Developing Guidelines in Nursing Care of Children with Autism Spectrum Disorder in High Technology Health Care Settings

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De som är specialister på mina problem är jag och min mamma.

Abstract

Introduction. The high technology environment such as a radiology and anaesthesia department in a typical health care setting can many times be a frightening environment for children. Children with neurodevelopmental disorders, such as Autism Spectrum Disorder (ASD), have problems with communication and social interaction. They are dependent on routines and can have higher sensitivity to sensory stimuli than other children. These children are one group who constitutes special challenges in reducing anxiety and creating participation in a high technology environment. This can make them prone to frightening encounters in health care settings if not cared for with special consideration.

Aim: The overall aim of this thesis was to audit and enhance the care of children in a high technology environment in the health care system with a focus on children with Autism Spectrum Disorder.

Methods: A descriptive design was used with both qualitative and quantitative methods. In Study I, 32 nurse anaesthetists were interviewed to explore the actions and experiences of caring for children in a high technology environment using a qualitative method, known as the Critical Incident Technique (CIT). In the two following studies (Study II, III) a cross-sectional design was used and two national surveys were performed to obtain knowledge on the status in Sweden regarding the care of children with ASD in high technology environments. Sixty-eight anaesthesia departments, 38 paediatric departments and 86 radiology departments responded to the survey. Descriptive statistic was used for the answers apart from the comments part of the questionnaire where qualitative content analysis was used. Due to the limited existence of guidelines in these environments, the creation of evidence-based guidelines was performed in Study IV, using a Delphi method. The Delphi study was based on information gleaned from the previous studies and from the literature, and 21 experts identified in Study II and III were the expert panel developing the guidelines.
**Result:** Nurses identified children with special needs such as children with ASD as a vulnerable group in a high technology environment (Study I). Seven departments in the anaesthesia context had guidelines for caring for children with ASD in the perioperative context. In the other departments, the care of children with ASD was dependent on the knowledge of the nurse presently working there (Study II). None of the radiology departments in Sweden had guidelines on how to care for children with ASD going through a radiographic examination without anaesthesia (Study III). As a result of Study I, II and III, the need for structured guidelines for caring for children with ASD in a high technology context was identified and a set of guidelines and a checklist was created. The guidelines relate to the organisational structure for the care of children with deficits in social interaction, communication, sensory sensitivity and dependence on routines. The checklist relates to gleaning information about the specific child to be able to give person-centred care based on the specific characteristic of the child (Study IV).

**Conclusion:** Nurses working in a high technology environment in health care have diverse experiences of preventing anxiety in children with ASD coming for a challenging procedure. There are a limited number of evidence-based guidelines to decrease anxiety and to create participation in this group of children. Evidence-based guidelines were created as a tool for enhancing person-centred care in a high technology environment for this group of children. The fact that several problems are assembled under one disorder makes ASD a useful condition to have as a basis for formulating national guidelines. Guidelines that cater for the care of children with ASD in a high technology environment using a person-centred approach may also extend to the care for children with other neurodevelopmental disorders that exhibit some of the same problems as children with ASD.

Key words: Anaesthesia, autism, children, guidelines, nurses, participation, radiology
Original papers

The thesis is based on the following studies, which are referred to by their Roman numerals in the text:

**Study I**


**Study II**


**Study III**


**Study IV**


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Abbreviations and definitions

ASD = Autism Spectrum Disorder

CIT = Critical Incident Technique

UNCRC = UN Convention on the Right of the Child

CRNA = Certified Registered Nurse Anesthetist

DSM-5 = Manual of Mental Disorders number 5

EACH = The European Association for Children in Hospital

HCP = Health Care Professionals; this term includes nurses, but can also be other health care professionals and is used when it can be applied to more than one profession in the health care

High technology environment = Anaesthesia department and radiology department

ICF-CY = International Classification of Functioning, Disability and Health-Children and Youth version

ICN = International Council of Nurses

Nurses = The term nurses is used when talking about the radiographers, nurse anaesthetists and the nursing profession

Person-centred care = Care of the patient according to the model of Patient-centred care where the person and the relatives are seen as collaborators and active participant in the care of the person

QSEN = Quality and Safety Education for Nurses

SFS 1982:763 § 2 of the Health and Medical Services Act
Introduction

The hospital is an unfamiliar environment for children. Being separated from the parents in that unfamiliar environment can create a feeling of insecurity [1, 2]. Helplessness can occur when the children are not allowed to make up their own minds as they do in their everyday life. When in an unfriendly environment children can express feelings of insecurity, helplessness and rejection in connections with being admitted to the hospital [1, 3]. On the other hand, in an environment where they are listened to, children express that those who care for them are nice, pleasant, friendly and familiar [2, 4]. Children can become angry and depressed when the health care worker ignores them and talks about them above their heads as if they are not present. When children get proper information about the care, they can be involved in the care, are less anxious and can prepare themselves for the examination or procedure [5]. Coming to a high technology environment such as the anaesthesia and radiology departments and meeting strangers in an unfamiliar environment adds to the anxiety of children [6, 7]. Children with neurodevelopmental disorders such as autism spectrum disorder (ASD) have problems with communication, social interaction, are sensitive to sensory stimuli, have a dependence on routines, and are anxious in unfamiliar environments, and represent a vulnerable group in the high technology environment in health care. These children’s problems with interpersonal interactions makes them prone to have frightening encounters in the health care setting if not cared for with special consideration [8-10]. Parents of children with disabilities and ASD can experience struggles in the health care encounter, where the system is difficult to manage [11]. When parents encounter people, who are unfamiliar with their child’s condition, they feel vulnerable and helpless in their fight for the right treatment of their child [10, 12]. With empathy, understanding and respect the health care professionals can make a positive different in the experience of the encounter in the health care for the child and the parents [10-12].

As a nurse anaesthetist, I have anaesthetised both anxious and completely carefree children. I have anaesthetized children with developmental disorders such as ASD and worked with those children to create a friendly encounter for them. I have seen these vulnerable children in the health care setting and I
have also seen the struggle the parents of these children have, to ensure an encounter that enables the child to participate in the procedure.

The radiology as well as the anaesthesia department are high technology environments where the child comes for a procedure. The procedure often has a strict schedule to adhere to and limited time to build a relationship. This frightening, high technology environment, together with the limited time to get to know the child is a challenge for the parents, children and nurses. There is limited research about how to care for children with ASD in a high technology environment and therefore there is a need for evidence-based guidelines to care for these children in a high technology environment and therefore the focus on these two departments.
Background

Children in health care

Medical fears originate from previous frightening experiences while fear of the unknown and fear of danger and death originates from information given by others [13]. A child admitted to a hospital experiences fears related to being a patient where pain is the item most frequently mentioned. Second on the list is nursing interventions such as injections and other common fears in the hospital are separation from family, being left alone, exercise of power by adults and fears of instruments and equipment. In general, anxiety of the unknown is often experienced by children undergoing health care procedures [1, 14]. The conclusion being that the physical, social and symbolic environment of the hospital is frightening to children [15]. Behaviours that the child displays in trying to get out of the situation are crying, trying to run away and expressing negative emotions. In fighting the situation, the child displays physical resistance and uses words to express that they want to get out of the situation [1, 16-18]. The anaesthesia and radiology environments are high technology environments which can be specifically frightening to children [19, 20].

Children in a high technology environment

Preoperative anxiety as well as anxiety related to radiographic examination is common in children [19, 20]. Going to the operating theatre for anaesthesia and surgery or to an acute radiographic examination is a time for heightened anxiety in children. Between the ages of 6-12 years, children relate their fears to the unknown about what is going to happen, fear of being in pain postoperatively and having a cannula inserted [2, 6].

Preoperative anxiety can lead to decreased cooperation at anaesthesia induction, increased postoperative emergence delirium and increased postoperative pain. Preoperative anxiety can also result in postoperative negative behaviours such as sleep disturbances, nightmares, separation anxiety, apathy, general anxiety and withdrawal [21-24]. Anxiety related to radiographic procedures may lead to both short-term and long-term consequences. The short-term consequences may be that the child is crying,
afraid and uncooperative during the procedure, which may negatively influence the performance of the examination [25]. A child may develop negative memories of such events leading to long-term consequences such as intensified experiences and lower tolerance of anxiety during future procedures [26, 27]. When a child has not been prepared for the encounter and the nurse lacks the skill for handling children with ASD, the child may become anxious and uncooperative, resulting in the nurse physically restraining them for the induction of anaesthesia or during a radiographic procedure [28-31]. A child previously physically restrained for a procedure might show increased anxiety the next time the child presents in a hospital for another procedure [32] this increased anxiety can remain even into adulthood [33].

One way of decreasing anxiety in hospitalised children is to explain what is going to happen and to include the child in the care [2, 3, 34] which is the core of person-centred care [35]. Positive interactions with others -both children and nurses -also helps to defuse anxiety in these children. To cope with the experience of being in a hospital, children need their parents as a social support [2, 16]. To meet the nurse anaesthetist in advance who could create a trusting relationship with the child, and then have the same trusting nurse administering the anaesthesia decreases the anxiety in children [36]. Children coming for an acute radiographic examination for the first time can be anxious. They have pain from the injury which is exaggerated from the examination and the waiting time is often stressful [3]. Other ways of reducing the anxiety in a child for an acute radiographic examination is to give age appropriate information and involve the child in the examination as suggested by person-centred care [37-39] and altering the position of the child if they are uncomfortable. However, when the radiographers are short of time they do not take the time to explain to the child and they do not let the child be part of the examination [37]. For procedures in the radiology department such as a magnetic resonance imaging (MRI) scan, preparing the child in advance of the examination can decrease anxiety and increase participation during the examination. Age appropriate preparation and good communication between the children, radiographers and the parents may enhance the participation of children who undergo an MRI examination without deep sedation or anaesthesia [40]. Given those conditions, a child could be part of the decision making and the decision on how to go about the examination would be a decision shared between child, parent and nurse as in person-centred care.
For nurses working with children it is important to have a person-centred care perspective and take the specific need of each child into consideration when caring for children as described in the convention on the rights of the persons with disabilities article 7 and 25 and the EACH charter [41, 42]. One way of ensuring a person-entered care approach of the child is to have knowledge on how to meet and communicate with the specific child. To know the problems associated with neurodevelopmental disorders gives the health care professionals a tool to individualise the care of each child.

**Neurodevelopmental Disorders**

Neurodevelopmental disorder is an umbrella term for a group of conditions manifesting in the developmental period. Under the umbrella of neurodevelopmental disorders that is listed in Diagnostic and Statistical Manual of Mental Disorders number 5 (DSM-5) are: intellectual disability, communication disorders, attention-deficit/hyperactivity disorders, specific learning disorder, motor disorder, ASD and other neurodevelopmental disorders [8]. The common traits for these disorders are that they impair personal, social, academic or occupational functioning and manifest early in development. There is often an overlap between the disorders although the diagnostic criteria are distinctive to each disorder. However, one child can present with more than one of the disorders. Within each of the disorders there is a wide range of the manifestation of the problems between children. There is also a frequent co-occurrence of the disorders [8, 43].

**Intellectual disability**

Intellectual disability mainly manifests itself as difficulties in mental abilities. This could be presented as difficulties in reasoning, planning, learning from experience, solving problems and abstract thinking. These deficits make it difficult for the person to function independent in daily life. As in all of these disorders there is a wide range in the manifestation of the disorder from mild to profound disability where the functioning can range from mostly managing daily life on his or her own, to needing assistance with everything [8].
**Communication disorder**

Communication disorder includes a deficit in the use of language such as speech, sound of speech, repetitive speech (stuttering) as well as deficit in social communication [8].

**Attention-deficit/hyperactivity disorder**

Attention-deficit/hyperactivity disorder (ADHD) is characterised by impairing attention, hyperactivity-impulsivity and disorganisation. This is manifested in the inability to stay seated and to wait. The hyperactivity also cause fidgeting and more or less constant moving of the body. The impulsivity can be presented as intruding in other persons’ business or interrupting other persons speaking [8].

**Specific learning disorder**

Specific learning disorder relates to difficulties in learning academic subjects such as reading, writing and/or mathematics. These difficulties are manifest without intellectual disabilities and it might occur in intellectually gifted children [8].

**Motor disorder**

Motor disorder includes developmental coordination disorder, tic disorder and stereotypic movement disorder. This disorders relates to body function. It ranges from a deficit in coordinating body movement, clumsiness and slowness in movement, to stereotypic involuntary body movements or vocal tics. The stereotype movements can for example be hand flapping or head banging [8].

**Autism spectrum disorder**

The prevalence of Autism Spectrum Disorder (ASD) is approximately 1% of all children [8, 44]. ASD is a complex neurological developmental disorder characterized by persistent difficulties with social communication, both verbal and non-verbal, and social interaction in different contexts. Included in these difficulties are social-emotional reciprocity and creating and maintaining relationship (criterion A). Children with ASD often present with restricted, repetitive, behaviour. This restricted repetitive behaviour can include
exclusive interests, activities and body movement. Dependence on routines is another facet of the restricted, repetitive, behaviour. Children with ASD can also have atypical reactions to sensory stimuli (criterion B). These manifestations should be present in the early developmental period (criterion C) and cause significant difficulties (criterion D) and they could not be explained by other reasons (criterion E). The characteristics of children with ASD are in a wide range from mild deficits to profound deficits or lack of functioning, as stated in the name of the disorder, autism spectrum disorder [8].

Communication difficulties is one of the problems associated with ASD. A child with these communication difficulties is likely to interpret a spoken sentence literally. To phrase a request as a question might be confusing for the child and the child might not necessarily understand that the question is actually a request to act, for example switch on a lamp, but merely a question if he/she is able to switch on the lamp [45, 46]. Included in the communication difficulties there is a spectrum of difficulties with non-verbal communication, for example collectively processing facial expressions and other non-verbal communication cues which intuitively can lead to problems interpreting the communication of others. Likewise, the nurses working with the child can have difficulties to understand what the child is trying to communicate which can make the encounter problematic [46-49]. To use a pictorial schedule in advance can be a way of preparing the child and involve the child in the care [50-53].

