From the
Department of Learning, Informatics,
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Karolinska Institutet, Stockholm, Sweden

# Web-based learning design in paediatric perioperative care

## – the importance of including an educational framework and children's own perspectives

**Gunilla Lööf**


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# Web-based learning design in paediatric perioperative care

## – the importance of including an educational framework and children's own perspectives

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by

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*It always seems impossible until it´s done*
*Nelson Mandela*

*To Charlie Boy Boy*
*The King of Love*

# PROLOGUE

A little girl was whisked off to the hospital to have surgery. Not a sole had prepared her for this scary and life changing event. On edge, suspicious, afraid, like a journey into the unknown, no explanation was given her as to what to expect.

That day, I ran away from my own surgery. My mother found me by our car in the parking lot. Too embarrassed over my behavior to take me back into the hospital, we went home without having any surgery done. The plan was for a quick and fairly simple procedure. However, no understandable preparation was presented to me about what was to come. Still, I can remember how terrified I was. I was scared of syringes, strangers, pain, anaesthesia and death, because that was exactly what had happened to my grandmother some months before when she was at the hospital. Being brought to the hospital, I was certain the same would happen also to me. As a little girl, how in the world would I have understood better?

Working as a paediatric nurse anaesthetist and meeting worried and frightened children, immediately takes me back to the memories of the uninformed, scared little girl at the hospital parking lot. I can easily recall and recognise the feelings of panic and fear and, as an adult, I also reflect over the unfortunate consequences these experiences had for my relationship with health care during my entire childhood. What is most important is that I can also remember the relief and confidence I felt later in life when I was fortunate enough to meet health care providers who respected my fears, gave me sufficient time, and in an understandable way, informed and prepared me for the expected medical procedures. Although many years have passed by since my own experience, hospitalised children continue to experience fear and anxiety affecting them physically and emotionally. All medical providers meeting children during perioperative care must evaluate "*what they think they know*" about children's perioperative experiences, perspectives and need for preparation as well as consider "*why, how and what*" they do to them. The gift of a child's trust and confidence is given once, is quickly consumed and may be nearly impossible to regain if lost.

# ABSTRACT

The perioperative period is a significant and unforgettable life event for children with both short-term and long-term effects. Despite evidence highlighting the importance of including children's perspectives, their right to and need for preparation, children's views of the perioperative period are rarely sought and many are still arriving in the operating room unprepared and with preoperative anxiety. Today, there is an increasing availability of web-based preparation programs for children in paediatric care. The overall aim of the thesis is to provide understanding of how web-based technology can support children to learn about and be prepared for perioperative care.

The thesis adopted a pragmatic stance and employed different research approaches. All studies were grounded in children's perspectives and based on the Anaesthesia-Web (www.anaesthesiaweb.org), a widely used, comprehensive web-based preparation program.

In ***Study 1*** children's level of knowledge about perioperative care after receiving either interactive web-based information or conventional brochure material preoperatively was investigated in a prospective randomised controlled trial. In ***Study 2*** key educational principles in the development and design of websites for children in paediatric care were identified with directed content analysis based on a defined theoretical educational framework. In ***Study 3*** children's perspectives, experiences and perceptions facing anaesthesia and surgery were explored using inductive interpretative manifest and latent content ana-lysis. In ***Study 4*** children's use and experiences of a web-based perioperative preparation program were investigated with a directed content analysis based on the theoretical themes identified in study 2 that described children's learning on a website.

The ***results*** revealed that web-based technology can function as a significant resource for preparation and learning in paediatric perioperative care. Such programs have to change from simply providing information to incorporate the child's need to process the information in order to learn and understand. An interactive web-based design was shown to support children to obtain higher levels of knowledge about perioperative care compared with conventional brochure material. Analysis of children's use of and experiences with a web-based preparation program displayed how the inclusion of children's perspectives and an educational framework of children's learning can improve the development and design of websites in paediatric care. Important characteristics supporting children's learning on a website were found to let the child be; *In charge of own learning,* to *Discover and play*, to *Recognise events and situations and to identify with others*, to *Get feedback in the learning process* and to facilitate *Interaction with other children*.

Children's perceptions and interpretations of the perioperative period were found to differ from those of adults and health care providers. Understanding children's perspectives, and awareness of their need to process the information provided to understand and be prepared, are significant factors in establishing trust and confidence in the highly technological perioperative environment. Web-based technology constitutes an important part of children's preparation but helping children to become confident also require awareness of communication strategies and preparation as a continuous process, signified by perceptiveness and individualised adjustments during all perioperative phases. It is time to improve existing perioperative structures by taking account of children's perspectives.

# LIST OF SCIENTIFIC PAPERS

1. **Lööf G**, Liljeberg C, Eksborg S, Lönnqvist P-A.
   Interactive web-based format vs conventional brochure material for information transfer to children and parents: a randomized controlled trial regarding preoperative information. *Pediatric Anesthesia. 2017;(27)6: 657-664. ISSN: 1155-5645, doi: 10.1111/pan13142.*
2. **Lööf G**, Andersson-Papadogiannakis N, Karlgren K, Silén C.
   Web-based learning for children in pediatric care: Qualitative study assessing educational challenges. *Journal of Medical Internet Research/Perioperative medicine. 2018;1(2), doi: 10.2196/10203.*
3. **Lööf G**, Andersson-Papadogiannakis N, Silén C.
   Children's own perspectives demonstrate the need to improve paediatric perioperative care. *Submitted manuscript.*
4. **Lööf G**, Andersson-Papadogiannakis N, Silén C.
   Children's use of and experiences with a web-based perioperative preparation program: Directed content analysis. *Journal of Medical Internet Research/Perioperative medicine. 2019;2(1), doi: 10.2196/13565.*

# CONTENTS

# LIST OF ABBREVIATIONS

| | |
|---|---|
| AW | Anaesthesia-Web |
| BM | Brochure material |
| CI | Confidence interval |
| CS | Charlotte Silén |
| FAQ | Frequent asked questions |
| GL | Gunilla Lööf |
| IQR | Interquartile range |
| QCA | Qualitative content analysis |
| TQS | Total question score |

# INTRODUCTION

For most health care providers the entrance to the perioperative environment is the entrance to another day at work. For children and their families, it is an emotionally devastating experience which will be remembered for the rest of their lives. Procedures that are handled incorrectly will leave scars with short-term and long-term implications for the individual child and their wider family. Optimising a child's overall perioperative care is dependent upon appropriate preparation and communication. Listening to children's voices and viewing encounters from their perspectives are paramount in securing a smooth perioperative experience. This is also an investment in the perioperative experience of our future adults. Increasing use of web-based technology has created new opportunities for preparation of children and families for perioperative care. However, there is still a need to understand how children's experiences and use of web-based perioperative preparation programs can reduce preoperative anxiety, optimise understanding, cooperation, outcomes and decrease postoperative trauma.

