as possible. One of the specialist nurses considered simply being herself the most important tool, as it was through cooperation with colleagues that it was possible to create the peaceful environment needed.

The nurses reported that they did their best to make the waiting time for the children with ASD as short as possible by trying to prioritize. One nurse told of a family who chose to deviate when the child got too restless.

‘Even though we may know what [would be the best care], we are pressured from other sides.’

(Nurse 9, specialist)

## Unsafe working environment

Some nurses stated that the work with children with ASD could feel unsafe for both personnel and child, especially when dealing with older children. There was a feeling of not knowing what might happen; the children are strong and can act out physically when they feel pressured.

‘I have been hit sometimes, but I still feel that they don’t do it on purpose. I don’t think I get scared.’

(Nurse 3, specialist)

## Wish for change

The main thing missing at the emergency care clinic was time. The majority of the nurses suggested a proposed change in the routines: children with ASD should always have a higher priority and receive care more quickly. They also suggested a fixed routine regarding always offering the families a separate room. In addition, there should be a special room with a cosier interior and with fewer things in it. One nurse also called for more pedagogical procedural picture books to use in the preparation for children.

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## Caregiving

This domain discusses the nurses' experiences when encountering children with ASD and their families. They discussed issues that affect the care given and how they needed to adapt themselves to try obtain a positive outcome regarding carrying out procedures. Furthermore, they discussed their cooperation with parents and the strong feelings that emerged during the care of these children.

## Treatment and Care

### Information about diagnosis

The majority of parents informed the nurses about their child's diagnosis during triage. Some of the nurses expressed this as important information that could affect the treatment and care of the child, and that this was the reason why the parents tell them.

'[The feeling of calm] it came automatically when the mom told us that he has autism.'  
(Nurse 8, specialist)

### Continuity

Several of the nurses talked about the importance of continuity, which could be very difficult to achieve in an emergency care unit. They often tried to ensure that the same nurse interacted with the child during the entire care episode.

### Feelings

All the nurses reported strong feelings in connection with encounters with children with ASD. There was awareness that the children often had been involved in difficult situations before and a couple of them reported a feeling of responsibility for the encounter to go well. The nurses said that they continually tried to interpret the children's feelings; they could see that children often gave the impression of anxiety, stress or fear. The nurses described feelings of hopelessness and failure in connection with the care of children with ASD.

'And then one really thinks, oh God, what does

one do with these kids?! Is this right?! Or... should we... provide sedative? What should we do?! And I just felt that I have no idea...'

'It feels like... a form of abuse or violation... and it's not fun to perform such an act on another person.'  
(Nurse 10, specialist)

One nurse experienced it as difficult when the child became sad or upset, due to not knowing how much the child understands of what was going on.

'It is awful when it's like that he really cries from, sort of from the heart.'  
(Nurse 3, specialist)

## Interaction

### Interaction

All participants agreed upon it being very important to try and reach an optimal level of cooperation with the child. One nurse mentioned that it was important to respect the children's condition during care and wait until the child was more receptive of interaction. Another nurse said that occasionally they encounter parents who did not let the nurses interact with the child, sometimes as a predetermined opinion that it was not going to work out.

One of the nurses said that working with children with ASD was fun and challenging with the specific questions they got from many of these children. The majority of the nurses stated that the greatest difficulty was to communicate with the children that lack the ability of verbal communication. Nevertheless, they tried to inform and be clear even if there was no verbal dialogue.

Even though the nurses were accustomed to children not wanting to participate, it felt important for them to remain calm during procedures. It was important to work as a team with the parents; they usually know how to reach the child, how to best communicate information, and how to distract the child if necessary. Generally the parents worked well in this role. The parental steering was mostly positive but could be experienced as difficult when the nurse did not agree with the parents about an approach.

When interacting with parents it was of importance to acknowledge past experiences and assure them that the staff will do as good as possible.

‘The parents are the most important link.’

(Nurse 7, specialist)

The interaction between the child and the parents was usually seen as beneficial. However, sometimes it could also lead to the parents taking over the child's autonomy.