Difficulties with social interaction is another problem associated with ASD [8]. The basis for social interaction is to have the ability to understand other persons’ feelings and to know what to expect next in an interaction. Children with ASD have difficulties to interpret the verbal and non-verbal cues from other persons that is the way to understand the feelings of others [45]. One form of social interaction is taking the role of the other and understand the social cues of the other as described in symbolic interactionism [54, 55]. If the nurses possess knowledge about the specific child’s way of communicating and social interaction, it facilitates the nurses’ ability to take the role of the other, which is to understand the other's perspective and a key to successful support and empathic behaviour towards the child [55].
**Hyper- or hypo reactivity to sensory input** is another manifestation in children with ASD [8]. These children may show atypical reactions to *sensory stimuli*. They can overreact or underreact to sound, touch, visual stimuli, pain, heat and cold. These over or under reactions to sensory stimuli can make it difficult to understand the precise needs of the children or obfuscate one’s ability to fully understand what the child is experiencing [9]. When the child comes to the high technology department, there is a lot of noise with beeping machines and bright lights. In the high technology context, the nurses also touch the child, adjust position of the child, and fit equipment such as IV lines or other equipment. For a child who is sensitive to sensory stimuli this might be a challenging experience [46]. Just a simple action such as adjusting the light in the room can make the difference from uncontrolled anxiety to comfort in a child who is sensitive to bright light [56]. To take the needs of the individual child into account and to make the child a participant in the care is therefore important.

**Dependence on routines** and to know in advance what is going to happen is associated with ASD. When the routines are disrupted it can lead to extreme distress when the child is faced with even small changes in his or her immediate environment [57, 58]. For example, a book that is moved out of position in the bookshelf can cause extreme distress in a child [45]. Coming to the hospital is most of the times a disruption of routines for the child with ASD [50-53].

**The restricted, repetitive patterns of behaviour, interests, or activities** can be manifest as repetitive stereotype body movements or speech, and the restricted interests can be a source of intense focus with a strong attachment on special objects. These stereotype and repetitive behaviours can be self-calming strategies used by the child to cope with the situation [8].

Children with ASD have problems with communication and social interaction that can also be manifest in communication disorder, ADHD and intellectual disability. They can also have difficulties with learning in specific areas as in specific learning disorder and problems with stereotype repetitive body movement exhibited in conditions such as in motor disorder and severe intellectual disability. In comparison to children with other neurodevelopmental disorders, children with ASD are more dependent on routines and can have higher sensitivity to sensory stimuli [8]. The fact that
several problems have orchestrated effects under one disorder makes ASD a useful condition to have as a basis for formulating national guidelines. Thus, the focus in this thesis will be on children with ASD. Guidelines for the care of children with ASD in a high technology environment using a person-centred approach can probably also be used to care for children with other neurodevelopmental disorders that exhibit some or all of the same problems.

**Children with ASD in health care**

Children with ASD are more vulnerable than children with typical development in the health care setting. Due to their unusual reaction to sensory stimuli, difficulty communicating and heavy dependence on routines these children may need anaesthesia for procedures other children can undertake without sedation or anaesthesia [59-63]. Children with ASD have often co-occurrent conditions that require a frequent use of health care institutions which makes these children use the health care services more than children with typical development [60, 61, 64-67]. Children with ASD that use the health care system frequently also run a higher risk of having unmet health care needs than children with special health care needs without ASD [65, 68, 69]. In addition to having unmet needs, children with ASD experience even more anxiety in the health care system than children without ASD [70].

For children who are overly dependent on routines and familiar environments, a new environment can cause great anxiety [32, 58, 71, 72]. This can eventually lead to the child exhibiting a challenging behaviour such as hitting things and throwing objects around them, harming themselves or others. Nurses may interpret these behaviours as aggressive and they might not know how to deal with this type of non-compliant behaviour [32, 57, 58, 73]. Advance preparation, parental involvement and structured activity are ways to make the child comfortable and able to participate in the procedure [57].

Children who are hypersensitive to sensory stimuli do not participate in activities in daily life as much as typical developing children. The higher the score on hyper-reaction the lower participation scores [74]. Children with this problem can exhibit a challenging behaviour such as screaming, banging their head on the wall or throwing things and kicking things at people when they experience sensory overload. This behaviour can be challenging to other people but can be a self-calming strategy used by the child [49, 57].
When it comes to communication, a child that lacks a verbal language lacks the ability to understand the nurses’ verbal communication. The child may also fail to understand non-verbal communication because the language used contains symbols the child does not understand. On the same note, the nurses may also have the same difficulties in interpreting the communication of the child. This communication breakdown obstructs the child’s possibility to participate. When the child is not able to participate, or be engaged, it can result in the child not wanting to participate by being there either [32, 57].

For children with these problems it is important to know what is going to happen and to be familiar with the environment and procedure. To make this possible there needs to be an organisation in place that facilitates this in place [10, 58, 73, 75-77]. However, one should keep in mind that all children are different and have different needs. This means that one-size fits all planning is not a viable strategy for these children. The planning and care needs to be tailored differently for each child [76-78].

In the care of children with ASD the HCPs need to consider the manifestations of ASD in the child and how to accommodate for each child. Taking the wide variation of functioning between children with ASD into consideration it is necessary to see each child as an individual and care for each child according to person-centred care as described by Cronenwett [35].

Care without knowledge and without consideration to the needs of the specific child can cause great suffering in both the child and the parents [10]. The care can eventually end in physically restraining a child for anaesthesia induction or radiographic procedures which can harm the child, the parents and the staff [30, 31, 73]. To have evidence-based guidelines can be a tool aiding the nurses working in a high technology environment to create person-centred care for these children.

**Nurses practice in a high technology environment**

Both nurse anaesthetists and radiographers have their core competence in caring in a high technology environment. Both professions’ competence is to provide care based on the individual patient's needs and resources [79-83]. In providing this care, nurse anaesthetists and radiographers are bound to protect the human rights, values, customs and beliefs of patients and their families. It
is also the duty of the nurses to maintain personal integrity and, act to safeguard patients from unethical or illegal actions of any person [79, 81]. Within their scope of care is the requirement to create trust, confidence and security in the patient and the relatives. This can be accomplished through education and information given in a pedagogic way to the patient and significant others [82, 83]. This is in line with person-centred care [35].

The high technology environment makes it extra important to have the care of the patient as the centre of the work. Both professions’ work is based on a set of values from the International Council of Nurses (ICN) and their respective professional organisation, International Federation of Nurse Anaesthetists and The Swedish association of Radiographers [79, 82, 83] Code of Ethics. It is the basis for ethical behaviour and attitude, which means that every patient should be treated according to his or her individual needs [83].

Nurse anaesthetists and radiographers regards themselves as the patient’s advocate. This means that they should treat all patients with dignity and respect and according to the needs of the patients [84-86]. They guide their patients step-by-step to decrease the anxiousness of the patient through the sometimes frightening high technology environment [86, 87].

The specific scope of practice for the radiographer is to plan, perform and evaluate radiographic examinations or radiological interventions in relation to the quality of the image, patient safety and the radiation dose [82]. This means maximising the safety for children undergoing a radiographic examination and making sure that the images for diagnostic reasons are of excellent quality and at the same time minimising the radiation dose, and reducing anxiety and pain in children [7, 19, 88].

The specific work for nurse anaesthetists is to, after prescription from the anaesthesiologist, independently plan and administer anaesthesia to patients without serious health conditions, in accordance with the patient’s needs, and the treatment or procedures’ specific needs. It is specifically mentioned in the competence description for nurse anaesthetists that they should plan the care in a pedagogical and supportive way for patients with special needs, for example offering them the perioperative dialogue, especially when it comes to children with special needs in the health care system [83]. One of the aims
of the perioperative dialogue is to get the child to be a participant in the encounter.

**Participation in health care**

There are conflicting views about a child’s ability to participate in decision making [89]. Some nurses suggest that all children could be part of the decision-making process, while other nurses see constraints in the child depending on their age and intellectual capacity. Nurses also find it hard to let the children be part of the decision-making process if this is not verbally asked by the children and by the parents [5]. Parents regard it as natural that the children are involved in the decision making about the care. Respecting the children’s ability to be involved, is seen as a way to enhance the care and overall the wellbeing of the children [5], which is what person centred care is all about.

However, children’s ability of participation is dependent on the actions of the nurses and the parents. If the children are given age appropriate care and information and are allowed to participate then the children are able to make a competent decision [90-92]. Advance preparation, parental involvement, and structured activity are ways for nurses to enable the child to participate in the procedure [57]. Children use several strategies to negotiate a care situation. It takes sensitivity from the nurses to interpret and understand the children [91, 92]. To get the children’s views of their care can be challenging for the health care professionals [89] but children want to be part of the decision making and they want to be informed about their care. At the same time, they also want the parents to be there and to be their advocate making the decisions when the children do not feel they are capable or do not want to make the decisions [93, 94].

There is a power relationship between nurses and parents. Parents are expected to take on a vital role in the care of their children [95]. From the parents’ perspectives, they want to be part of the decision-making process. They want to make the decisions in collaboration with the nurses but they do not want to take the full responsibility for the decisions made [96-98]. Important aspects for the parents are to be informed about all aspects of the care of the child and that the nurses listen to them. Parents wants to be able to be there and comfort their child [99, 100]. However, parents of children with cognitive and
behavioural disabilities are less likely to be part of the decision-making process than parents of children with physical disabilities [101]. Parents of children with communication problems, difficulties in social interaction, high dependence on routine and sensitivity to sensory stimuli, such as children with ASD, report even less shared decision making than parents of children with special health care needs without those problems [102].

In the bio-psycho-social model of the International Classification of Functioning, Disability and Health-Children and Youth version (ICF-CY) participation is defined as involvement in life situations [103]. Within the family-participation-related constructs there are two essential components of participation. Those two components are attendance and involvement. Attendance can also be described as being there and involvement can be described as engagement, where attendance is a requirement for involvement [104, 105].

Children discussing participation in medical communication, described occasions when they were involved (engaged) and not involved (engaged) even though they attended the discussion. The children also stated that it was natural to be involved since they were affected by the disease. However, the children wanted to choose their level of involvement and to let someone else be there and being engaged for them in some instances [106].

When it comes to challenging procedures in the health care, children may be frightened and not even want to “be there” nonetheless want to be “engaged” [3, 29]. Working according to the principles of person-centred care could be one way to involve the child in the care.
Conceptual standpoints

Person-centred care

Person-centred care is one of the nurses’ quality and safety competencies (QSEN). These competencies are developed out of a need to meet future challenges in the health care. The intention is to reduce the suffering of patients and improve the quality and safety of the persons cared for. This resulted in six quality and safety competencies in nursing: patient-centred care (Swedish Society of Nursing changed this to person centred care), teamwork and collaboration, evidence-based practice, quality improvement, safety and informatics. The quality and safety competencies are intended to clarify what is required of nurses and to be integrated in the education at the undergraduate and graduate levels [107, 108]. The quality and safety competencies are included as standards for the nursing profession according to the Swedish Society of Nursing [108]. Within each of the quality and safety competencies there are three learning objectives; knowledge, skills and attitudes (KAS). These learning objectives are what the nurses need to possess in order to be able to work within the framework of the quality and safety competencies to ensure a high quality of care for the patients [35].

Cronenwett (2007) defines person-centred care as: “Recognize the patient or designee as the source of control and full partner in providing compassionate and coordinated care based on respect for patient’s preferences, values and needs” [107].

Morgan (2012) defines person-centred care as a holistic (bio-psycho-social-spiritual) approach to provide care that is respectful and individualised, allows for the negotiation of care and allows for selection by a therapeutic relationship in which people are empowered to be involved in decisions about their health at all levels that the person wish to receive care [109].

To be a patient means that a person is automatically put at a disadvantage. To end up at the bottom of the chain in a hierarchical organisation being in a vulnerable situation when something is wrong with your health. Added to this is the cognitive disadvantage a patient will experience through lack of knowledge. With this in mind, it becomes important to find a way to see and
treat the patient as a person with his or her own ability to make active choices [110]. With this unequal power balance, it can be a challenge to become equal partners in the care. The partnership in person-centred care can be described as a mutual process where both the patient and the health care professional brings their knowledge and work together for a growing understanding [111].

The learning objective knowledge, associated with person-centred care for the advanced nurse, is to analyse all the dimensions of person-centred care. This includes knowledge about the person her/himself, the family, friends and the community and its impact on the person. To analyse and care for the physical as well as the emotional wellbeing of the person is also part of the knowledge. Within person-centred care the nurse is also supposed to empower patients and their next of kin in the entire health care process [35]. For children with communication and social interaction problems, it implies that the parents of the child would be consulted as partners in the care to glean knowledge about the child [96].

In the learning objective skills, the nurse should have the skills to grasp the person’s values, preferences and needs and to communicate that to the rest of the health care team. The nurse should be sensitive to and care for the person with empathy. Included in these skills is also the task to ameliorate the organisational culture so that person-centred care is part of the culture of the organisation [35]. The nurses’ necessary preconditions mean that the nurses are professional, knows him/herself and has developed skills in interpersonal relationships [112].

In the attitudes part of the learning objectives, is the willingness to value the health care situation from the person’s perspective. To respect and encourage the person to express their needs and acknowledge the person as an expert on their own health and needs [35, 113]. Another important aspect is to understand one’s own attitudes when working with persons from diverse backgrounds and views on life. To honour the person’s and significant others’ partnership in all aspects of the care and to critically reflect on all aspect of the care and to take in ethical consideration in the care permeates all of the learning objectives [35].
Translating this to paediatric care it can be described as a child-centred care approach, which means that it is the child that is in focus. The nurses view the child as a person belonging to a family [39].