# BACKGROUND

## Children's experiences of hospitalisation

Hospitalisation is a significant and memorable event in the life of children and families. It is a stressful experience, which may cause psychological and behavioral consequences, affect treatment, recovery and future dealings with medical services.[1-3] Hospitalisation includes new impressions and routines in a strange environment. Children have to cope with symptoms of their disease and experience frightening and painful procedures.[4-9] Many children are also exposed to elements of physical restraint to allow clinical procedures to be completed.[10-13]

Children's own experiences of hospital-related fears mostly relate to symptoms of pain, illness and invasive procedures.[4, 6, 8, 14-16] Other stressors involve activity restrictions, decreased independence, separation from daily activities, family and friends.[4, 6, 8] Children express how feelings of loneliness, insecurity, and uncertainty of what to expect makes them scared, sad and in need of protection.[4, 9, 15-17] Insufficient information and preparation,[4, 6, 8, 9, 18] lack of involvement[18-20] and deficient communication with the health care providers are also expressed as stressful factors.[8, 18]

Children's reactions to hospitalisation and medical procedures have been well documented over the years.[21-26] Anaesthesia and surgery are described as some of the most stressful events for hospitalised children and parents.[27-29] Already in the 1940's it was observed that children being hospitalised undergoing perioperative procedures developed a variety of physical and psychological problems which could last for a long time.[13, 30]

## Preoperative anxiety

Preoperative anxiety is a common and well described phenomenon affecting up to 60% of all children undergoing perioperative procedures.[29, 31, 32] As an emotional state preoperative anxiety is characterised by subjective, consciously perceived feelings of tension, apprehension and nervousness accompanied by activation of the automatic nervous system.[33] Children may express their preoperative anxiety verbally, behaviorally, subtly or explicitly.[29] Variables such as the child's age and developmental competency,

temperament, previous negative medical experiences, attitudes of the health care providers and anxiety of the parent have been identified as predictors for the occurrence of preoperative anxiety.[1, 34] Adequate understanding, prevention and management of preoperative anxiety are imperative since high levels of anxiety can lead to adverse psychological and physiological outcomes.[34]

Preoperative anxiety is associated with negative postoperative sequelae as emergence delirium *(agitation when emerging from anaesthesia)*, maladaptive behavior, increased postoperative pain and analgesic requirements and delayed hospital discharge.[1, 29, 31, 35, 36] Except for behavioral consequences preoperative anxiety activates stress responses resulting in increased levels of steroids and predisposition to postoperative infections.[37-40] In addition to its immediate consequences, preoperative anxiety has also been shown to negative delayed and long-term consequences resulting in general anxiety, apathy, temper tantrums, eating disorders, enuresis, fear of death, separation anxiety, sleeping problems and delayed recovery.[1, 2, 31]

The frequency of behavioral changes in children after perioperative care is up to 3.5 times higher in those with preoperative anxiety.[41] Even though the frequency of negative behaviors for most children is limited and decreases with time,[28, 41] it is found that almost 70% of children suffer from negative behaviors the day after surgery, 45 % on day 2 and 23% at 2 weeks after surgery.[41] Long-term follow up shows persisting negative behavior for 20% of children at 6 months and for 7.3% after one year.[28] This prolonged disruption in psychological well-being will have potentially negative effects on future health care encounters but also jepoardise to re-emerge in other performances and situations.[3, 42] For many children their negative experiences will leave indelible and persistent memories which might well influence their adult perception of perioperative processes.[43]

Although the entire perioperative process is stressful for children the anaesthesia induction, based on physiological and behavioral data, is estimated as the most stressful part during the perioperative period.[28, 29] Induction of anaesthesia involves a variety of rapid individual evaluations and judgements relating to both the child and parent, the situation and to some extent to the experience and preferences of the anaesthetic team. Recommended practice for anaesthesia induction consists of inhalational or intravenous methods. Even though one mode of induction may be over the other in particular clinical situations the choice of method for induction can play a crucial role in generation of perioperative anxiety.[44] Anxiety during the anaesthesia induction is correlated with postoperative excitement in the recovery room[41, 45] and reported by

Kain et al[35] emergence delirium occurs in 12-18% of all children undergoing anaesthesia and surgery. Additional factors found to be correlated with preoperative anxiety in children include; the unfamiliar situation presented by the hospital setting, uncertainty about anaesthesia and outcome of the surgical procedure, medically invasive or diagnostic procedures, fear of pain, separation from parents and loss of control.[3, 28, 29, 46]

Parents also experience significant distress and anxiety from their child's condition[28, 47-49] and parental anxiety is strongly related to children's preoperative anxiety, maladaptive behaviors and pain.[28, 50] Parents reactions to their child's anaesthesia include observing their child's distress prior to induction, seeing their child becoming limp during induction, separation from their child after induction, and remembering past negative experiences.[51, 52]

## Strategies for reduction of preoperative anxiety

Today, both pharmacological and non-pharmacological interventions are available for management of children's preoperative anxiety.[27, 53, 54]

### PHARMACOLOGICAL INTERVENTIONS

In the past, pharmacological interventions were necessary to provide smooth and safe anaesthesia. The main goals were to achieve a general stress reduction, to provide control of autonomic reflexes and to counteract side effects of anaesthetic drugs and procedures. With the development of both the practice of anaesthesia and anaesthetic agents, and the availability of distraction and preparation programs, the need for routine pharmacological preparation of children has decreased markedly.[54] To avoid the undesirable and adverse pharmacological side-effects[54-56] and to help children to develop appropriate strategies to deal with similar situations in the future,[27, 56] the value of non-pharmacological strategies are increasingly recognised.[3, 27, 55]

### NON-PHARMACOLOGICAL INTERVENTIONS

***Parental presence*** during the induction of anaesthesia is a controversial, widely discussed question, differently practiced over the world.[53-55] Research suggests that parents often prefer to be present during their child's induction of anaesthesia and believe that their presence is helpful. However, evidence to date is not consistent that this decreases children's preoperative anxiety and increases child compliance.[53, 55] Since parents are considered the primary source of affection and comfort and are functioning as important stress-regulators for children, their presence, from a psychological point of view

has been reported as crucial, in such a highly stressful and major life event as anaesthesia.[44, 54] Parental presence during induction of anaesthesia has also been argued as a civil right for both children and parents[54] and of importance to empower the child's coping abilities.[27, 57, 58]

***Distractive stimuli*** such as video-games, toys, cartoons, clowns, music and hypnosis have been shown to reduce children's anxiety by stimulating healthy emotions and redirecting children's attention from the stressful event to relaxing or entertaining stimuli.[53, 55] It is also suggested that waiting areas equipped with animated cartoons, toys and games help children decrease their anxiety during the waiting periods.[59, 60]