### Assessment

As part of the assessment of a child's status, the nurses put great trust in the parents' ability to interpret the child's symptoms. Some of the nurses stated that they perceived the parents as adequate in their assessment, while a few also said that it felt a bit scary to have to put faith in the parents' assessment being correct. When controlling vital signs during triage and the interaction did not work well, the nurses let the parents do the controls of vital signs. Sometimes the nurses needed to rely on their clinical eye to get an assessment of the child's status.

‘I don't want to have to fuss and create any unnecessary anxiousness if I don't really have to.’

(Nurse 10, specialist)

In cases where it was difficult to assess the child visually, a couple of the nurses chose to ask the physician to go to the child and do their assessment earlier. The same thing applied to many of the nurses when it came to ordering blood samples during triage; they chose to wait, and not risk the child having to undergo an unnecessary test or to have to undergo further tests later on.

### Procedures

Adaptability and flexibility seem to be the strategies that worked best during medical procedures. All nurses spoke about thinking outside the framework and guidelines, trying to follow the child and wait until he/she is ready.

‘I have taken part in situations that are somewhat weird [...] like “we usually give enemas on the floor”,

that they already have developed methods for and then it's just to go along with them [...].’

(Nurse 9, specialist)

The preparation for procedures was seen as being the most important tool. The nurses tended to go through the material and inform the children. Some also used the pedagogical procedural picture books developed by the play therapists. This material had been a very efficient aid even for children who had have traumatic experiences from previous blood sampling. The nurses talked about the fact that some children were in need of very thorough preparation while other children did not want to know anything. For the latter group, information became a source of stress. Procedures ran much more smoothly if the child could distract him- or herself with the help of pictures or movies.

In cases where good cooperation was difficult to achieve, the nurses tried to find alternative solutions. A couple of them had administrated nitrous oxide to help the child to become more relaxed and be able to undergo blood sampling, injections or enemas. For many cases, however, it ended up with the parents and nurses ultimately having to retain the child.

‘Because everyone doesn't want everything, and not everyone is going to agree with your ideas, unfortunately.’

(Nurse 10, specialist)

The nurses reported that they tended to address the physician to question and discuss the need for procedures when they believed it would be too difficult or traumatic for the child. They talked about the physician not always understanding the magnitude of the child's experience. One nurse talked about the importance of always knowing and understanding the purpose of the blood sampling.

‘It doesn't feel good if I'm not convinced myself that something is necessary.’

(Nurse 10, specialist)

**Table 1: Examples of coding**

Meaning unit	Condensed meaning unit	Code
'It's sort of what you encounter and such, and you take with you what feels good. Personal experience.'	You take with you what feels good through personal experience	Personal experience
'it was hard, because he fought, he was really angry, he became really, really wretched'	It was hard because he fought and was very angry	Violent child
'usually the parents are really meticulous with telling, because they also want us to understand and treat their children'	The parents usually tell us that they want us to treat their children well	Inform about diagnosis
'we needed to find a way and eventually, although there were many setbacks, we got a result'	Many setbacks can lead to a result	Getting results

**Table 2: Domains, Categories and subcategories**

Domains	Resources		Caregiving	
Categories	Knowledge	Context	Treatment and care	Interaction
Subcategories	Experience of autism spectrum disorder	Surroundings	Information about diagnosis	Interaction
	Knowledge acquisition	Unsafe working environment	Continuity	Assessment
	Development	Wish for change	Feelings	Procedures

## Discussion

The findings in this study show the complexity in encounters between nurses and children with autism spectrum disorder and their parents in an emergency care unit. The nurses reported a lack of knowledge on how to handle challenging situations adequately; they asked for further education. They wished they could have the possibility to always offer the families a separate room and possibility to reduce the waiting-time. The nurses were dependent on the parents' participation and knowledge to be able to provide care for the children.

The nurses reported that they lacked knowledge and asked for further education. Patricia Benner's theory of becoming an expert nurse states that a combination of education, tutoring and experience is

the key [1,2]. The participants lacked both tutoring and education. The majority got their knowledge from purely experience. The lack of knowledge and the need for more education among nurses are also described from a parental view in a study by [10].

In the current study the nurses reported that they did their best to make the waiting time for the children with ASD as short as possible by trying to prioritize [8]. claim that the long waiting times are a trigger for challenging behaviour. A previous study has shown that when being forced to wait to see a physician, children with ASD have an increased risk of behaviour escalation and not being able to cope [16].