Person-centred care is in line with The European Association for Children in Hospital (EACH) charter for the care of children in hospitals. This charter is in accordance with the UN Convention on the Right of the Child [114]. This charter states the right of the child to have their parent or guardian with them 24 hours a day, while admitted to a hospital and for the child and the parents to be involved in the care [41]. To cope with the experience of being in a high technology environment in the hospital, children need their parents as a social support [2, 16].

**Person-centred care in a high technology environment**

In the high technology environment, such as radiographic and anaesthesia environment, the benefit of parental presence is discussed. [115-119]. One of the reasons is that frightened parents can increase the anxiety in the child [115, 120, 121]. Working according to the principles of person-centred care in the radiographic environment, the parent is present and seen as adding to the safety of the environment [25, 88]. The parents can be involved in the care, helping with distraction, positioning and comforting the child [25, 88]. Younger children especially benefit from having a parent present during radiographic procedures and at anaesthesia induction. A child’s sense of security increases with parents being present in the radiology and anaesthesia department [19, 116]. At anaesthesia induction, the anxiety level of children was recorded as the same with or without parental presence. However, for those children separated from their parents, the child’s anxiety peaked at the time of separation [122]. Person-centred care in the anaesthesia department means that children have the right to have their parents present with them at anaesthesia induction until they are put to sleep and thus there will not be any separation and no anxiety for that reason [116, 117, 123]. Behavioural preparation for children and parents reduces the anxiety for the children, both pre-and postoperatively [117]. In Sweden, parental presence at anaesthesia induction has been routine for a long time [123].

To incorporate a child-centred care, it is important to have both a child-focused perspective and a child’s own perspective. The child perspective can
be seen as parents and nurses having the best interest of the child in focus without actually asking the child. A child’s perspective can be seen when the child is involved and asked about their opinion [38, 124]. It is important to listen to the voice of children and to promote the human rights of the child with a disability to be heard [125].

The best interests of the child should always be taken into consideration [41, 114] and the care should be adapted to the individual needs of the child and mitigate physical and emotional stress in the child. This does not just imply that the children have the right to have their parents with them at all times in the hospital, it also states that nurses should create a partnership with the parents and the child in their care of the child. Both the child and parents should be able to participate in the care in a manner that is appropriate for their level of understanding. [41]. In order to accomplish this, evidence-based guidelines could be a tool for the nurses.

**Evidence-based care**

Evidence-based practice is defined by Cronenwett (2009) as using the combination of evidence and clinical expertise in the care where the preferences and values of the patient and family are integrated in order to deliver optimal care [35]. The nurses should be able to analyse how the existent evidence affects the provision of care and how the organisational culture affects the provision of evidence-based practice and be able to critically reflect on all aspects of the care [35].

The use of evidence-based guidelines in connection with a procedure has the effect of decreasing anxiety in children when they come to the hospital for a procedure, and equips health care professionals with skills to manage these children in a stressful situation and avoids the use of physical restraints [126]. In the International Council of Nurses’ (ICN) code of ethics it is stated that: “The nurse demonstrates professional values such as respectfulness, responsiveness, compassion, trustworthiness and integrity” (page 2). “The nurse is active in developing a core of research based professional knowledge that supports evidence-based practice (page 3)” [127].

In order to implement guidelines in the clinical setting, the health care professionals need to acknowledge that there is a problem that needs to be
addressed [128-130]. There is also a need for the organisation to buy into the need for guidelines and to promote the implementation of those and the managers to support the use of the guidelines [128-132]. Nurses need education to enhance their skills to implement clinical guidelines in practice [133]. Hindering factors for the implementation of guidelines can be lack of resources such as a shortage of personnel, a heavy workload and a lack of education [132, 134, 135]. An environment not equipped to work according to the outline of the specific guidelines, can be another factor obstructing implementation of evidence based guidelines [134]. Guidelines need to be perceived as beneficial and reliable for nurses to implement them. To facilitate the implementation of guidelines, the structure of the guidelines needs to be accessible [129, 131, 132, 136, 137]. Collaboration with other health care professionals is important for nurses to implement clinical guidelines [133] and feedback of results from the managers is another factor seen as vital for a successful implementation of guidelines and that all the health care professionals are involved in the creating of the guidelines [129, 131, 132, 134, 136]. Persistent, ongoing support from passionate leaders, is an essential condition for successful implementation of clinical guidelines [131, 137, 138].

According to the Health and Medical Service Act of Sweden, the health care system is supposed to fulfil the requirements for good care [139]. Within the scope of practice for a radiographer and a nurse anaesthetist in Sweden it is stated that they are to practice according to experience and evidence-based practice. They are also to develop the care and implement evidence-based research into their practice [140, 141]. Evidence-based guidelines are used to improve quality and patience safety in health care [126, 142].

**Symbolic interactionism**

According to symbolic interaction the individual is seen as a thinking, active participant in the environment. Social reality is created in symbolic interaction with others and reality is seen through the meaning of symbols. Human behaviour is explained with more focus on interaction than personality and society’s impact on individuals [55]. Interaction can be regarded as a shared code of ritual conduct that governs our interactions with each other. These shared rituals are necessary for us to understand each other. The symbols used in interactions are words and body language. When we understand and use these shared codes, they create mutual trust and build and sustain social
relationship [55]. Another key element is taking the role of the other which is to understand the other's perspective and it is one of the keys to successful teaching, support and empathic behaviour. It also helps the person to understand how one's own actions affects others [55, 143]. Knowledge is seen as pragmatic, and those actions tested and working for the individual are remembered and learned [144].
Rational for the thesis

Children with ASD have the same rights as children with typical development to be cared for according to their specific needs [42, 114]. Children with ASD have difficulties with social interaction and understanding verbal and non-verbal communication, a dependence on routines and sensitivity to sensory stimuli. However, there is a wide range in the level of the manifestation of these deficits within the ASD definition. It can vary from slight difficulties with communication to an almost complete inability to interpret verbal and non-verbal communication [8]. Children with ASD and their parents struggle in their contacts with the health care system [10, 11] including difficulties navigating the health care system [10, 11, 145] or nurses lack of knowledge about the problems associated with ASD that causes a problem in the interaction with the child [10, 49, 146]. The care of the child might be dependent on who is working when the child comes to the department, if the child is cared for according to their specific needs or not [10, 146]. When the health care professional does not listen to the child and parents, it can lead to frustration and ultimately to an uncooperating and challenging behaviour in the child [10, 57]. The ultimate result can be that the child will be physically restrained for a procedure which might be traumatic for the child, the parent and the nurse [10, 31, 147]. There is limited research on how to care for children with ASD in a high technology context, especially in the radiology context, where a child is cared for without sedation or anaesthesia. To improve the care of children with ASD and try to deliver good care on equal terms and according to the Health and Medical Services Act [139] and in line with the UN Convention on the Rights of the Child [42, 114], there is a need for evidence based guidelines on how to care for children with ASD in the high technology environment.
Overall aim

To audit and enhance the care of children in a high technology environment in the health care systems with a focus on children with Autism Spectrum Disorder.

Specific aims:

- To describe the care of children and children with ASD in a high technology context from nurses’ perspective (Study I, II and IV).
- To describe the care of children with ASD in a high technology context from a person-centred care perspective (Study I, II, III and IV).
- To describe the care of children with ASD in a high technology context from an organisational perspective (Study I, II, III and IV).
- To enhance the care of children with ASD in a high technology context through developing evidence-based guidelines (Study IV).
Methods

Design

In order to answer the overall aim of the thesis and the research questions a descriptive design was used. In the first study a qualitative method, Critical Incident Technique (CIT), was used to explore the actions of nurse anaesthetists and their experiences in connection with caring for children. To gain knowledge on the situation in Sweden regarding the care of children with ASD in high technology environments, a cross-sectional design was used and two national surveys were performed [148]. With the lack of guidelines in the high technology environment the creation of evidence-based guidelines were performed using the Delphi method [149, 150]. The Delphi study was based on the information gleaned from the previous studies and from a literature review. An overview of the structure of the studies are presented in Table 1 and the relationship between the studies is presented in Figure 1.

In Study I it was only nurse anaesthetists who were interviewed. In the results, they are regarded more broadly as nurses working in a high technology context as that is the focus in this framework. Children in general were the core group in Study I, and children with special needs such as ASD were identified as an extra vulnerable group. This led up to the focus on this group of children in this research and ultimately the creation of guidelines for children with ASD to support children, parents and nurses when a child with ASD comes to a high technology health care environment (Study IV). The ontological and epistemological frameworks are in nursing science and have a holistic view on reality [148]. The base is a naturalistic perspective where reality is seen as a complex entity [148, 151].
Overview

In order to answer the aims of the thesis the following designs were used:

- A Critical Incident Technique was used to explore nurses’ views of managing children in the anaesthesia context (Study I).
- A survey method was used to describe and investigate the management of children with ASD from an organisational perspective (Study II and III).
- The Delphi method was used to develop guidelines for the management of children with ASD in the anaesthesia and radiology context (Study IV).
Table 1. Overview of the structure of the studies,

<table>
<thead>
<tr>
<th>Study</th>
<th>Aim</th>
<th>Design</th>
<th>Participants</th>
<th>Data collection</th>
<th>Data analyses</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>To explore nurse anaesthetist’s experiences and actions when administering and caring for children requiring anaesthesia</td>
<td>Descriptive qualitative approach</td>
<td>(n=32) CRNAs from three different hospitals</td>
<td>Interviews according to Critical Incident Technique</td>
<td></td>
</tr>
<tr>
<td>II</td>
<td>To describe the current set of guidelines for the preparation and care for children with ASD in the perioperative setting across Sweden as well as explore the content of these guidelines in detail.</td>
<td>A nationwide survey in anesthesia and pediatric departments of the existence of guidelines</td>
<td>Anesthesia department (n=68) and pediatric departments (n=38)</td>
<td>A web based questionnaire and telephone calls</td>
<td>Descriptive statistics and content analyses</td>
</tr>
<tr>
<td>III</td>
<td>To investigate the prevalence of guidelines and routines used nationwide when children with ASD are taken care of and examined in the Radiology Department during the peri-radiographic process.</td>
<td>The study has a quantitative design. A nationwide survey of radiology departments</td>
<td>(n=94) Radiology departments throughout Sweden</td>
<td>A web based questionnaire and telephone calls</td>
<td>The data was scrutinized, using descriptive statistics.</td>
</tr>
<tr>
<td>IV</td>
<td>To develop guidelines to better care for children with ASD, particularly regarding these children’s preparation for anesthesia and radiographic procedures</td>
<td>In this study a modified Delphi method was used</td>
<td>(n=21) Experts in anesthesia and radiology department and from ASD interest group</td>
<td>Three rounds of web based questionnaires</td>
<td>Descriptive statistics and content analyses</td>
</tr>
</tbody>
</table>

ASD= Autism Spectrum Disorder; CRNA= Certified Registered Nurse Anaesthetists
Study I
To explore nurse anaesthetist’s experiences and actions when administering and caring for children requiring anaesthesia.

Study II
To describe the current set of guidelines for the preparation and care for children with ASD in the perioperative setting across Sweden as well as explore the content of these guidelines in detail.

Study III
To investigate the prevalence of guidelines and routines used nationwide when children with ASD are taken care of and examined in the Radiology department during the peri-radiographic process.

Study IV
To develop guidelines to better care for children with ASD, particularly regarding these children’s preparation for anesthesia and radiographic procedures.

Figure 1. Relationship between the four studies
Participants

Study I

A purposeful sampling was used to get maximum variation in demographic data (Table 2). Altogether, 32 Certified Registered Nurse Anaesthetists (CRNA) from three different departments were included in the study. The head of each of the three departments was contacted with information about the study and they all gave their approval. Further information was sent to the head of each department who then gave the information to CRNAs and asked for participation. The head of department was asked to select participants to get as wide a variation as possible. The percentage of female CRNAs is higher than male CRNAs which made an impact on the sample [152].

Table 2. Sociodemographic and professional data of the nurse anaesthetists presented as numbers

<table>
<thead>
<tr>
<th>Age range</th>
<th>Female /Male</th>
<th>Years of experience as a CRNA</th>
<th>Working in a children’s hospital/general hospital</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>3-5</td>
<td>6-10</td>
</tr>
<tr>
<td>31-40 yr</td>
<td>7</td>
<td>4/3</td>
<td>2</td>
</tr>
<tr>
<td>41-50 yr</td>
<td>14</td>
<td>12/2</td>
<td>3</td>
</tr>
<tr>
<td>51-60 yr</td>
<td>9</td>
<td>9/0</td>
<td>1</td>
</tr>
<tr>
<td>&gt; 61 yr</td>
<td>2</td>
<td>1/1</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>32</td>
<td>26/6</td>
<td>6</td>
</tr>
</tbody>
</table>

CRNA = Certified Registered Nurse anaesthetists
Study II and III

A population-based sample was used since all anaesthesiology departments (n= 68), and paediatric departments (n= 38) in Sweden were included in the sample. In the survey of the radiology departments all departments performing more than 100 000 radiographic examinations a year (n=94) were included. In total 200 questionnaires were distributed and the chairpersons at each of the departments received the surveys. The instructions to the chairpersons at the anaesthesia, paediatric and radiology departments was to forward the questionnaire to the appropriate person within his or her department, if he or she did not readily possess the applicable information. The distribution of the questionnaire was followed by a phone call to non-responders. In total 93 phone calls were made.