A wide base of evidence supports the the paramount role of ***preparation programs*** in decreasing anxiety, improving cooperation and compliance with health care providers and medical procedures, teaching coping skills, reducing negative behaviors and psychological trauma, and fostering a faster recovery.[27, 34, 61, 62] Preparation helps children to decrease their unrealistic expectations; process, prepare for and understand procedures; increase their sense of self-control and gain trust and confidence in health care professionals.[61-63] Despite this evidence, there is a continuing debate about the most appropriate design and content of perioperative preparation programs.[64] The current available programs usually include verbal information, brochure-material, videos, play therapy, hospital tours and pre-admission clinics.[64, 65] Web-based preparation programs are new and increasingly attractive options.[66, 67]

## The paediatric patient

Historically, children did not have any rights. They were either seen as property or in need of protection. Children's perspectives were marginalised and, in many cases, silenced. The adults objective views on children's perspectives were sought and research was done *on* children, rather than *with* them.[68] There was a widely held belief that children were not capable of understanding and providing accurate accounts of their experiences due to developmental immaturity. Adults were also assumed to be able to extrapolate memories from their own childhood and thereby identify the concerns of children.[18, 69] Arguments against involving children in research were based on a belief that data obtained from children was unreliable and for ethical concerns over children's vulnerability and need for protection.[68]

Today, there is an increasing awareness that children's perspectives and experiences differ from adults, making adults acting as proxies for children

inappropriate and insufficient.[68, 70, 71] True protection of children requires protection of their rights, which includes enabling them to express their opinions and facilitating dissemination of those views.[68, 72] There is a growing international recognition that children have the right to participate in matters affecting their lives.[19, 20, 73] Access to information about health, illness and medical procedures is largely recognised as one of the fundamental rights of children in a medical clinical context.[19, 68]

The right of children to express themselves is protected by international and national laws. *The European Convention on the Rights of the Child*[74] challenged the way in which children were treated, sought to secure improvements in their lives, and pointed out that the best interest of the child should be a primary consideration in all actions concerning children. In its 10 articles, *The European Association for Children in Hospital*[75] has set down hospitalised children's rights to participate in their preparation and in health-related decisions.

By *Swedish legalisation*[76] all patients have the right to have a say, participate in their own care and get individually adapted information when in contact with the health care. With this, children are entitled to be listen to, involved and prepared for medical procedures in relation to their age and understanding. Health care providers are also obligated, not only to assess and meet patient's need for information, but also to follow up their understanding and participation.[77]

## A CHILD PERSPECTIVE AND THE CHILD'S PERSPECTIVE

***A child perspective*** is based on adult's outside perspectives of children's conditions, experiences, perceptions and actions, with the child's best interest in mind. ***The child's perspective*** is characterised by the child's insider perspective on the conditions, experiences, perceptions and actions, based on what the child finds as important. The child perspective means showing an interest in the child's world and what is best for them whereas to understand the child's perspective means listening to and considering children's voices.[69, 70] Children are able to self-report their feelings, thoughts and opinions.[18, 64] Despite the awareness of the importance of involving children in their own care, children's views are rarely sought or acknowledged within healthcare settings.[18, 19, 64, 78] Without including children's self-report it is impossible to understand their experiences and perspectives.[8, 78] Exploring children's opinions and experiences can help us to understand the child's world, evaluate the effectiveness of interventions and improve the effectiveness of the service provided.[18, 70]

## CHILDREN'S CONCEPTS OF ILLNESS AND PERIOPERATIVE CARE

Children of different ages suffer from different stressors during the perioperative care.[53] With the developmental considerations in mind is not surprising that children are more likely to have misconceptions about perioperative procedures and therefore are at a greater risk than adults for the development of perioperative stress.[16, 79, 80] Understanding children's concepts of illness and perioperative care are key in attempts to generate age-appropriate preparation.[80, 81] It is also important to understand that children who are unwell and highly stressed may be functioning at lower cognitive levels than they otherwise would.[61]

***Infants (0–1 years)*** display natural curiosity as they explore their environment and body. In early infancy anxiety is caused by sudden loud noises and loss of postural support. Stranger anxiety is peaking between six and twelve months and around one year of age children are fearful around strangers, in unfamiliar situations and with unfamiliar objects.[82] For infants, parental presence, routines and predictability contribute to an environment of security and the greatest stress for children in this group during perioperative procedures is probably the parental separation.[83, 84] Infants are particularly sensitive to caregiver's reactions since they use emotional information gained from caregivers as a means to evaluate strange situations.[85]

***Toddlers (1–3 years)*** interact with their environment through their senses. They begin seeking autonomy and are developing a free will. Toddlers are well bonded to their parents. In combination with children's lack of perspective of time the separation from parents during perioperative procedures will be highly stressful and experienced as if they might have disappeared. Toddlers may be too young to accept explanations but will mostly respond to distraction and comforting measures.[82, 86, 87]

***Pre-school children (3–6 years)*** are curious and live in a world of rich fantasies and active imagination. They are developing their language and social skills but have a tendency to misinterpret words and concepts that require abstract thinking. Pre-school children are becoming egocentric and might have explanations for illness based on superstition, magic or a form of punishment for real or imagined behaviour. They might also believe that illness and accidents are contagious. Pre-school children have a general idea of what the body consists of and they are aware that different body parts are vulnerable and fear injury. However, they may have difficulties in separating inner and exterior realities which can make pain be experienced as something associat-

ed with external events. Their magical thinking contributes to fear of the unknown, including ghosts, goblins, darkness and frightening masks.[16, 80, 82, 87]

Pre-schoolers understanding of the perioperative procedures is limited and suggested to be the same as *"being sick, going for a doctor's check-up or taking a nap"*.[79] Common perioperative stressors include painful procedures, fear of failure and being criticised, immobilisation and loss of control, the perioperative environment, technical equipment and separation from parents.[86, 87]

***School-aged children (6–12 years)*** have improved language skills, increased logical thinking and improved perspective abilities. Children in this age-group are increasingly able to understand the concepts of illness and gain a sense of competency by demonstrating their knowledge and skills. They can grasp the seriousness of medical situations, verbalise feelings, understand cause and effects, the reasons for and consequences of procedures. From preoccupation with a world of fantasy, school-aged children begin to separate fantasy from reality. The body is divided into constituent parts and structure can be separated from function. At this age children can understand that illness can occur from inner processes as well as from external trauma. Being sick is not the result of magic spells or punishment, but can be explained by factors such as bacteria and viruses. However, in stressful situations, magical explanations and misconceptions about surgery can still occur.