The nurses suggested that the families would always be offered a separate room with a cosier



interior and with fewer things in it to reduce stressors. The stressors that can be found in an emergency care unit can be a reason for challenging behaviour. If the child is brought in to a calm room as soon as possible, the examination and the procedures will more likely be successful [17]. Children with ASD require a calm environment where nurses speak one at a time, using concrete language [18,20]. In a pilot study, nurses went through an intense education program with the aim of reducing challenging behaviour in children with ASD. They minimized stimuli such as light and noise, and received knowledge about the diagnoses. The result was that the nurses felt more secure and that when their knowledge increased, the challenging behaviour decreased [20].

The nurses were dependent of the parents' participation and knowledge to be able to provide care for the children. They leaned a lot on the parents' interpretation of their child and some of them expressed feelings of insecurity when having to rely on someone else, even though medical responsibility really rested with them, during triage. Earlier research has shown that parents underestimate pain reactions in their children with ASD during venepuncture procedures. Children with ASD were also rated to experience a higher level of pain than children in the comparison group [21]. To assess the level of pain the child experiences, the nurse may have to modify the strategies, especially with the non-verbal children. It may be necessary to base the assessment on behaviour and parental input about the child's usual behaviour. Many children with a more high-functional ASD are able to verbally self-report their level of pain. This can be done with the aid of a visual pain assessment tool [18].

The parents were considered to be the experts and were left with a great responsibility of being advocates for their children. Not only are they required to care for their children as parents, they are also required by the nurses to interpret the child's symptoms and inform the nurses how to interact with the child. These parents are forced to take much more responsibility than parents of children without ASD [22].

Davignon et al. [8] describe the parents' wish for better procedural preparation. A procedure-based

child-friendly storybook about a procedure can make it possible for the parents to prepare the child during waiting periods [7]. Communication and preparation were things the nurses in this study worked with, however they mentioned the lack of time and the need for more pedagogical procedural picture books.

Many nurses reported going to the doctor and disputing the need for the procedures that the doctors had advised. This requires courage, strength and experience. Even if all cases differ, the chance of equal and safe care increases with education and knowledge [1,2]. According to the Convention of the Rights of the Child we are obligated to always see to the greater need of the child and be advocates for their wellbeing [23].

### **Limitations**

To best serve the aim of the study, the author chose to conduct interviews. The subject chosen can be complex, and interviews allow probing questions in addition to the opportunity to develop deeper understanding. Using qualitative content analysis gives the reader an interpretation while still leaving room for the reader to further interpret and choose themselves at what level the findings are transferable to another context [12].

When a purposeful sample is used saturation can be reached with a relatively small number of participants [12]. During this study the nurses all told of different children and experiences. Many encounters were similar, and the nurses all spoke of comparable feelings. To evaluate whether saturation was reached can be difficult, since the stories varied even if the author considered them to have the same core.

The transferability of the findings should be considered in context, and even though the interviews were conducted with nurses in a large paediatric emergency care unit, one must keep in mind cultural differences as well as that some of the difficulties perhaps are related to the size of the unit. However, the size of the unit also entails a greater number of encounters with children with ASD, which leads to more experience and therefore greater knowledge.

The nurses in the study all worked in the same hospital, and therefore reflected a similar working environment. Nursing education most likely differs between countries, and this should be taken into consideration when comparing existing knowledge.

The first author has previously worked with children with ASD. The author has actively tried to ignore any pre-understanding that could affect the analysis. During the interviews the author was careful to remain neutral in body language and follow-up questions so as not to affect the participants.

## Conclusion

Since there is a great insecurity among nurses when it comes to encounters with children with autism spectrum disorders and because we have a responsibility to care for all patients with an equally open mind, the authors are of the opinion that there is a need for deeper knowledge. By describing nurses' experiences while caring for children with ASD, we can better understand strategies for the development of paediatric emergency care; that is, we can clearly see the need for education and tutoring necessary for the nurses to become experts in their field. All healthcare personnel are different, but by forming routines and structure dealing with how to care for children with ASD, we can facilitate the care.

There is little research done on this subject, and the authors conclude there is a great need to further examine the area. As a compliment to this study it would be of value to examine the parental view of visits to an emergency care clinic.

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