Finally, eight of the anaesthesia departments only answered the initial questions in the questionnaire, since they did not anaesthetise children (or, more relevantly, children with ASD) and the instructions were then to end the response. Among the paediatric departments, one paediatric department did not provide surgical care for children, and another department did not care for children with ASD. They only cared for children younger than 12 months (36). In the radiology departments eight departments did not respond resulting in 86 responses (Table 3).

Table 3. Number of departments responding to the questionnaire from anaesthesia, paediatric and radiology departments (n=192)

<table>
<thead>
<tr>
<th>Type of Department</th>
<th>Caring for children with ASD</th>
<th>Not caring for children with ASD</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anaesthesia Department</td>
<td>60</td>
<td>8</td>
<td>68</td>
</tr>
<tr>
<td>Paediatric Department</td>
<td>36</td>
<td>2</td>
<td>38</td>
</tr>
<tr>
<td>Radiology Department</td>
<td>46</td>
<td>40</td>
<td>86</td>
</tr>
<tr>
<td>Total</td>
<td>142</td>
<td>50</td>
<td>192</td>
</tr>
</tbody>
</table>

ASD=Autism Spectrum Disorder
**Study IV**

A sample of 30 persons were approached to participate in a Delphi study for creating guidelines for caring for children with ASD in a high technology context. Health care professionals working with children with ASD were identified from the surveys (Study II and III). Two researchers working in the area of ASD and one person representing the Swedish Autism and Asperger Association were also approached. In the first questionnaire, 19 experts responded where some of the responses were returned anonymous. Two of the anonymous responses could have come from four experts so questionnaire number two was distributed to all four experts to make sure everyone who responded to questionnaire number one also got questionnaire number two. All the experts who got the second questionnaire responded. The final sample was 21 experts from different hospitals in Sweden. Five of the experts came from radiology departments, and 15 experts came from anaesthesia departments with one from the Autism and Asperger Association. Four of the participants had relatives with ASD. There were no experts included from the paediatric departments since the aim was to create guidelines for a high technology environment and the paediatric department was not considered a high technology environment. Table 4.

Table 4. Demographic data of participants in the Delphi study

<table>
<thead>
<tr>
<th>Demographic aspects</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nurse Anaesthetist</td>
<td>14</td>
</tr>
<tr>
<td>Radiographer</td>
<td>5</td>
</tr>
<tr>
<td>Other profession</td>
<td>2</td>
</tr>
<tr>
<td>Relatives to a person diagnosed with ASD</td>
<td>4</td>
</tr>
<tr>
<td>Female</td>
<td>20</td>
</tr>
<tr>
<td>Male</td>
<td>1</td>
</tr>
<tr>
<td>Age</td>
<td>m = 54 year; range (38-67)</td>
</tr>
<tr>
<td>Working experience</td>
<td>m= 30 year; range (14-43)</td>
</tr>
</tbody>
</table>

m=mean;
Data collection

*Critical Incident Technique (Study I)*

Critical Incident Technique (CIT) was developed by Flanagan at the end of World War II to identify successful behaviour from the most competent pilots in the United States Air Force during critical incidents to solve practical problems [153]. CIT should be looked at as a set of principles which must be flexible for the given situation. CIT is a procedure to collect important facts about human behaviour in specific situations and the situations should be well defined and the goals of the actions clear. Flanagan (1954) has described five steps; 1. Identification of the general aim of the study; 2. Planning and specifications; 3. Data collection; 4. Data analysis; 5. Interpreting and reporting [153]. The method can elucidate aspects of best and worst practice in nursing, and help nurses to understand their role in the interaction between nurses and patients [154]. Different data collection methods can be used such as observations, interviews and written self-reports [153].

In this study, data was collected using semi structured interviews by the researcher and were digitally recorded. The interviews were transcribed verbatim by a secretary. Two test interviews included in the study were performed to ensure that the questions and the interview technique would capture the required information. The interviews ranged in duration from 9 minutes to 60 minutes and the CRNAs were informed prior to the interview that the questions would focus on critical incidents in relation to anaesthesia induction in children. The CRNAs were asked to describe critical incidents in children age 3-12. The opening question was: “Can you tell me an incident when you were giving anaesthesia to a child where you felt that the child was calm going to sleep?” Likewise, “Can you tell me an incident where you felt that it wasn’t good, the child did not cooperate and was anxious going to sleep or you had to cancel the surgery due to the child being too anxious?” Follow up questions were given to clarify an incident. The time frame for the situation chosen to find incidents that met the aim was from the first encounter with the child through to anaesthesia induction.
Survey research (Study II and III)

Surveys are commonly used to gather information from a population in health services [155]. The information is gathered with direct questioning by means of self-report. Any information that can be trusted as self-reported can be obtained by means of a survey. The data can be collected in different ways such as personal interviews, telephone interviews or questionnaires. A common use of surveys is to describe a certain phenomenon at a certain time [148, 155]. When using a questionnaire, the wording of the questions should be done with care, avoiding ambiguous phrasing. It is important not to ask two questions in one, but each question should be phrased in a way that is clear and precise. The questionnaire should preferably be tested with colleagues or as pilot in a small group in the research population [155]. In this study the questionnaire was tested with a colleague before disseminated to the respondents.

To create a questionnaire, the researcher needs to have knowledge about the research area. In addition to the questionnaire, the responders should receive a cover letter with information about the aim of the study, investigator contact details as well as an indication of how the information will be used [155].

Nationwide cross-sectional surveys were performed, using the web questionnaire tool esMaker®, to explore the existence of guidelines for caring for children with ASD in the health care system. A questionnaire asking for the existence of guidelines for caring for children with ASD was sent out to all anaesthesia, paediatric and radiology departments performing >100 000 examinations per year in Sweden. The departments were asked to attach any guidelines and state the name of any person working with these children. The questionnaire (Appendix A and B) contained a field for comments on how the departments worked with these children or comments could be emailed separately to the contact person. The chairpersons at the anaesthesia, paediatric and radiology departments received instructions to forward the questionnaire to the appropriate person within his or her department, if the chairperson did not readily possess the applicable information. The web-based survey to the radiology departments was sent by email to some and by postal mail to others (Figure 2). Two reminders were sent by email to all participants with a listed email address and by postal mail for those without listed email addresses. Departments that did not respond to the questionnaire received a
follow-up phone call to ensure that all information would be obtained. The internal drop-out rate was 10 (9.6%). In all, 192 completed questionnaires were analysed within this study: 68 from anaesthesia departments, 38 from paediatric departments and 86 from radiology departments. Ultimately, eight anaesthesia departments were unable to participate beyond completing the initial questionnaire, since they did not anaesthetise children with ASD and, thus, had little information of relevance. Similarly, one paediatric department did not provide surgical care for children, and another department did not care for children with ASD (Table 3).

![Figure 2. Overview of emails and phone calls](image)

**Delphi method (Study IV)**

The Delphi technique is named after the Greek god Apollo who had the ability to predict the future [156]. The technique was developed by Olaf Helmer, Norman Dalkey, Ted Gordon and associates in the 1950s at the Rand corporation in California where it was used by the US Air Force [157]. The Delphi technique is a method used to develop consensus among researchers in an area with limited evidence or contradicting evidence. The method is a group of experts working together to reach consensus. The group will work independently of each other and the viewpoints are collected and presented as the view of the group, with no individual mentioned [149, 158]. The Delphi technique uses multiple rounds of surveys with controlled feedback and with the interpretation of the experts’ opinions sent back to the expert panel. These
survey rounds may be iterated for several rounds until consensus are reached or the predefined numbers of rounds are fulfilled. Using the internet for sending surveys is cost- and time effective [159] and these rounds should be iterated for a maximum of four rounds.

In Study IV consensus was decided to 60% agreement in the first round and 80% agreement in the following two rounds [160]. See Figure 3 for details.

**Figure 3. Flowchart of the process in creating the guidelines**

**The first round:** Items from the literature (Table 5 and 6) and from the surveys (Study II and III) were identified to create the first round. From the surveys items were extracted from the two guidelines attached to the questionnaire and from the comments in the questionnaire. The questionnaire was discussed in the research group before the final version was created. The questionnaire also included demographic questions before the items were presented. Included in those items was a checklist of 15 different aspects. The
questionnaire was emailed to the identified experts using the tool esMaker®. The experts were instructed to answer “yes” or “no” to the question if the item should be part of the guidelines and insert or email comments to the researcher. A reminder was emailed one week after the initial questionnaire.

The second round of the questionnaire was created from the ratings of the first round and comments of the same. The experts had three alternative answers to choose from these items: “1. To be included, 2. To be rephrased, 3. Not to be included”. They were also invited to add comments. The second questionnaire was emailed to the experts plus another two experts from the first round.

The third round of the questionnaire was created from the ratings of the second questionnaire and requested that the experts answer yes” or “no” to the question whether the item should be included in the guidelines or not. The experts could also comment on the items. The third questionnaire was emailed to the experts with a reminder two weeks after the initial questionnaire. After a reminder, all experts responded.

Analyses

Critical Incident Technique (Study I)

The transcribed interviews were read by the researcher at the same time as listening to the digital recordings to ensure credibility since the interviews were transcribed by a secretary. The data were read over and over again for the researcher to become familiar with the content. Critical incidents were identified and grouped into experiences and actions (n=193). Within respective group, the incidents were registered either as successful behaviour or unsuccessful behaviour. Meaning unites were extracted from the behaviours. According to CIT [161] the behaviours were compared in order to find similarities and differences and grouped together in subcategories. The subcategories in Experiences; (n=16) and in Actions; (n=25) were then compared for similarities and differences and then grouped into categories (Experiences; n=6 and Actions; n=6). From the categories emerged two main areas in both Experiences and Actions.
Content analyses (Study II)

Content analysis is a systematic way of compiling a body of text, images and symbolic matters. Content analysis can be used both as a quantitative and a qualitative method. When used as a qualitative method it can be used with a deductive or inductive approach [162]. The text analysed with qualitative content analysis can be obtained from interviews, narratives, open-ended surveys, focus groups, observations and from books and other literature, that is any written text [163]. Hsieh & Shannon (2005) describes three different types of qualitative content analysis. Those are conventional content analysis, directed content analysis and summative content analysis. In Study II, conventional content analysis has been used. It can be described as inductive content analysis and is best used when existing research about the phenomenon is limited. The researcher immersed themselves in the data and derived codes, subcategories and categories. Conventional content analysis according to Hsieh (2005) was used to analyse the guidelines and the comments given by the responders in the survey (Study II) [163].

The first step in the analysis process was to repeatedly read the comments and guidelines to get a sense of the whole. The next step was to identify meaning unites, from those meaning unites develop codes and grouped the codes together to subcategories. The subcategories were then sorted in groups with similar content to create categories. Two researchers independent of each other organised the subcategories into categories. These categories were then discussed to reach a negotiated consensus according to Bradley (2007) [164]. The subcategories and the categories were also discussed in the larger research group and a consensus was reached as per Figure 4.

![Figure 4. Overview of analysis model](image-url)
Survey research (Study II, III and IV)

Descriptive statistics was used for analyses of the quantitative data in Study II, III and IV. The comments in Study IV were compiled and taken into account when rephrasing the items. There were no guidelines present and only a few comments in Study III, hence only quantitative analyses carried out. Descriptive statistics using SPSS was used in Study III. In Study IV descriptive statistics was used to decide which the items should be kept or discarded. The study was carried out in three rounds.

Delphi method

The levels considered for agreement was 60% for the first round and 80% agreement for the two subsequent rounds [160].

In the first round in Study IV those items that had received an agreement level of 60% or more were used to develop round number two (Table 5 and 6).

In the second round those items receiving an agreement level of 80% or more were used for the third round. The item “During preparation it is important that the Health Care Professionals encourages the child in an appropriate way” was discarded (Table 5 and 6).

In the third round, items with an agreement level of 80% or more were used for the final guidelines and two items were discarded. These items were “Health Care Professionals are responsible for asking the parents if they need any extra support in connection with the health care visit,” and “The Health Care Professionals can preferably support the child in their use of self-calming or coping strategies.” Consensus was considered to have been reached at this stage (Table 5 and 6).

The same procedure was applied to the checklist, resulting in one aspect being removed. This aspect was “How the child shows confidence in someone”. The remaining aspects received from 0 to 3 “no” responses. The final guidelines consisted of 14 items and a checklist containing 16 aspects, (Appendix I and II).
For the overall aim and specific research questions in this thesis, a second analysis was performed. A deductive analysis method was used with the 4 studies and the characteristics of ASD as an analysis template.

Table 5. Overview of the level of agreement between the Delphi rounds

<table>
<thead>
<tr>
<th>Rounds</th>
<th>Total number of items</th>
<th>Number of items with &lt; 60% agreement</th>
<th>Number of items with 60-80% agreement</th>
<th>Number of items with 80-100% agreement</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>86</td>
<td>17</td>
<td>19</td>
<td>50</td>
</tr>
<tr>
<td>2</td>
<td>42</td>
<td>0</td>
<td>1</td>
<td>41</td>
</tr>
<tr>
<td>3</td>
<td>33</td>
<td>0</td>
<td>3</td>
<td>30</td>
</tr>
</tbody>
</table>

Table 6. Description of the process of creating the checklist

<table>
<thead>
<tr>
<th>Processes</th>
<th>Total number of items</th>
<th>Items transferred from round 1 to round 2</th>
<th>Items deleted</th>
<th>Number of merged items</th>
<th>Number of items added</th>
<th>Total numbers to next round</th>
</tr>
</thead>
<tbody>
<tr>
<td>Round 1</td>
<td>86</td>
<td>23</td>
<td>18*</td>
<td>45➔15</td>
<td>4</td>
<td>42</td>
</tr>
<tr>
<td>Round 2</td>
<td>42</td>
<td>26</td>
<td>1</td>
<td>15➔7</td>
<td>0</td>
<td>33</td>
</tr>
<tr>
<td>Round 3</td>
<td>33</td>
<td>30</td>
<td>3</td>
<td>0</td>
<td>0</td>
<td>30</td>
</tr>
</tbody>
</table>

*= One item with agreement was discarded, that was the item; I,” Special guidelines for caring for children with ASD are needed”
Ethical considerations

Research is performed to gain new knowledge. In order to have the best health care possible, research is needed to evaluate the treatments procedures and methods to ensure that the best possible care is given to patients. The studies (I-IV) follow the principals from the Helsinki Declaration [165]. In Sweden, there is no need to ask for ethical approval from an ethics board if the study does not have an intent to make a physical or psychological impact, and a written consent from the participants is obtained [166].