School-aged children's body awareness and fear of the risk of illness causing bodily injury and disability are more pronounced than earlier. Procedures or treatments can be seen as mutilating and contribute to concerns about the way the body might be changed. Children in this age-group can also be intimidated by encountering the perioperative technical equipment.[80, 82, 86, 87] Even though school-aged children tolerate separation from parents to a higher extent than earlier separation anxiety can still be present during the perioperative care. During the school-aged years children's concerns or fears about death also emerge. Since sleep and death often are associated, for children in this age-group, it is understandable that not waking up after anaesthesia is a common perioperative fear.[80, 82, 86, 87] Because school-aged children fear the unknown, illness and bodily harm concerns related to what they will or not will remember after anaesthesia may also be raised. [87]

***The Adolescence (12–18 years)*** is a dramatic period in children's lives associated with important physical and psychological changes. Adolescents demonstrate abstract thinking, understand how their body is functioning and the reasons for invasive procedures. They can also draw conclusions from given information and calculate the consequences of planned actions. Adolescents need privacy and independence and may clearly mark their integrity by maintaining distance from their surroundings. Dependence on parents and health care providers, which can be a natural consequence of illness and hospitalisation, can therefore be problematic.[80, 82, 87] Adolescents are often concerned about being in control of their bodies. Changes that are made to their body or being dependent on help due to an illness can be experienced as a violation of their integrity.[86] Common concerns during perioperative procedures include, loss of control, waking up during anaesthesia, pain and the possibility of death.[80, 82, 87]

## The perioperative period

The perioperative period is a term used to describe the three distinct phases of any surgical procedure, which includes the preoperative phase, the intraoperative phase, and the postoperative phase. The initial phase, called ***the preoperative phase,*** begins with the decision to have surgery is taken and ends when the child is wheeled into surgery. This phase can be extremely brief, such as in the cases of acute trauma, or require a long period of preparation. The second phase, known as ***the intraoperative phase***, involves the surgery itself. It starts when the child enters the operating room and ends when the anaesthesia and surgery is over and the child enters the post-anesthesia care unit. During the intraoperative phase, the child will be prepared for anesthesia and surgery and the vital signs will be closely monitored. The final phase, known as ***the postoperative phase***, is the period immediately following surgery. As with the preoperative phase, the period can be brief, lasting a few hours, or require months of rehabilitation and recuperation. Postoperative care is mainly focused on monitoring and managing the child's physiological health and aiding in the post-surgical recovery.[88, 89]

## CHILDREN'S PARTICIPATION IN PERIOPERATIVE CARE

The importance of patients understanding of their own illness, treatment and care have lately been acknowledged as important factors related to patient safety. Patient participation and self-care capability are expected to contribute to patient's well-being and to the effectiveness, efficiency and safety of treatment and care.[90-92] Patients need for structured preparation and good communication with health care providers have been highlighted as important factors to reduce the risk of important information being forgotten or misunderstood.[93-96] Increased understanding of the preparation given is also highly correlated with patient satisfaction.[97, 98]

Children's participation and compliance during perioperative processes have important implications for outcomes and system efficiency as well as for provider and patient safety.[11, 99] Eliciting children's views and preferences are also essential to provide perioperative care responsive to their needs.

Even if children are not always mature enough to make independent choices, and their possibilities to participate may seem limited in the highly technological perioperative environment, there are always opportunities for them to participate in one way or another. Preparation is an important part of children's participation by helping them gaining control of the situation and building understanding and security for what is to come.[99] However, most children continue to report lack of preparation,[64, 100-102] do not participate in their own care[18-20] and arrive with preoperative anxiety in the operating room.[1, 31, 64]

The child's view of the perioperative care is often not considered[64, 102] and usually described from health care providers' and parents' beliefs about what children understand.[64] Also, even though it has been shown that children can identify their needs for preparation and so contribute to the development of perioperative preparation programs, their participation in the developmental processes of such programs is rare.[64, 102]

Capturing children's perspectives requires health care professionals to incorporate children's right to participate in all aspects of health care delivery. They should be sensitive to children's expressions and informational needs and should enable children's participation to allow them to make their views known on issues affecting their lives.[6, 70, 78] Children's voices provide valuable insights into their experiences, understanding and perceptions of the perioperative care expressed from their own view.[8, 58, 64, 99, 103]

### CHILDREN'S DESIRE FOR PERIOPERATIVE PREPARATION

Children have their own individual experiences of the perioperative care. They have many questions, want to be prepared in order to understand their illness and be involved, consulted and heard in relation to their preparational needs.[64, 102] Smith et al[64] highlights children's desire to understand their medical condition and procedures planned and to receive information about anaesthesia, pain, the perioperative environment, timing of procedures and family support. Despite children's call for both general and specific procedural information,[101] there is evidence that the majority of children request comprehensive perioperative information. Fortier et al[102] reports most children to desire detailed preparation concerning their surgery, including information about anaesthesia, perioperative procedures, the occurrence and duration of pain, potential complications and discharge procedures.

Wollin et al[46] emphasises that the fear of the unknown and lack of knowledge are crucial factors in increasing anxiety in children. Children want to be prepared for what to expect when entering the operating room. The environment and equipment can seem strange and threatening and the child may be approached by health care providers dressed in unfamiliar surgical uniforms.[46] Children also request information about parental presence during different stages of the perioperative processes and information related to timing of perioperative procedures.[100, 101]

Reports also indicates the importance for children to preoperatively understand how the surgery will impact their lives afterwards. Here, information about specific regimes and potential complications are requested.[46, 104] The value of having access to a continuous dialogue with the health care proviers preoperatively, are expressed as important from both children and parents, to optimise the experiences of being prepared.[104] Most children also express how extended information and different ways for delivering information are helpful in their preparation.[64, 102, 104]

## Preparation for perioperative care

Today, health care is patient centered, holistic and promotes self-care and empowerment.[105] Patient education has an important and growing role in the implementation of procedures and treatments, as well as in recovery processes.[63, 91] Education of children and parents for perioperative care is of great importance,[63, 106] and requires specific knowledge and expertise.[107] Health care providers are often unsure of what to tell a child *(content)* about a forthcoming procedure, how the information should be conveyed *(format)* and

when it should be provided *(timing)*. Provision of preparatory medical information to children often seems to be based on clinical intuition[61] and based on delivery of information[102] rather than on empirical knowledge and mechanisms associated with how children perceive, process and learn from such information.[61, 102]

Learning includes both a content: *what* has to be learned, and a process: *how* the learning proceeds, the strategies the learner use, the motives, intentions, and how the situation or the task on hand is interpreted.[108] Regarding perioperative preparation of children studies so far mostly have focused on the *what-aspect* achieved by a one-way distribution of information, in different formats, from the health care providers to the families. However, even though information constitutes the content part of learning it is not the same as learning for children who need to process the information provided to learn and fully understand.[108, 109] For optimal outcome of the preparation of children for perioperative care the *how-aspect* of children's learning has to be recognised and implemented.

Special circumstances for learning are created during perioperative processes as children are facing situations which for most of them are filled with frightening impressions and experiences. Changing perspective from children's need for information to their need for learning is expected to increase our understanding about how children's participation during the perioperative care can be supported.

## PREPARATION OF CHILDREN

Appropriate preparation provisions are of key importance in the effective management of children's medical procedures but it is not only important to inform children. To provide and give information is only a part of children's learning process. Children need to process information about their illness and health to learn and fully understand.[108, 109] Careful consideration needs to be given to *what* sort of information children should receive, *when* it should be received and *how* it should be provided to make it most possible for them to process the information.[53, 61, 62, 110] Preparation programs should be tailored to individual needs such as age, developmental level and previous experience of hospitalisation.[34, 61, 64]

Children represent a spectrum of ages whose need and abilty to process and learn from given information differs widely. It is thus important that the information is designed and conveyed in a manner which is consistent with the child's cognitive and psychological development level.[61, 100, 111]

It is also crucial that the information is communicated in a suitable quantity and at the most appropriate time related to how children of different ages process information. The younger the child the shorter the time interval should be between preparation and the medical procedure.[53, 63, 112] Since children are unable to focus their attention for a longer period their preparation should also be repeated and provided on a continuous basis to make them able to process the information given.[34, 61, 100] Providing children with detailed information specific to their needs has been shown to increase their knowledge and enable them to make sense of what is happening. Without appropriate information children may have difficulties generating accurate expectations of what they will experience.[113] Since expressions used by children for description of medical issues differ between ages it is also important that the information is clear, concrete and appropriate to the child's cognitive level.[61, 100, 102] Because it may be difficult for children to translate procedural information into a clear set of expectations about what they will experience, inclusion of sensory information can help the child formulate their expectations. The available evidence therefore suggests that the information should be concrete and a combination of both procedural (*what will be done*) and sensory information (*what will be experienced*).[61]

Children have different experiences of illness and hospitalisation. For many their previous medical experiences are negative and distressing resulting in increased levels of anxiety.[61, 102] It has been found that children with a history of anaesthesia and surgery do not require less preparation as compared to children who never had surgery.[102] Children undergoing repeated perioperative procedures thus require preparation equal to children experience anaesthesia and surgery for the first time.[3, 61, 102]

## PREPARATION OF PARENTS

While a child is hospitalised, the entire family is involved.[114] Parents are most important as a link between the child and the health care providers and have a major role in children's preparation.[100] Reduction of parental anxiety is shown to decrease children's anxiety[115] and information passage to children via parents is vital since a well-prepared parent usually transmits the same to the child.[116] Children have also expressed the importance of support from parents to process the information given by health care providers.[113] In light of parent's important role for children's preparation and support they must be prepared to carry out this role most

effectively. Preparation programs should therefore also be directed to them.[27, 61, 63, 100, 117] Participation in preparation programs reduces perioperative anxiety in most parents[28, 47, 62] not only when the information is provided directly, but also through their child's preparation,[3, 118] given that parents could be indirectly involved in the preparative activities through their child.[65] Parents appreciate comprehensive and detailed information about their child's hospitalisation.[41, 62, 119] They who are prepared for and understand their child's expected behavior as well as their role are also more supportive during procedures.[120] Despite this, most parents report insufficient understanding and that their own stress levels could have been reduced if they had been better prepared.[48]

## WEB-BASED PREPARATION

The digital age is upon us and to varying degrees integrated into everyday life in most countries around the world. In Sweden, 92% of the population has a computer, 93% have access to the internet, 56% own a tablet and 77% a smartphone. Most families with children (87%) have multiple computers, tablets and smartphones. The age at which children start using the internet is notably earlier nowadays (67% of two year olds) and the proportion who use it daily increases with age (32% at age 2 years, 50% at age six years, 75% at age 10 years and 96% of teenagers).[121]

Web-based technology is a rapidly emerging source of health services which has been shown to efficiently convey information in a number of health areas.[122-126] There is a move in health care to incorporate health information technology to increase access to patients, patient engagement and improve health care provider–patient communication and decision making to minimise the gap between evidence and practice.[127-129] With the proliferation of technology and the ubiquitous presence of internet and mobile media more effective communication methods have become available to help improve delivery of information and education to children and families in relation to paediatric care.[129-132]

The literature supports the use of web-based technology in patient education with a positive impact on knowledge acquisition and communication between patient and health care providers.[133] Web-based technology opens up new possibilities in patient education and offers a totally new approach which provides patients with improved opportunities for empowerment.[134] Patients bring a variety of experiences and learning preferences to the educational environment. Strategies to ensure

the success of patient education programs involve more than the delivery of information. Information must be delivered in a way that is accessible and meaningful for the learner. Web-based technologies can be customised to support this important educational concept.[133]

Studies on adults show that a patient-tailored multimedia website combining text, animation and video is effective to support the understanding of the information provided by the anaesthesiologist. The use of such a website gave a significant increase in knowledge compared to only verbal information, or verbal information combined with brochure material.[97] Despite the use and evaluations of web-based programs in other areas of paediatric care[135-137] evidence is lacking about the use of such programs within the context of the perioperative care. However, the few existing evaluations of a web-based preparation program, in paediatric perioperative care reports to be well received by children and parents, effective for preparation and reduction of immediate behavioural outcomes, including decreased preoperative anxiety and emergence delirium.[66, 67]

Today, there is an increasing development and availability of web-based programs for children in the paediatric care. Web-based information can be interactive and patient centered but if it is not used with consideration of learning processes it might work only as another information provider. Receiving information does not mean one has learned and understood. Learning is a process about constructing one's own understanding.[138, 139] Children need to process information about their illness and health to learn and fully understand.[108, 109] Web-based preparation programs therefore have to change focus from information provision to learning.

## About learning

### ASSUMPTIONS ON HOW WE LEARN

Learning, in this thesis, is based on the assumption that children's new understanding is constructed in relation to previous knowledge, perceptions and experiences of hospitalisation and perioperative care. Learning always implies the integration of two different processes: an internal psychological process of elaboration and acquisition within the learner, and an external interaction process. Both processes must be actively involved for learning to take place. Thus, all learning will always include three integrated dimensions: content, acquisition and environment.[108] The *content* is what is learned from various sources of information. In the *acquisition* of the information, the learner constructs meaning and the ability to develop functionalities to deal

with new challenges. The dimension of incentives within acquisition includes the availability of mental drivers such as emotions, motivation and a will to run the learning process and develop functionalities to deal with new challenges. The *environment* stands for the interaction process between the learner and the social, cultural and material environment.[140]

Piaget[141] believed learning to be a dynamic process consisting of two different, but complementary, processes: assimilation and accommodation. The most common type of learning in daily life refers to *assimilative learning* in which the meaning of new information is integrated into existing knowledge, cognitive structures or patterns without restructuring the current schema. If new information causes inconsistencies which the learner is unable to relate to existing schemes or patterns and the experiences are valued as important and worth acquiring, *accommodative learning* takes place. The accommodative learning is based on assumptions that new understanding is related to previous understanding as the learner continuously constructs new mental structures in the brain which are connected to previous ones. [140, 141]

Learning is a process whereby new or modified interpretations of perceptions and experiences are synthesised and involves the whole person. Meaning, knowledge and understanding are created based on different kinds of information and by and in interaction with people, artifacts and the environment.[138, 139] No one can passively receive understanding and skills from others. Learning is a multifaceted phenomenon which requires processing of information cognitively, emotionally, socially and through testing and practical actions.[109, 140]

Meaningful learning in the sense of understanding and comprehension comprises cognitive and social dimensions, that interacts in the learning process.[142, 143] Bandura[142] and Vygotsky[143] emphasised that learning is social in nature. We learn and construct meaning from and in interaction with others and the environment. Already Dewey[144] described that awareness and understanding of what we encounter and experience is dependent on continuous stimuli from other people and the environment. The individual takes on values and desires of others and assesses successes and failures in relation to others and the social context. Variation is central in the learning processes. When the learner perceives something different compared to previous experiences, the learner's ability to be aware of different aspects of a phenomenon or a situation increases. Without variation there will be no discernment or learning.[145]

## CONCEPTS OF LEARNING

In this thesis the concepts of pre-understanding, motivation, learning processes and the outcome of learning will be used to reflect on and analyse children's learning in relation to perioperative care.