The principle of autonomy, the principle of non-maleficence, the principle of beneficence and the principle of justice are guiding principles in nursing research [167].

There are always ethical considerations in research whether the research includes human beings. The aim of the research needs to be clear so that the researcher knows what the knowledge can be used for. When the research includes human beings, it is of utmost importance to protect the rights and basic freedom of all humans [166]. The well-being of the individual involved in the research must be more important than anything else.

In all research the individual must have all information available about the research project to be able to decide if they want to participate or not and to know the impact of participation. Certain caution should be taken to make sure the information method is appropriate for the individual and that the individual is not dependent on the researcher in any way. At the end of the project the participants are eligible to know the result of the research [165].

The researcher should not have any conflicting interests that might influence the result of the research outcome. The researcher should have appropriate scientific knowledge and knowledge about the research methods used [166], because it is not ethical to perform research without proper knowledge and indeed the outcome of the research might in that case not be of quality; even improper results may come out of the project.

The principle of autonomy prevents the right to self-determination of man. It guarantees a respect for the integrity of the person. It includes the
voluntariness of the participants in research. [167]. It is critical to protect the
dignity, the confidentiality, the privacy and self-determination of the
individual [165] and in this research project the confidentiality of the persons
involved is guaranteed. The data are stored in a locked fire proof cupboard
and on a safe database. No individual can be identified in the findings
presented (Study I-IV).

In Study I where nurse anaesthetists were interviewed, the directors at each
hospital gave approval for the study to be carried out in their departments.
Participants received information by postal mail about the purpose of the study
and that participation was voluntary, data confidentiality was ensured and that
they had the freedom to withdraw without giving any reason. Written consent
was obtained. For Study II and Study III sending in guidelines and answering
question on opinions of how to take care of children with ASD was not seen
as an ethical issue. Participants were free to decide whether to answer or not.
In Study IV the names of all participants were confidential. Each respondent
only knew what she/he answered and did not know who the other participants
were.

**The principle of non-maleficence** means that the research should not do any
harm [167]. The research has been carried out in a research group with
knowledge and experience of research. This would prevent distorted research
methods that can cause harm. None of the participants can be identified which
potentially could have caused distress to the person.

**The principle of beneficence** means that the research should do good for the
individual or society [167]. The research (Study I-III) leading up to guidelines
(Study IV) for enhancing the care of a vulnerable group of children is seen as
leading to benefit for children, parents and health care professionals.

**The principle of justice** means that the researcher has to protect vulnerable
persons or groups [167]. Study I-IV has not included any vulnerable
individuals or groups as participants. However, the aim of the research was to
enhance the care for the vulnerable group of children with ASD, which means
that the principle of justice is adhered to.
Result

High technology dependent departments, such as radiology and anaesthesia departments, can be a frightening environment for children (Study I). Nurses identified children with special needs such as children with ASD as a vulnerable group in the high technology context (Study I). None of the radiology departments in Sweden had guidelines on how to care for children with ASD going through a radiographic examination without anaesthesia (Study III). Seven departments in the anaesthesia context had guidelines for caring for children with ASD in the perioperative context. In the other departments, the care of children with ASD was dependent on the knowledge of the nurse presently working there (Study II). As a result of Study I, II and III, the need for structured guidelines for caring for children with ASD in a high technology context was identified and a set of guidelines and a checklist was created. The guidelines relate to the organisational structure for the care of the children with deficits in social interaction, communication, sensory sensitivity and dependence on routines. The checklist relates to gleaning information about the specific child to be able to give person-centred care based on the specific characteristic of the child (Study IV). See Tables 7 and 8 for guidelines and checklist related to characteristics with references and Appendix I and II for the guideline and checklist.

Care of children in a high technology environment from a nurse perspective (Study I, II and IV)

In the care of children, the nurses described that their main focus was to create a rapport with the child. The nurses talked about the importance of seeing the specific child, prioritized the needs of the child and acted accordingly. “The important thing, I think when you meet a child it is to meet the child at the child's own level, it is very important no matter what age, not to intrude, be very sensitive to what their boundaries are and slowly approach them. You have a short time to somehow get a communication and it does not always need to be a verbal communication” (Study I). To evaluate the situation and change their actions to fit how they interpreted the needs of the child and the situation was described by the nurses. It could be the mode of anaesthesia induction or how they used time and equipment. Refraining from using
frightening equipment before it was absolutely necessary was another example of the way in which they optimised the situation (Study I). This was a general overarching approach described when caring for all children. However, working with children diagnosed with ASD the nurses talked about the need of specific knowledge about the manifestations of ASD in order to care for the child in an appropriate way (Study II, IV). This need is addressed in the guidelines where it is stated that those nurses working with children with ASD need this knowledge about the characteristics of ASD, such as difficulties with communication, social interaction, sensory sensibility and dependence on routines (Study IV). There were also nurses commenting that they did not think they needed any specific knowledge about ASD. They cared for all children according to the specific needs of each child, but after a day of education the nurses realized that they needed this specific knowledge (Study II).

Distraction was described as a strategy that was used in different ways to divert the child’s attention from the procedure being performed. Available devices such as watching video, playing videogames and choosing stickers were used. Finding out and talking about the child’s interests was another way distraction was described (Study I). The expert panel found it important that any special interest a child with ASD had would be known to the nurse who cared for them. One aspect in the checklist was to investigate the child’s specific interests (Study IV). An example described by a nurse was the child’s special interest in videogames and that was used as a distraction during the procedure (Study I).

One of the categories in Study I was to create participation: to make the child an active participant in the situation. The nurses involved the child in the situation by asking the child to be responsible for a task. “Then I asked if she could remove her band aids herself and she did” (Study I). One of the items in the guidelines address ways of communicating with a child with ASD (Study IV). The Delphi panel wanted to have an example of how to phrase a clear statement that is understandable for a child with ASD. See item 11 in the guidelines (Study IV).

To have knowledge about ASD when caring for a child with ASD was addressed in Study I, II and IV. In the category information transfer in Study I, the nurses talked about the importance of knowledge about the child with
special needs such as ASD (Study I). Sometimes nurses themselves took the initiative to transfer information and knowledge about a child to another colleague in order to enhance the care of a child (Study I, II). To use their own knowledge and skills as nurses was described as “I use my own knowledge and skills as a nurse” (Study II). The expert panel stated that health care professionals should have knowledge about ASD in the care of children with ASD (Study IV). In some cases, the opinion from the nurses was that all children were cared for in the best way, so a specific care plan for children with ASD was not needed (Study II). However, the nurses also found it frustrating when they met a child and then realized the child had ASD and that they could not care for the child in a way they were satisfied with. “and it is like …this doesn’t work, this doesn’t work, this doesn’t work”! (Study I).

A lack of the necessary conditions to prepare the child with ASD sometimes led nurses to use physical restraint for anaesthesia induction (Study I and II). “If it doesn’t work you use mask induction against the resistance of the child “run over them” (Study II). “So we had to physically restrain him then and inject (the anaesthesia drug) but you do not feel good, you feel that this is so wrong”. (Study I). From a nursing perspective, this affected their working environment negatively. They felt they could not do their job in a proper way and they felt they were doing a bad thing instead of working according to their ethical code.

Care of children with ASD from a Person-Centred Care perspective (Study I, II, III and IV)

To see the individual child and modify the care according to the need of this specific child taking the child and the parents as equal partners in the care is the core concept of person-centred care. The parents were described as particular important actors in the creation of person-centred care for children with ASD. The parents were asked to be an active participant in the preparation and the tailoring of a specific care plan addressing how to best care for the child. The specific areas covered were: communication, social interaction, sensory sensitivity and dependence on routines (Study I, II, III, IV). To create an individualized care plan for each child was the core concept that permeated the existing guidelines (Study II). Creating a plan included collaboration with the parents to glean knowledge about the child to better facilitate preparation and care. This was seen in all four studies (Study I, II,
III, IV). “They listen to the parents (description of) how it is and create a tailored plan according to that” (Study II). Participation of both the child and parents was seen as important by the nurses and the expert panel (Study I, II, IV). The parents were asked to be active participant in the preparation and the child was able to be part of the decision making. When the plans were made together with the child and the parents the anxiety associated with the procedure was reduced (Study I, II). “We take wishes and anxieties into account and when the arrangements are planned it is done together with the child and the parents” (Study II). For the health care professionals to initiate contact with the parents in order to prepare for the procedure in cooperation with parents’ recommendations was described (Study I, II, III, IV). “And I was in contact with his mother first, I did not meet the child in advance, but it was his mother I meet and I got all the information from her. And [then we] took pictures [of me and the environment] then she went home and prepared the child at home” (Study I).

This child specific plan included familiarising the child by arranging a visit to the department where the child could get to know the nurse and the environment before the procedure. When children are overly dependent on routines, such that deviations cause them anxiety, one way to address this problem is to familiarize the child with the health care environment and to the nurses prior to any treatments (Study I, II, III, IV).

Included in this plan was to make a conscious decision regarding sedative premedication depending on the specific child was part of the care. To evaluate the child and the use of sedative premedication according to the result of that evaluation was described (Study I, II, IV) ”We did not bring him into the operation theatre, but we waited in the holding area and then we could call the anaesthesiologist straight away and say that we needed to give Sufenta® to this boy, because that is what we did last time [and that worked]” (Study I).

Even without existing guidelines there were nurses talking about partnering with the child and with the parents to benefit the care (Study I, II, III). Without guidelines, the person-centred care became dependent on the ability or attitude of the nurse working at the time of the care (Study I, II and III).
To adapt the care according to the needs of the specific child was one way the care was described (Study I). The checklist was created as an aid to the nurses and the parents so that all aspects of the need of the child would be included in order to be able to provide person-centred care. The checklist covers the child’s communication pattern, social interaction, sensory sensitivities and dependence on routines (Study IV).

**Care of children with ASD from an organisational perspective (Study I, II, III and IV)**

The organisation of the work can either facilitate or obstruct the possibilities to give high quality care to children with ASD in the radiology and anaesthesia context (Study I, II, III, IV). In the anaesthesia departments, seven out of 60 departments stated they had guidelines for preparing and caring for children with ASD. Of those seven departments, two sent in their guidelines (Study II). Of the paediatric or radiology departments, none had any guidelines for preparing and caring for children with ASD (Study II, III).

Having access to information about the child in advance is the first step to be able to prepare for the specific child and design the care to accommodate for the needs of the individual child (Study I, II, III, IV). One nurse expressed that “I did not know that [the child did not have any spoken language and was diagnosed with ASD] so I was taken by surprise” (Study I). In one department with guidelines there were structures in place to identify the child with ASD “When we get the notification about the scheduling for anaesthesia then we get in touch with the parents” (Study II). With early notification that a child with ASD was scheduled for a procedure in place, then there are possibilities for the nurses to prepare for the encounter (Study I, II, IV).

The absence of sufficient information about the specific child and their preferences in advance of the procedure obstructed the possibility for the nurse to make the needed preparations for the child (Study I, II, III). “I see when I approach [the child] to greet [him], that he is not really there and it turns out that he has autism” (Study I). “If it is a child coming for the first time we do not do anything special, we just hope for the best” (Study II). In other places a child with ASD could be identified if they came to the informational visit offered to all children (Study II). With sufficient information, the necessary preparations could be made to accommodate the child’s specific patterns of
communication, social interaction, sensory sensitivity and dependence on routines (Study II, III and IV). “In our routines, we offer a preoperative dialogue where we gather information and an individual plan is created together with parents, the surgeon and the staff” (Study II).

The planning of the care also included continuity in the nursing staff taking care of the child. One nurse described one occasion “And the guy came [with me] into the operating room and [he] is very curious, no problems, he comes running in the hallway and throws himself around my neck and calling [my name] out loud……and he puts on the pulse oximeter” (Study I). Nurses talked about the advantage of being familiar to the child as the child who is overly dependent on routines and familiarity meets someone he or she knows. The nurse also knows the child and has all the information needed to tailor the care for the child (Study I, II and IV). The nurses sent photos of themselves so the child, when coming to the hospital, would meet a familiar face (Study I, II). “(We) send a letter with a photo of the nurse anaesthetist who is going to anaesthetise the child” (Study II). “They had some pictures, they had got a photo of me in the mail so I guess he recognised me” (Study I). This became one of the items in the guidelines to address dependence on routines and the need for familiarity (Study IV). The nurse designated to take care of the child was specifically familiarised with him or her (as well as his or her particular needs). “The nurse anaesthetist with extra education on ASD who is going to anaesthetise the child is booked in latest two weeks in advance……this nurse takes care of the child pre- and postoperative and meet the child and parent for a preparation visit” (Study II).

If the child came for several procedures to the same department, the same nurse took care of the child whenever possible. Pictures, suitable for the child, were used to facilitate communication with the child (Study I, II). In the Delphi Study the expert panel agreed that there should be realistic pictures available as communication support for those children accustomed to the use of pictures as communication tools (Study IV).