### *Pre-understanding*

Pre-understanding, described by several researchers[108, 138, 144] as significant for learning, means all humans have conceptions and perceptions about situations we are facing. Pre-understanding is built on emotional, cognitive and practical lived experiences, knowledge acquisition and reflections which are more or less conscious. Pre-understanding is a prerequisite and constitutes the basis for interpretations of new experiences and thoughts, understanding and appraisal of what is seen, heard and experienced. The individual interpretation of the world always starts with what is already know which helps to understand but also to react if something seems odd, different or frightening. Although the awareness of the pre-understanding is often not apparent, it will direct the individual attention and action. Pre-understanding can thereby be a barrier for learning when thinking gets obstructed and the ability to see and consider other perspectives decreases. Children bring varied levels of experience and learning preferences to the educational environment that is offered. From an educational perspective it is a challenge to understand existing features of the pre-understanding of a group of children, for example children of a certain age, as well as the variety of children's individual pre-understanding within a group.

### *Motivation*

Consensus can be found among educational researchers that the learner's motivation is vital to stimulate the start and maintenance of a learning process. Some common features related to the characteristics of motivation have been highlighted in different learning theories.[108, 141, 144, 146] The experiences of meaningfulness are crucial to stimulate the motivation to learn. The learner has to be driven by a will to understand and/or manage something. To learn has to be important, for different reasons. Meaningfulness can be triggered both by external factors, like *"I will get a reward of some kind"* or *"someone will be very proud if I manage something"*, or internal factors, like *"my curiosity is awakening"* and *"I want to find out how something works"*. Meaningfulness is also triggered when previous approaches used to solve problems are not working and new questions that need to be investigat-

ed arise. The individual experiences an urgent need to understand and begins to search for information of different kinds in order to cope with the situation. The experiences of something being fun and exciting are also important for meaningfulness.[147]

According to Piaget[141] humans pursue equilibrium in relation to the environment. Each action requires an interpretation of what we see and experience (*assimilation*). Insufficient understanding creates imbalance and the searching for explanations via reconstruction of thoughts, searching for explanations and understanding, to restore the balance (*accommodation*), starts. Achieving balance, to understand and manage, becomes an important form of feedback which, in turn, stimulates continued learning.

### *Learning processes*

The individual's processing of information in different ways and on different levels is central and constitutes the essence of the learning processes. The learner does not only receive information but also interprets and connects the information to already existing knowledge and thereby constructs new understanding. Feedback on learning achievements is very important in this learning process.[148, 149] Knowledge is stored, interpreted and incorporated in the memory, in the brain using concepts related in semantic networks. In order to recognise situations, facts and solve problems, new knowledge has to be associated with the individual existing conceptual structure. New information must have a new meaning for the individual to be included and perceived as part of the whole. This highlights the importance of processing perceived problems and questions and not only of being offered a complete answer.[150] A creative learning process can be based on an investigative approach to the situations and problems encountered by the learner. All senses are needed to capture new information and process existing knowledge cognitively, emotionally and by action. By processing the new information, analysing the old and new understanding, new understanding and knowledge can be constructed.[138, 140]

Play constitutes a central part in children's life and an important part of their learning process.[151] Interactivity is an important part of children's play which enables children to learn by using all their senses to understand the situations encountered.[152] The concept play, which relates both to free and rule-based activities, has connotations of many different kinds of activities and meanings for both children and adults. Play, playfulness and imagination can, in an overall perspective, be understood as a process of engagement,

transformation of signs, meaning making, reflection and meta-reflection. These perspectives relates play to learning activities. Learning involves playing activities and playing can also be understood as learning activities.[151]

### *The outcome of learning*

Learning processes are meant to result in understanding, ability to perform skills and maybe changed attitudes and behavior depending on the learning situation.[108, 138, 150] It is important to change problematic frames of reference, such as mindset and habits of mind. From being fearful and unprepared children's learning helps them to understand and become capable of changing their perspectives and definitions of the perioperative procedures.[139] In this case the learning goals are related to children and parents being prepared for a hospitalisation and more specifically for the perioperative care. This means for the child to understand what is going to happen and being able to cope with the situation. Of importance is also that both children and parents experience safety and confidence. The outcome of children's learning on a website will appear mainly when they attend the hospital, which may be too late. Thus, it is also important to support children's learning processes by enabling optimal prerequisites for them to evaluate their learning via the website prior to the hospitalisation. Feedback on the learning achievements can support the learner to be confident that the message is understood correctly or make clear that one needs to repeat or try again.[149, 153]

## Web-based learning

Web-based technology opens up possibilities and offers approaches to learning in congruence with the assumptions about learning mentioned above. Interactive play constitutes a positive driving force for learning without constraints and compulsion which enables children to be active and with the use of all senses explore new ways for understanding and learning.[152, 154, 155] Compared to traditional education materials web-based technology can expand the range of things that children can create and in doing so enable them to encounter ideas that were without the new technology, not accessible to them.[156] As a learning tool web-based technology offers a number of avantages in the health care context, including a widespread availability, tailoring of information to the individual needs, a private learning environment and an immediate reinforcement of the learning that has occurred.[61, 66, 67, 133, 157]

Web-based technology also enables children contact with experts or others facing similar health challenges. The social integration and sharing of information that occurs through these connections may increase children's involvement, learning and understanding of medical conditions.[133] New communicative conditions make learners become not only consumers of information but also producers of information and active members of learning communities. With new resources for communication, new demands and new possibilities are raised for learning.[151]

When developing web-based preparation programs for children in paediatric care the awareness of the diversity of ages and cognitive developmental levels are central. Children need opportunities to learn in a way that works for them.[18, 34, 61] To meet individual learning needs it is also important to keep in mind that the individual pre-understanding of children of the same age will vary depending on their previous experiences, knowledge and approaches to learning.[61]

Motivation is stimulated both by a challenge and the experience of having to master something, as well as by the feeling of succeeding.[108, 144] Feedback on the learning achievements plays an important role in stimulating motivation and is also part of experiencing meaningfulness.[148, 149] Well-designed computer programmes offering children some control over the learning activities, and providing opportunities for choices or imaginative expression, facilitate children's creative approaches to learning and increase interest and engagement.[154] Children's motivation has been shown to increase when they are involved with engaging and fun web-based technology.[154, 158] Computer learning activities can elicit high levels of interest in and focus on the learning task that does not tend to diminish over time.[159, 160]