The time allocated for the care of children in the department was decided within the organisation. There was not always enough time allocated (Study I, II) “They used to come for a preoperative visit, but that is discontinued because it takes too much time” (Study II) and “There is time pressure, the next surgeon is almost standing outside the door and knocking and wants to
come inside so I became stressed then” (Study I). This quotes illustrate how some organisations valued time. Time spent to prepare children for a procedure was considered to be waste of resources and time. Each procedure had an allocated time frame and to keep within this time frame could be stressful for a nurse when working with a child that needs longer time. For the organisation to allocate enough time for the procedure it is important to reduce the stress in the nurse and hence give the nurse a better chance to give good care to the child (Study II, III and IV).

According to the nurses, time management was important in the care of all children. For children diagnosed with ASD who are overly dependent on routines, it was extra important to avoid waiting time as well as having a stressed nurse working with the child trying to force the child to hurry up (Study I, II, III). It was likewise important to schedule the procedure at a time of the day that was suitable both for the child and the department (Study II, IV). Minimising waiting time that could stress the child was another important aspect of time (Study I, II, IV) “So a quarter to eight was I sitting out there and waiting for them, it wasn’t they who waited for me but I waited for them” (Study I).

For children with ASD it was of importance that the environment was adapted to minimise sensory stimuli for those children who are hyper sensitive to light, sound or other sensory stimuli (Study IV). With this in mind, it was also important to minimise the number of people in the proximity of the child (Study I, II, IV).

If for some reason the same nurse couldn’t care for the child all the time, the information about the child was passed on to the nurse caring for the child so it would provide consistency in the care (Study I, II). “We had talked quite much me and my colleague [about how to manage this] how we should do and what they had decided, for it was important for this child also to do it in the right order as they had decided” (Study I).
Enhancing the care of children with ASD through evidence-based guidelines (Study IV)

As a result of Study I, II and III, the need for structured guidelines for caring for children with ASD in a high technology context was identified and a set of guidelines and a checklist was created. The guidelines relate to the organisational structure for the care of children with problems with communication, social interaction, sensory sensitivity and dependence on routines. The checklist relates to gleaning information about the specific child based on the specific characteristic of the child. With this information about the child, it is possible to give person-centred care (Study IV). The guidelines were divided into 5 different areas.

In the area of challenges with communication the expert panel agreed on the importance of planning for the entire health care encounter from the preparation of the child through to the discharge of the child. All the planning should preferably be done in collaboration with the parent/guardian of the child. It is important to take the expertise of the parent/guardian into account. The health care professionals assigned to care for the child need to know the means of communication used by the child and this information can be gleaned from the parents. Pictures are mentioned in the study as one way to communicate with the child. These pictures should preferably be as realistic as possible. For children accustomed to pictures, those can be used as a support for the child to follow the procedure and be familiar with the routine. It is also important that the health care professionals know how to adapt their spoken language to the child’s level of understanding; it is important to use a distinct language and avoid using a symbolic language the child has difficulties interpreting. The first item on the checklist is to get the information on how the child communicates. The child’s likes and dislikes can be part of the communication. How to communicate to get the child to cooperate and the likes and dislikes of the specific child are aspects of the checklist. To get the information on how the child displays anxiety is also a part of communication and for the health care professionals to understand how to interpret the behaviour of the child in a correct way. See Tables 7 and 8 for further details.

The challenges with social interaction associated with ASD is also addressed in the planning together with the parents. The expert panel agreed on the following key points. The health care professional tasked with caring for the
child should have knowledge about the problems associated with ASD in social interaction, and especially the particulars of the specific child. The checklist consists of specific questions addressing the functioning of the specific child such as what works and what does not work in the social interaction with this specific child. There is also one item in the checklist about eventual cognitive impairment in the child. See Tables 7 and 8 for more details.

The characteristic **sensory sensitivity** is addressed in the planning where all knowledge about the functioning of the particular child needs to be taken into account. Addressing the sensory sensitivity in the child, there was a consensus in the expert panel for the importance to have a space at the department where sound and light can be adapted to the needs of the child. The health care professional working with the child needs to know how the child reacts to sensory stimuli. The checklist address this in questions regarding touch, sound and light. There is a specific question of what in the environment that makes the child anxious and what calms the child. See Tables 7 and 8 for details.

The characteristic of **routine dependence** is addressed in the planning together with the parents. Adding to the planning, the panel agreed that once the planning is done the structure of the plan should preferably be adhered to, since even small changes in routines and the environment can cause extreme anxiety in the child. Pictures can be used as a support for the child to follow the procedure and be familiar with the routine. The scheduling of time was another item to accommodate the needs of the child dependent on routines. The importance of an appropriate time for the health care visit was agreed on from the expert panel. That is to balance the different needs of allowing enough time for the encounter and at the same time minimise extended waiting time for the child. Both of these factors can cause unnecessary anxiety in the child. The child should also be allowed to bring a familiar object from home that the child is attached to. See Tables 7 and 8 for details.
Table 7. Items in the guideline related to characteristics and their supporting references

<table>
<thead>
<tr>
<th>Guidelines</th>
<th>Communication</th>
<th>Social interaction</th>
<th>Sensory sensitivity</th>
<th>Dependence on routines</th>
</tr>
</thead>
<tbody>
<tr>
<td>Planning</td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>1. Prior to scheduling a procedure, the department must be clearly informed of the child’s special needs and/or diagnosis [73, 75, 77, 168-170].</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>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 parents/guardians [73, 168-170].</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>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 [10, 73, 76, 77, 168-170].</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>4. Where appropriate, the department should prepare a specific plan for relevant premedication [77, 168, 170].</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>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) [77, 168-170].</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
</tbody>
</table>
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 pictures regarding the procedure, which make it easier for the child to follow the process) [168, 169].

<table>
<thead>
<tr>
<th>Features of the environment</th>
</tr>
</thead>
<tbody>
<tr>
<td>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 minimise any other stimuli that may result in discomfort for the child [76, 77, 168-170].</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Use of time</th>
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</thead>
<tbody>
<tr>
<td>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 [73, 77, 169, 170].</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Communication</th>
<th>Social interaction</th>
<th>Sensory sensitivity</th>
<th>Dependence on routines</th>
</tr>
</thead>
<tbody>
<tr>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Communication</td>
<td>Communication</td>
<td>Social interaction</td>
<td>Sensory sensitivity</td>
</tr>
<tr>
<td>------------------------------------------------------------------------------</td>
<td>---------------</td>
<td>--------------------</td>
<td>---------------------</td>
</tr>
<tr>
<td>10. The department should have picture support available for children who are accustomed to relying upon picture support. This support should feature specific, realistic pictures of all stages of the procedure, and the pictures must follow the planned structure of the procedure [168, 169, 171].</td>
<td>X</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>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 &quot;soon&quot; or other similar temporal abstractions, HPCs 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].” [46, 172].</td>
<td>X</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td><strong>Features relating to the HCP</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. The HCP tasked with caring for the child must possess knowledge/education about the practical implications of having autism [46, 73, 168, 169].</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>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 parents/guardians 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 [10, 168].</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14. During the procedure itself, the department should only involve as few HCPs as is necessary [46, 77, 169].</td>
<td></td>
<td></td>
<td>X</td>
</tr>
</tbody>
</table>
Table 8. Items in the guideline related to characteristics and their supporting references

<table>
<thead>
<tr>
<th>Factor</th>
<th>Communication</th>
<th>Social interaction</th>
<th>Sensory sensitivity</th>
<th>Routine dependence</th>
</tr>
</thead>
<tbody>
<tr>
<td>How the child communicates (e.g. language, pictures, other) [76, 77, 169].</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The child’s special interest(s) [10, 76, 77, 168].</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>What the child likes [77, 170].</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>What the child dislikes [77, 170].</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>What works to achieve cooperation when interacting with the child [77].</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>What does not work to achieve cooperation when interacting with the child [77].</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>What calms the child [10, 76, 77].</td>
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<td>What makes the child anxious [77].</td>
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<td>How the child shows anxiety [76, 77].</td>
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<td>How the child responds to touch [76].</td>
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<td>What environmental factors make the child feel calm [10].</td>
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<td>How the child reacts to sound [76].</td>
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<tr>
<td>How the child reacts to light [76].</td>
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<tr>
<td>Other special needs of the child [168, 170].</td>
<td>X</td>
<td>X</td>
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<tr>
<td>The child's degree of cognitive impairment [170].</td>
<td>X</td>
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<tr>
<td>What the child would like to bring from home [73, 76, 77, 169].</td>
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Discussion

Methodological considerations

Trustworthiness (Study I - IV)

Trustworthiness relate to the truth of the research. It is to evaluate the methods used in the research in order to assess the quality of the research. The researcher needs to describe the methods used and give reasons for the choices made both contextual and methodological to make the process transparent. This transparency is needed so that the reader can assess the quality of the research. In quantitative methods, the rigor of the research can be described in terms of reliability and validity. In qualitative research, the quality of the research concept can be defined by the trustworthiness of the research [151]. Lincoln and Guba (1985) introduced four concepts to define trustworthiness in qualitative research. Those terms are: credibility, dependability, confirmability and transferability [151]. Both rigor and trustworthiness describe the quality of the research.

Credibility in CIT was ensured by the researchers’ knowledge about anaesthesia to children so that appropriate questions could be designed. The familiarity of the context also helped to inform further in-depth questions when the participant had difficulties in expressing themselves. When there were participants who had difficulties in recalling specific incidents, a general conversation about giving anaesthesia to children was held. As the conversation continued, they all recalled vivid memories of specific incidents [153] (Study I). In inductive content analyses, it is important that the data is as unstructured as possible [173]. In the self-reported questionnaire, the respondents were just asked to give comments. The nurse anaesthetist and paediatric nurses were using their own words to describe the procedures they were using when working with children with ASD to alleviate anxiety (Study II).

Dependability refers to the stability of the data. For the data to be dependable, it is important that the data does not change over time or in different conditions. Dependability asks the question whether the findings of a study would be the same when performed later with the same participants and in the
same context [173]. In CIT, the participant’s ability to recall events is crucial to ensure dependability of the study as it is the interviewer’s responsibility to help the informant to be as specific as possible [174]. In this study, the same interviewer performed all the interviews to make sure the interviews followed the same pattern. The participants recalled incidents that had stuck in their memory as a very good experience or an experience that was not good and they described in detail the incidents, detailing what happened. When the nurse anaesthetists had, difficulties expressing themselves, the researcher asked probing questions to glean all the details in the incidents (Study I). In the open-ended question in the questionnaire, the nurses described what they were doing. If a researcher would ask the same question later, the routines used at the departments could have been changed and thus different.

**Confirmability** refers to the data being accurate to the information the responders provided. This can be obtained by two researchers conducting the analysis or that the research group come together and discusses the categorisation and reaches a consensus [173]. When the researchers are familiar with the area they can have preconceived opinions. To prevent this to influencing the result, the research team had repeated discussions about the findings and finally reached negotiated consent [175]. In the analysis, the research team discussed the analysis of the subcategories and the categories and reached a consensus (Study I and II). In Study II, two researchers analysed the data independently then met and reached consensus about the subcategories and categories.

**Transferability** refers to the extent to which the findings can be transferred to other settings or groups. It is ultimately up to the reader to decide if the findings can be transferred to other setting. The researcher can provide suggestions, but it is up to the reader to decide. To make it easier for the reader to make a decision, the researcher should present the result with richness and in a way so that the reader can follow the process and look for alternative interpretations. The researcher can use quotations from the respondents to support and highlight the findings [173]. In Study I and II the data was presented with a richness and supported by quotations. A child with ASD has the same sensitivities and difficulties in different medical settings thus it should be transferable to other medical procedures a child undergoes.
Reliability in a survey research relates to the reproducibility of the instrument and the administration of the survey. The first step is to formulate a research question and decide whether a survey is the best way to answer the question [176]. In this thesis, the only way to know if there existed guidelines for preparing and taking care of children with ASD in the anaesthesia and radiology context was a survey. The questionnaire was tested in a small group before distributed to the respondents. To identify respondents, the list of hospitals at the Swedish Association of Local Authorities and Regions was used to identify all hospitals in Sweden for the anaesthesia and paediatric departments. For the radiology departments, the Swedish Radiation Safety Authority was also used. The chairperson of all anaesthesia departments and radiology departments were identified and was the recipient of the survey (Study II and III). There was no external dropout in the anaesthesia and paediatric departments since all departments that had not responded, received a phone call and therefore responded to the survey. In the radiology departments, there was dropout rate of 8%.

For the Delphi study, the previous responses from each of the experts were not fed back to the experts in the next round, which might have been a weakness. A strength is that the experts were anonymous to each other, but not to the researcher which means that the answers were not influenced by other responders.

Validity in a survey research relates to what extent the questionnaire measure the construct under investigation [176]. One of the obstacles is the response rate that tend to be low, e.g. under 50%. The other obstacle is that the questions in the questionnaire can be interpreted in various ways. Care should be taken with the wording when constructing a questionnaire to minimise the risk of the question to be ambiguous. The advantage with surveys are that they are flexible and can be used in many different ways. However, it is difficult to gather deep information about complex matters such as human behaviour or feelings which are disadvantages of surveys [148]. To check the face validity of questionnaires for the surveys, a researcher revised the questionnaire before it was sent out. For the Delphi questionnaire, the research group went through the questions to check face validity of the questionnaire. The question addressing the number of children with ASD anaesthetised or how many children with ASD who went through a radiographic examination was hard to answer for the respondents. In the departments, they record patients by the
radiographic examination or by the procedure performed under anaesthesia, not their underlying diagnosis. That question was dismissed. The first Delphi questionnaire was constructed from items in the literature and from the responses of the surveys.

Another fundamental aspect of validity in a Delphi study is the choice of experts [158]. In this thesis, the expert was mentioned from the departments as skilled persons working with children with ASD in their respective departments. These persons were familiar with the context as well as children with ASD. This strengthens the validity of the Study. However, there were no psychologists or psychiatrists in the expert group which might be viewed as a weakness. Another limit of Delphi studies is the risk of failure to recognise disagreements [158]. In the questionnaires, there was the possibility of respondents to give comments. These comments were weighted into the construction of the next round of questions to address the disagreements.