Web-based technologies can be designed to involve all senses to stimulate the learning process. Consciously, stimulating and use of all sences with a variety of multimedia features complementing each other intellectually, emotionally and practically, optimises the learning process.[140, 145, 160] As a tool in the learning process web-based technology gives the learner specific opportunities for information seeking, communication and processing of information.[154,160,161] A number of studies indicate the use of web-based technologies to support learning and to provide children with opportunities to learn and practice skills in an engaging and interactive environment.[54, 160, 162-164] Web-based technology make it possible to engage children in collaborative learning and problem-solving activities previously thought to be too sophisticated for them to carry out at very young ages.[155, 165]

Rochelle et al[165] report that learning with web-based technology is most effective when characterised by an active engagement, participation in groups, frequent interactions and when feedback is provided and connections to the real world are made. The development of sophisticated computer games has resulted in new approaches to learning principles emphasising the role of elaboration, playing and engagement.[151, 161] Through interactive learning with a variety of games, pictures and sounds, children experience the content in different ways and receive several associations which help them to remember and assimilate new information.[166]

The use of web-based technology is associated with improvements in children's skills for reading, languages, mathematics and hypothesis formation.[156] Well-designed web-based learning activities also can improve children's development of concepts and cognition, planning, problem-solving, abstract and reflective thinking, analysing of information and scientific reasoning.[154-156, 165]

The dynamic nature of web-based technology seems to help children to create mental models[165, 167] and concretely explore abstract scientific concepts that would have been difficult for them to manipulate and learn without electronic components.[154, 165] It can help children to understand health concepts and their complex relationship and to formulate thoughtful and plausible theories about the events behind the observable data.[159] Web-based technology can also be effective for comprehension and recognition of unfamiliar words, understanding of cause and effect and for introducing children to abstract concepts, which were previously considered too advanced for their age group.[154, 155, 165, 168] Technology-based activities can also engage children in collaborative learning, reasoning and problem-solving activities[155] The fact that children are not only served the content but must be active stimulates creativity and imagination which leads to engagement and an extended attention span.[154, 165, 169]

## Rationale

Children's vulnerability in relation to paediatric care highlights their need for preparation customised for their age, maturity and level of understanding. *First* this is a question of children's legal rights and wellbeing. *Second* it's a question of enhancing self-care capability and empowering children to participate and managing their own perioperative experiences. *Third* this is a question of patient safety.

Internet is a learning resource for the modern patient. Despite the rapidly increasing development and use of web-based preparation programs in paediatric care evidence is lacking about children's comprehension of such programs for children's experiences and outcome of procedures. In addition, utilisation of children's own perspectives and their involvement in the developmental processes of web-based preparation programs is rare. The strategies in this research involve the need for two radical changes related to paediatric perioperative care.

***The first change*** is the move from a child perspective to children's perspectives and based on their experiences secure children's participation both in their own perioperative care and in the development of preparation programs. Children can help us understand what, how and when they need information to learn, understand and cope with the perioperative care. Such a knowledge base can be used to create optimal possibilities for children's learning processes to support their sense of coherence, ability, autonomy and self-care.

***The second change*** relates to children's understanding of the preparation provided. Instead of focusing on information we would like to introduce the discourse of children's learning. Changing perspective from children's need to only receive information to their need for learning is expected to increase our understanding about how children's participation during perioperative care can be supported. This is even more important in our society today with all the possibilities to provide information on internet and social media. Web-based information can be interactive and patient centered but if it is not used with consideration of learning processes it might work only as another information provider. Web-based preparation programs for children therefore have to change from health care providers only giving information to focus on the learning processes being central.

There are important discussions in the society today about disadvantages of children's increased use of internet. A decision was made to not inquire into this complexity in this thesis which instead will focus on the possibilities related to development of web-based preparation programs in paediatric care.

Learning theories and processes related to children's learning in connection to the analysis of the use and understanding of web-based preparation programs represents an important part in this research. Some basic assumptions are based on knowledge about child development, research on children's experiences of hospitalisation and perioperative care as well as knowledge about the role of verbal, written and visual data in communication. This project builds on the assumption that being well prepared means that children have learned and understood what is going to happen and thus are able to participate in the perioperative care based on their own needs and perspectives.

# AIMS

The overall aim of this thesis was to provide a deeper understanding of how web-based technology can support children to learn about and be prepared for perioperative care.

To achieve the overall aim of the thesis, the specific objectives for the included studies were:

**1.** To investigate the degree of information transfer to children and their parents that receive either web-based information or traditional brochure material preoperatively.

**2.** To elucidate key educational principles in the development and design of websites for children in paediatric care.

**3.** To explore children's perspectives when facing anaesthesia and surgery.

**4**. To analyse children's use of and experiences with a web-based perioperative preparation program in relation to an educational framework of children's learning.

# METHODOLOGY

## Research approach

The overall aim of this thesis was to provide a deeper understanding of how web-based technology can support children to learn about and be prepared for perioperative care. Different research approaches were used. A quantitative approach was chosen for the first study and study three to four adapted different qualitative approaches. The choice of different research approaches should be seen in relation to the different objectives for the included studies and to the continuous process of the project. The research takes a pragmatic stance since the underlying meaning of the aims primarily was derived form a real-world setting and the intention for the research was to increase the understanding and knowledge for practical application and improvements.[170]

A **paradigm** is defined as a framework of beliefs underlying the research. It includes ideas about the world (ontology), how it can be understood (epistemology) and studied (methodology).[171] The ***ontology*** represents the study of being, the nature of existence and structure of the reality. The ***epistemology*** represents the theory of knowledge, its origin, nature and limits. The ***methodology***, the research design or plans that shape the methods to be used in the studies.[172, 173] The basic beliefs that define paradigms can be summarised by the responses given by the proponents of any given paradigm to the following fundamental questions. The ontological question: *"What is the form and nature of reality and, therefore what is there that can be known about it"*? The epistemological question: *"What is the relationship between the knower and what can be known?* The methodological question: *"How can the inquirer go about finding out whatever he or she believes can be known?"*[173]

Paradigms have been described as positivism, post-positivism, critical theory, constructivism and participatory paradigm and can be understood to compromise a set of ontological and epistemological assumptions guiding the individual research or a scientific field.[173] The various paradigms are characterised by differences in their approach of how to conceptualise and conduct research and in their contribution towards disciplinary knowledge construction.[174] Each paradigm thus has important consequences for the research that follows in terms of procedure, interpretations and findings.[172]

Based on the descriptions of paradigms by Guba and Lincoln[173] the paradigm of the quantitative part of this research (Study 1) is **positivism**. The *ontology* of positivism is realism meaning there is one static and fixed reality which can be captured, assumed to exist in an absolute sense and the aim is to explain the social world in terms of laws, cause and effects. The *epistemology* is related with objectivism which assumes the findings represent the truth and that the researcher is capable to investigate the object of the study without influencing it or being influenced by it. Science is accurate and certain in contrast to values, opinions and feelings. Positivistic *methodology* is concerned with the prediction and control of a phenomena, involving trials to confirm or falsify hypothesis to support or disprove a theory. The methodology is designated to isolate and remove subjectivity and bias. With the positivistic standpoint the quantitative study included in this research aimed to investigate the degree of information transfer to children and their parents that receive either web-based information or traditional brochure material preoperatively. The hypothesis was that web-based format was associated with better information transfer as compared to printed options.