**Discussion of the result**

The result of this thesis shows that the care of children with ASD is dependent on the organisation of the work and on the knowledge, skills and attitudes of the individual nurse caring for the child. The work should be organised in a way that enables the individual nurse to care for a child with ASD in a person-centred approach and the nurse should have knowledge about ASD to be able to provide care in a person-centred care approach. The result shows the need for planning the health care visit to be able to create an environment where the child can participate and the nurses can communicate with the child in a way the child understands. It was shown that there is a lack of structured guidelines for the care of children with ASD in a high technology environment. In Study IV, evidence-based guidelines were created. These guidelines and the checklist were created together with health care professionals to facilitate the care of children with ASD. The guidelines and checklist were created to assess the characteristics of the individual child and to adjust the environment to the needs of the specific child to be more in line with person-centred care (Study IV). These evidence-based guidelines address qualities in both the organisation and the nurses caring for these children. The guidelines give the nurses a tool aiding them to provide person-centred care for the child with ASD.
Evidence-based guidelines

There were departments stating that they did not need any specific guidelines for children with ASD because all children were cared for according to their individual needs so nothing extra was needed for these children (Study II). It could be argued that following guidelines would hinder individualized, person-centred care of the child. In Enskär (2012) the expert nurses were more reluctant to use evidence-based guidelines because they sometimes perceived guidelines as an obstruction for individualization of the patient care and they did not think they needed guidelines or rules to care for the children. The expert nurses stated that they based their care on their own experience and intuition [177]. In Study II, there was also one paediatric department likewise stating that they did not think they needed any guidelines in the care of children with ASD. However, after a day of education on ASD, the nurses realized their knowledge gap and the need for evidence-based guidelines (Study II). This can be compared to Matthew-Maich et al. (2013) where one of three departments also stated that they did not need to implement evidence-based guidelines because they already cared for their patients in a good way. However, when looking at the facts, comparing one department with the other departments who had implemented evidence-based guidelines, many gaps in the quality of the practice was seen in that department compared to the other two departments [131]. This indicates that evidence-based guidelines can enhance the quality of person-centred care instead of obstructing it. Akenroy (2016) also showed that implementing evidence-based guidelines can improve the quality of the care [178].

The core of person-centred care is to provide care based on respect for the persons’ preferences, values and needs. In the attitudes part of the knowledge, skills and attitudes framework, nurses should try to understand their own personal beliefs and values about the care of a suffering person [35]. To realise their own knowledge gap as nurses, is really to work according to person-centred care as in which was described in the department (Study II). According to person-centred care, the nurses should possess the knowledge to analyse barriers and facilitators to person-centred care and also possess the skills to work with the organisation so that the persons and families’ preferences are assessed and supported [35].
Lack of guidelines and lack of knowledge about ASD made it hard to provide the care expected to children with ASD (Study I, II, III). The responsibility of the organisation is to use evidence-based practice [126, 179]. It can also be a demand arising from outside the institution that drives the implementation of evidence-based guidelines, not simply the organisations identification of a problem [129, 180]. The patients and families who want to be cared for with dignity, respect, sharing information, partnership and collaboration the cornerstones of person-centred care can also push for a change in the culture. The managers in the health care system influence the caring culture in a department and they are the ones who can change the visions in a department to create a culture of person-centred care to include the family in the care that is a responsibility for the leadership in the health care setting. It is beneficial if the top of the organisation is fully supportive of the change if it should prove to be a successful and sustainable change. It should also be recognised that a change in the culture of care takes time [180].

**Planning for the care of children with ASD**

The result showed that an early identification of a child with ASD scheduled for a procedure enabled the planning of the care to suite the child and to provide person-centred care for the child in a high technology environment (Study I, II, III, IV). The importance of early identification to allow for the possibility to prepare in advance together with the patient and the parents is clearly documented [10, 73, 76, 77, 181].

Nurses described that they met children with ASD when they came for anaesthesia and that they were taken by surprise by this and thus they could not prepare the children as needed. When the nurse did not know in advance that a child with ASD would come, it was impossible to make any arrangements in advance (Study I, II). It is incumbent on nurses to care for the patient with respect for the patient’s dignity the need of the individual regardless of social or economic status, personal attributes or the nature of health problems as stated in their professional codes [79, 141] and to be able to practice according to person-centred care and evidence-based practice [179]. In order to provide person-centred care to a child with ASD, the nurses need to know in advance that the child is coming and there need to be evidence-based guidelines available for those health care providers working with the children [10, 73, 76, 77, 170].
When the planning of the care for the child is accomplished in collaboration with the parents and the knowledge about the needs of the specific child is communicated from the parents to the nurses, then an individual care plan for the child can be created (Study II, IV). To individualise the care after the specific needs of the child is important [76] and to involve the parents in the planning of the care of the child is of beneficial for the child, the parents and the nurses [10, 46, 66, 72, 169, 182]. For children with a disability such as ASD, the parents are a resource that is much needed by the health care professionals the care of the child [52, 58, 73, 77]. In the result of the studies, nurses spoke of asking the parents about the child and the guidelines clearly states that the care should be planned and carried out in cooperation with the child and the parents (Study I, II, III, IV). The parents also found it important to be part of the care of their child and are pushing for a change towards a more person-centred care [10, 180, 183].

Nurses talked about the need to have the parents as collaborative partners in the care (Study I, II). Parents were regarded as the definitive source of information about the child with ASD (Study II, III, IV). In order to be able to take the role of the child, the nurses needed information about the child. They needed to know how the child communicates, how the child displays anxiety and how the child responds to sensory stimuli (Study II, IV). This could be described as taking the role of the other according to symbolic interactionism [55] and in order to glean all the specific characteristics of a child, a checklist could be an aiding tool.

Within the guidelines there is a checklist created to ask the parents about the child’s specific needs. The questions in the checklist glean information about the child’s communication pattern, how the child interacts socially, how the child reacts to different sensory stimuli and areas of routine that is important for the child (Study IV). A checklist can be seen as an opposite to person-centred care, but it can also be seen as an aid to be able to provide person-centred care. Parents and health care professionals advocate the use of a checklist to glean the information of the particular child so that the care can be tailored to the needs of the child [52, 147].

Knowing what calms the child and how the child expresses anxiety helps the nurse to make a correct interpretation of the behaviour of the child. That
information can be gleaned from the checklist created in Study IV. When the nurse interprets the situation with a child diagnosed with ASD from the shared understanding of interactions with a typical developing child, the interpretation in the interaction with the child diagnosed with ASD can become misinterpreted [57]. Children with ASD tend to engage in repetitive behaviour and speech, stereotypical of the disorder [8]. This behaviour can be used as a self-calming strategy and thus increase when the child becomes uncomfortable or anxious [57] and if not known by the nurse it can be interpreted as aggression instead of a self-calming strategy [57].

When the questions in the checklist are answered by the parents of the child, the nurse can acquire knowledge about the specific child’s calming strategies. A strategy could be to bring an item of comfort from home if applicable for the child as asked for in the checklist (Study IV) and is also described by others in the literature [76, 77]. To know the specific characteristics of the child can help the nurse “take the role of the child” and make a more accurate interpretation of the child’s behaviour in the language of symbolic interactionism [55]. From the nurses’ perspective, knowing the child in advance and having knowledge about the child’s specific needs makes it easier to provide person-centred care to the child and the guidelines and checklist created in Study IV make this possible. The guidelines can be seen as giving the nurses a tool to be better equipped to “take the role of the other” in this case the child.

The environment

The guidelines address the waiting environment (Study IV). A waiting room can be a challenge for a child with ASD. The unfamiliar environment where there are a lot of sensory stimuli such as a lot of people, bright lights and a lot of noises can trigger an agitated behaviour in the child resulting in decreased compliance for the examination or procedure [10, 12, 77]. The unfamiliar, busy environments, waiting time and nurses without knowledge about ASD, can create anxiety in children with ASD in the health care setting [146, 184]. To have a space at the department that is low in sensory stimuli is helpful for a child, who is sensitive to sensory stimuli (Study IV). The need for such a specific place in the health care setting is described in several studies [73, 76, 146, 147, 170, 185].
The use of time

The waiting time as well as the scheduling of the procedure at a time suitable for both the child and the department is addressed in the guidelines (Study IV). To minimise the waiting time for a child, there was a description of a nurse waiting for the child instead of the child waiting for the nurse (Study I). It is suggested to schedule the procedure for anaesthesia where fasting is required as early as possible in the day and to minimise waiting time (Study IV). For radiographic examinations, the scheduling should be done in collaboration with the parents to suit both the child and the department (Study III). Study IV describes a balance between minimal waiting time and enough time not to stress the child and the nurse (Study IV). Children with ASD are often inflexibly dependent on routines. This routine dependence can lead to extreme distress when the child is faced with even small changes in his or her immediate environment [8]. It is important for the child dependent on routines, not to alter what is previously decided on such as an excessive waiting time [12, 57, 66, 169].

Communication with children with ASD in a high technology environment

The nurses described a lack of knowledge regarding how to communicate and approach a child with ASD (Study I, II, III). To meet a child with ASD who is lacking in symbolic ability and just see what is in front of them without interpretation, can become quite confusing for the nurse without knowledge about ASD. The interaction can become confusing and the child becomes agitated because they do not understand what the nurse means and cannot make themselves understood [11, 169]. These communication difficulties can make it hard for the child to understand what the nurse tries to communicate and to be understood. The child needs to understand and to be understood. To understand the world of a child with ASD, symbolic interactionism could be a tool that could help [54, 186]. According to symbolic interactionism, reality is developed in the interaction with others [187]. The meaning of reality is an interpretive process. The meaning reality has for the individual is dependent on the context in which the individual exists and in interaction with others [186]. The dilemma for a child with ASD in the interaction with the nurse is that the reality is interpreted in different ways to how the nurse interpret reality [57]. The nurses need to have knowledge about the world of the child and
how the child interprets the symbols used in communication, such as words and body language in order to be able to provide person-centred care.

There is one item in the guidelines suggesting that the language used in the interaction with the child should be a plain language without any symbols, since a child with ASD have problems to transfer a symbol to the real object (Study IV). In order for the nurse to try to understand the child, the nurse needs to have knowledge about the world of the child with autism [57, 188].

In some of the anaesthesia departments, pictures were used in the communication (Study I, II) and in the guidelines, and there are suggestions for the use of pictures to help in the communication of impeding procedures (Study IV). The guidelines also state that realistic pictures should be used (Study IV) because low functioning children with ASD have difficulties understanding that a graphic black and white picture is a symbol. It is easier for them to understand that a picture in colour represents symbols, not merely an artistic rendering. The closer the picture is to the real thing, the easier it is for these children to understand the symbolic value of the picture [171]. When the nurse does not have knowledge about the world of a child with ASD, the communication can break down completely, leading to increased frustration in the child and the nurse (Study I, II).

**The health care professionals**

Continuity in the nurses caring for the child was mentioned as beneficial for the quality of the care (Study I, II, III, IV). Lindberg et al (2012) shows that the continuity of the nurses caring for a child made the parents feel like being “received by warm hands” [10]. To have knowledge about ASD was also mentioned as an important factor (Study II, IV). It has been described that the quality of care can be enhanced by knowledge about ASD in the nurses caring for the child, so that the care the child receive is not dependent on the person working at the time [11, 46, 146]. Lack of knowledge about ASD and lack of continuity in the nurses caring for the child has been described by parents as “a constant struggle” [10].
Participation of the child

The point of the created guidelines in Study IV is to have a tool to work with in order to make the child participate in the care. The nurses’ main experiences of caring for children with special needs that require anaesthesia was that it was difficult to get the children to participate and thus have a calm induction (Study I). This could be interpreted as a breakdown of the communication because the nurse was not able to take the role of the other using the language of symbolic interactionism [55]. To get the child to participate is the goal for the nurses caring for the child. The two concepts of participation described are “being there” and “engagement” [104].

As a contrasting experience a well-prepared child came in to the operating theatre asking for the things to do, and just went ahead and put herself to sleep (Study I). This child was clearly not just being there but was also engaged in the procedure. In a high technology environment, both being there and engaged can be problematic to achieve. Participation seen as being there can be achieved if the child accepts to be present for the procedure. For the child to be engaged means that the child should be an active participant in the procedure [104, 105]. To set the stage so that a child can be able to participate in the care is a challenge for the health care system and using person-centred care could be one way of getting there [106]. If the child does not want to participate, being there can be achieved by the nurse and or parent physically restraining the child, i.e. holding the child [28-32].

To physically restrain a child whom, they could not get to participate was described by the nurses (Study I, II). Physical restraint can be defined as the use of force to overpower a child in order to keep the child in place without the child’s consent [189]. The use of restraint for procedures in children can cause long term negative consequences for the child and can worsen their anxiety the next time they come for a procedure [32, 190]. For a radiographic examination, it is advised to only use physical restraint as a last resort in a life-threatening situation [191]. Having the UN Convention of the Right of the Child in mind and the negative consequences for the child, physical restraint should not be used unless as a last resort.

Physical restraint was described as a last resort to cope with an uncooperative child (Study I, II). Children with ASD are more likely not to participate for
anaesthesia than children with typical development which can lead to the child being physically restrained for a procedure [30-32, 73]. On the other hand, in Study II there are suggestions that it was a plan to physically restrain the child and to have the parents help in the restraint to make it possible to anaesthetise the child (Study I). To use physical restraint to make a child “be there”, in any other situation then a life-threatening situation, is hard to be seen as neither participation or person-centred care. Especially with the knowledge that a distressing health care experience can cause psychological trauma to the child and further increase distress in the child for the next visit [192-194].

Many nurses however, are uncomfortable using physical restraint for an anaesthesia induction (Study I, II). To use physical restraint to perform a procedure on a child is to violate the dignity of and increase the anxiety of the child [32, 73]. Using physical restraint in a not life threatening situation goes against the human rights and the ethical values that are the fundamentals of the code of ethics for the nurse anaesthetists and radiographer [79, 81]. Both positions that it is acceptable and that it is a last resort are discussed in (Study II) and in previous research [29-31]. When restraint is needed as a last resort it should be performed in a safe way for the child [28, 29]. It has been a discussion to use the word immobilise instead of physical restraint because it sounds less harsh. They are, however, two different concepts. Physically restraining is without consent of the child while immobilisation should always be with consent from a patient who has difficulties to be still. To be still is important in a radiographic examination to get a correct image which in turn is important to produce a correct diagnosis [28].

It is described in Study I, that parents wanted the child anesthetised against the consent of the child and required the nurse to physically restrain a child for the procedure and the nurse complied, restraining a child for anaesthesia in a non-life threatening situation (Study I). There are perceptions from health care professionals that holding a distressed child for a procedure is an acceptable way to get the procedure done as long as the parents acknowledge the action. The physical restraint is justified by that it is done in the best interest of the child [29]. According to EACH, physically restraining a child in a non-life threatening situation and failing to take account of the child’s best interest and dignity, is against the code of practice in the UN Convention on the Right of the Child and person-centred care [79, 114, 141, 195, 196]. Listening more to the parents than the child can be seen as family-centred care
which Kuhlthau et al. (2011) showed improved the outcome for children with special needs [197]. However, it is not enough to involve the family in the care, the child needs to be the focus of the care. When the parents’ wishes go against what the nurses know is the best care for the child, the family-centred care creates a conflict [198] that might have been solved with person-centred care [29]. On another note, nurses cancelled and rescheduled surgery for children who were too anxious to participate and explained to the parents so that they were involved in the decision-making process (Study I) and this is in line with person-centred care. The role of a radiographer and nurse anaesthetist is to demonstrate professional integrity and ethical conduct. The nurses are supposed to care for the patient with respect for human dignity and the uniqueness of the patient, irrespective of social or economic status, personal attributes, or the nature of health problems [79, 141].
Conclusion

Nurses working in a high technology environment in health care system have diverse experiences of preventing anxiety in children coming for a challenging procedure. Children with special needs, such as children with ASD, are one group who represent a special challenge in reducing anxiety and creating participation. Involving the child and the parents in the preparation as in person-centred care is one way to reduce anxiety.

The organisation need to enable the possibility to for a child with ASD in a person-centred approach through notification that a child diagnosed with ASD is schedule for a procedure and scheduling of nurses with knowledge about ASD to care for the child.

There are a limited number of evidence-based guidelines in the high technology environment to decrease anxiety and to create participation in children with ASD. To be able to provide person-centred care to children with ASD, structured, evidence-based guidelines are needed.

Evidence-based guidelines are created as a tool for enhancing person-centred care in a high technology environment to children with special needs such as children with ASD coming in to hospital for a challenging procedure. The fact that several problems are assembled under one disorder makes ASD a useful condition to have as a basis for formulating national guidelines. Guidelines for the care of children with ASD in a high technology environment using a person-centred approach can probably also be used to care for children with other neurodevelopmental disorders that exhibit some of the same problems.
Future research

The next step is to through an intervention test the guidelines for caring for children with ASD in the radiographic and perioperative setting. The study is a quasi-experimental control intervention study based on the developed guidelines for caring for children with ASD in Study IV.

Guidelines developed in Study IV will be implemented in radiology and anaesthesia departments chosen for the study. Parents of children with ASD will be contacted by mail when a radiographic examination or a procedure requiring anaesthesia is scheduled with information of the study and then asked for consent to participate. If consent is given, the parents will be called and more information will be given. The intervention is based on the guidelines developed in Study IV. Earlier research shows the complexity of the disorder where children diagnosed with ASD are calmer in a special environment customized to the need of the individual child [10, 71, 170]. The outcome will be measuring anxiety in the child if possible by the child, or by proxy with the use of information from parents and nurses. Biological stress markers, such as cortisol in saliva, will be another measurement of anxiety in the child.
Svensk sammanfattning


Barn med en neuropsykiatrisk funktionsnedsättning, till exempel barn med autism, har problem med kommunikation, social interaktion, är känsliga för sensoriska stimuli, till exempel ljud, ljus eller beröring, och är dessutom beroende av rutiner. Dessa barn utgör en utsatt grupp i den högteknologiska miljön inom sjukvården och detta gör att dessa barn löper en stor risk att ett besök inom den högteknologiska miljön på ett sjukhus riskerar att bli en skrämmande upplevelse. För barn som redan är oroliga kan ett besök i denna miljö ytterligare förstärka deras oro inför andra besök inom sjukvården.

För att förhindra detta behöver dessa barns besök vara välplanerade och genomföras på ett sätt som tar hänsyn till det individuella barnets fungerande och behov. Fokus i denna avhandling är således förberedelse och omhändertagande av barn med autism i en högteknologisk miljö inom sjukvården. Att tillgodose barnens behov kan åstadkommas genom att skapa nationella riktlinjer för omhändertagande av dessa barn där deras individuella behov tas till vara.

Critical Incident Technique (CIT), där sjuksköterskor intervjuades, användes i studie I. I de följande två studier gjordes kartläggningarna genom användandet av webbaserade enkäter. Kommentarer från den öppna frågan och de riktlinjer som bifogades enkäterna analyserades med hjälp av kvalitativ innehållsanalys. För studie IV där de evidensbaserade riktlinjerna skapades användes Delphi teknik som är en metod att skapa konsensus inom en expertgrupp om det som forskningen handlar om, exempelvis att formulera evidens-baserade riktlinjer.

Barn med särskilda behov, till exempel autism, identifierades av anestesisjuksköterskor som en utsatt grupp i den högteknologiska miljön. Anestesisjuksköterskorna beskrev sina erfarenheter av att vårda barn inför och under anestesi och deras agerande för att få barnen att medverka i vården. Det framkom att de barn som de tyckte var svårast att vårda samt att få ett lugnt insomnande var barn med speciella behov, som barn med autism (studie I). Utifrån detta resultat utfördes två nationella kartläggningar för att få kunskap om hur det ser ut i Sverige vad gäller vård av barn med autism i högteknologiska miljöer såsom röntgen och anestesiavdelningar (studie II och III). För att få kunskap om hur barn förbereddes för anestesi innan de kom till anestesiavdelningen tillfrågades också barnavdelningar om de hade riktlinjer för förberedande av barn med autism inför en procedur som krävde anestesi. Resultatet av kartläggningarna var att det var sju avdelningar inom anestesin som nämnde att de hade riktlinjer, men att det på barnavdelningar inte fanns några riktlinjer för förberedelse av barn med autism inför en procedur som kräver anestesi. Det var endast två anestesiavdelningar som bifogade sina riktlinjer (studie II). Ingen av de radiologiska avdelningarna i Sverige hade riktlinjer för omhändertagande av barn med autism när de skall genomgå en radiologisk undersökning utan anestesi (studie III). I kartläggningarna fanns det också möjlighet att beskriva hur man arbetade med barn med autism även om det inte fanns några generella riktlinjer och att namnge om det fanns någon
personal som arbetade speciellt med dessa barn. På vissa av de avdelningar som saknade riktlinjer var vården av barn med autism beroende av kunskap om autism hos den sjukköterska som arbetade vid vårdtillfället. På andra avdelningar saknades kunskap om omhändertagande av dessa barn (studie II och III). Genom resultaten från studie I, II och III identifierades behovet av strukturerade riktlinjer för vård av barn med autism i en högteknologisk miljö och evidensbaserade riktlinjer samt en checklista skapades. Riktlinjerna inkluderar strukturen i organisationen som planering av vården, miljön för barnet att vistas i och att personal som arbetar med dessa barn skall ha kunskap om funktionsnedsättningen. Checklisten avser att inhämta information om det specifika barnet för att kunna ge personcentrerad vård baserad på barnets fungerande (studie IV).

Det faktum att flera problem, som till exempel problem med kommunikation, social interaktion, känslighet för sensoriska stimuli, samt beroende av rutiner samexisterar under diagnosen autism, gör denna neuropsykiatriska funktionsnedsättning till ett användbart tillstånd att ha som utgångspunkt för att formulera nationella riktlinjer. Riktlinjer skapade för vård av barn med autism i en högteknologisk miljö kan troligen också användas för att ta hand om barn med andra neuropsykiatrisk funktionsnedsättningar som uppvisar några av de problem som ses hos barn med autism.
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References


Appendix I

Riktlinjer för förberedelse och omhändertagande av barn med autism inför anestesi och radiologiska undersökningar

Planering

1. Inför bokning av en procedur skall det finnas tydlig information till berörda avdelningar om barnets speciella behov/diagnos.


3. Barnets speciella behov skall efterhöras i kontakten med föräldrarna/vårdnadshavarna. (Checklista fylls i enligt bilaga 1). Det är viktigt att vara lyhörda för föräldrarnas/vårdnadshavarnas kunskaper om det specifika barnets behov.

4. I förekommande fall görs en specifik planering av relevant premedicinering.

5. Vårdansvarig personal ansvarar för att göra en helhetsplanering inför, under och efter proceduren i samråd med föräldrar/vårdnadshavare. Enskilt förberedande besök skall om behov föreligger bokas. Se checklista (bilaga 1) för vad som skall efterfrågas.

6. Viktigt att planering samt utförande av omhändertagandet vid proceduren har en struktur som följs. Strukturen kan med fördel brytas ner i mindre delar, till exempel med hjälp av bildstöd, som gör det lättare för barnet att följa med i förloppet.

Miljö

7. Avdelningen ansvarar för att det finns en avskild plats för barnet för förberedelse samt för utförande av proceduren där stimuli är minimerad (exempelvis ljud och ljus beroende av det specifika barnets behov).
Tidsaspekter

8. För att minimera risken för förskjutningar i programmet och därmed onödig väntetid för barnet, bör avdelningen boka en tid som minimerar risken för väntetid. Tiden skall passa barnets rutiner.


Kommunikation

10. Avdelningen ansvarar för att det finns specifika, realistiska bilder om proceduren för de barn som är vana vid att använda bildstöd. Bilderna skall följa strukturen för hur proceduren fortskrider.

11. Personalen behöver anpassa språket till barnets kommunikationsnivå. Tänk på att använda konkret språk och att inte använda symbolspråk. Exempelvis använd inte ordet ”snart” eller andra liknande abstrakta tidsangivelser. Använd istället en konkret tidsangivelser som exempelvis ”när all sand har runnit ner i botten på timglaset, skall vi göra detta”.

Personal

12. Vårdansvarig personal som skall leda barnet genom proceduren behöver ha utbildning/kunskaper om vad det innebär att ha autism.


14. Det är viktigt att se till att det bara är ett fåtal personer som är involverade i mötet och vården av varje enskilt barn.
Appendix II

**Checklista för information om the barnets funktion**

1. Hur barnet kommunicerar (språk, bilder, annat)

2. Barnets specialintresse

3. Vad barnet tycker om

4. Vad barnet inte tycker om

5. Vad som fungerar

6. Vad som inte fungerar

7. Vad som lugnar barnet

8. Vad som oroar barnet

9. Hur barnet visar oro

10. Hur barnet reagerar på beröring

11. Hur barnet reagerar på ljud

12. Hur barnet reagerar på ljus

13. Barnets andra speciella behov

14. Barnets grad av kognitiv funktionsnedsättning

15. Hur miljön skall vara för att barnet skall känna sig lugn

16. Vilka saker barnet gärna vill ha med hemifrån
Appendix III

Frågor i enkäten i studie II.

1. Söver eller sederar ni barn inför undersökning, behandling eller kirurgi? (Om nej behöver du inte fylla i mer.)

2. Om ja, ungefärligt hur många barn sövs eller sederas på er avdelning per månad? Ange antal?

3. Söver eller sederar ni barn med autismspectrumtillstånd inför undersökning, behandling eller kirurgi? (om nej behöver du inte fylla i mer)

4. Om ja hur många barn med autismspectrumtillstånd sövs eller sederas under en månad? Ange antal anestesier. Ange antal sederngar

5. Har ni några riktlinjer för hur ni förbereder barn med autismspectrumtillstånd inför anestesi eller sedering? (Om ja, var vänlig bifoga riktlinjerna nedan)

6. Har ni några riktlinjer för hur ni tar hand om barn med autismspectrumtillstånd när de kommer till avdelningen för att sövas eller sederas? (Om ja, var vänlig bifoga riktlinjerna nedan)

7. Har ni någon specifik person som är ansvarig för omhändertagandet av barn med autismspektrumtillstånd? (Om ja, var vänlig bifoga namn och e postadress)

8. Kommentarer:

Appendix IV

Fågor i enkäten i studie III

1. Tar ni emot och vårdar barn med autismspektrumtillstånd inför en röntgenundersökning? (Om nej, behöver du inte besvara fler frågor)

2. Om ja, ungefärligt hur många barn med autismspektrumtillstånd undersöker ni per månad? Antal:

3. Sövs dessa barn inför undersökning? (Om ja, behöver du inte besvara fler frågor)

4. Har ni några riktlinjer för att förbereda barn med autismspektrumtillstånd inför en röntgenundersökning? (Om ja, var vänlig bifoga riktlinjerna)

5. Har ni några riktlinjer för hur ni tar hand om barn med autismspektrumtillstånd under undersökningen?

6. Har ni någon specifik person som är ansvarig för omhändertagandet och undersökning av barn med autismspektrumtillstånd? (Om ja, var vänlig bifoga namn, position och e-mailadress)

7. Kommentarer

8. Vilken enhet arbetar du på?
   Namn på enhet, sjukhus och ort