The paradigm of the qualitative parts of this research (study 2-4) is **constructivism** which holds there are multiple interpretations and that the goal of research is to understand how individuals construct reality within their own context. The ontology in the constructivist field is viewed as being relativistic and related to the individuals' perceptions and interpretations. The *epistemological* perspective states there are diverse interpretations of the subjective reality and the research finding are constructed from a relationship between the researcher and the participant. Compared to the positivism methodology where knowing is something discovered a constructivist *methodology* states it is something socially constructed through participation and interaction with others. The methodology in constructivism is hermeneutical and dialectical in the meaning that the researcher interprets the construction presented by the research object and compares and contrasts them through a dialectic interchange. Interviews and observations are commonly used methods for data collection in hermeneutic research in which knowledge is seen as created in interactive and relational conversations. With the constructivist standpoint the qualitative studies included in this research aimed to explore children's own perspectives of the perioperative care (study 3) and children's use of and experiences with a web-based perioperative preparation program in relation to an educational framework of children's learning (study 2 and 4).

Boldly stated, quantitative methods, aimed to generalise findings dominate the positivist and post-positivist paradigms while qualitative methods, aimed at a deep understanding of specific causes or phenomena, without erasing differing perspectives in particular context, are more common in interpretative paradigms.[175, 176] Reliance on the traditional positivistic paradigms has been the dominant norm for exploring the phenomenon of paediatric perioperative care. Although the quantitative paradigms provide valuable information on the psychosocial sequelae of children's responses an account of children's own perspectives of the perioperative care is missing.

## Research with children

### METHODOLOGICAL IMPLICATIONS RELATED TO RESEARCH WITH CHILDREN

Children's involvement in research is vital for understanding their lives, ensuring their right to participate in matters that affect them and for enhancing the value and credibility of findings. Ethical considerations have shifted significantly from a focus positioning children as vulnerable and requiring safeguarding by adults including researchers, to an emphasis on recognising children's agency and competency, and highlighting children's participatory rights. Respectful research is situated in the lives of children and founded on the assumption that children's experiences and perspectives should be taken into account. Children and young people have to be viewed as persons with their own rights and as worthy and capable of recognition and respect in research.[68, 177] Wide evidence is now also demonstrating that children are competent participants in research processes as long as researchers recognise the ways in which children communicate and facilitate their participation.[71]

Research with children differs from research with adults. *First*, children experience unequal power relations due to their marginalised position in an adult-centered society. *Second*, there is a risk that the adult researchers' perceived assumptions and attitudes to children will affect the choice of methods and how the data is interpreted. *Third,* the research process with children will differ due to the inherent differences in children's cognitive developmental levels.[178]

A central concern when conducting qualitative health research with children is eliciting data that genuinely reflect their perspectives.[179] Key methodological issues identified in research with children relates to the epistemological question about the different cultures of childhood and adulthood and

to the heterogeneous nature of childhood itself. Except for on a cognitive developmental level adults and children also differ in perceptions, perspectives and constructions of the world. Even though adopting a child's perspective, the adult researcher thus has to be aware to not collect and interpret children's world through various layers of their own experiences of childhood.[71, 178, 180] In order to contrast childhood and adulthood, children often are recognised as being part of one homogenous group. Research with children thus also includes the recognition of that children are a highly differentiated group with consequent methodological implications. The researcher has to recognise both *the culture of the childhood* and *the culture of the individual child*.[71]

## DATA COLLECTION WITH CHILDREN

There is an increasing need for taking children's perspectives into account in the context of paediatric perioperative care.[99, 102] One way to let children participate and contribute with knowledge about their perspectives is to let them speak for themselves in interviews. However, interviewing children is a challenging and complex task, and the field is normatively loaded. Interviewing children who are reluctant to talk or communicate and aiding children to verbalise their experiences, especially at a highly stress-point as during the perioperative period, are other factors affecting the interview situations.[180, 182] As utilised in this research an important part of the data collection in association with interviewing children thus is the combination of observations.[71, 180-182] Interviewing children is about building trust to an adult stranger which can take time and might require pre-meetings and multiple interviews. Since the feasibility of child interviews especially are dependent on the interviewer's ability to interact and gain children's confidence establishing trust must be considered as crucial for the result of the research. [180, 182]

All interviews included in this research were conducted in a semi-structured manner. Before the interviews started children's willingness to participate were re-checked by the researcher. The interview technique and the questions were modified to be compatible with the individual child's linguistic and cognitive stage of development. Considerations were taken to children's limited ability to understand abstract concepts and the interviews were concentrated on concrete facts and situations.[71, 180, 182] The interviewer was flexible for changes and prepared with an alternative structure to come close to children's experiences. Alternative expressions and phrases were prepared if the child couldn't understand or refer to the used vocabulary.[182] A reflective interview technique was used, to check what the child really meant or said, when inconsistencies

were identified in children's answers.[183] Since children's behavior and attitudinal preferences, often is context dependent, the interview space was tailored to the individual child's wishes and sometimes the interviews were performed during activities.[72, 182]

When interviewing children, it is recommended to allow for an informal conversation and to encourage children to use their own words.[71, 182] The atmosphere surrounding the interviews was relaxed and the interviews had a conversational character. The interviews began with an open and general conversation about the child's interest and daily activities which gave the interviewer an opportunity to develop rapport, distract, and individualise the interview technique. To put less weight on the child's verbal ability, and forge a path for understanding of the child's experiences, the interviews proceeded with a series of close-ended to questions help the child to begin to engage in the interview process and assist in identifying openings for additional questions.[182]

The conversation continued with specific questions about preparation strategies and perioperative procedures. Children were assured there were no right or wrong answers and that it also was accepted to not having any answers at all[180] The interviewer was actively engaged in the conversation and asked follow-up questions as; *"what do you mean?"*, *"can you explain?"*, *"can you tell me a little bit more about that?"*, *"where have you learned that?"*.[180]

To provide further access to the questions and concerns related to children's experiences and understanding the interviews continued with open-ended questions, which enabled the child to be true to the variety of way to mediate thoughts and feelings. Not only may predetermined questions be inappropriate for the particular child but may also fall outside the context of their experience.[182, 184] The open-ended question related to children's experience of the hospitalisation was adapted for children's different chronological and cognitive developmental levels.[71, 180, 182] To encourage children to expand on their experiences they were asked; *If you were to tell a friend about hospitalisation, anaesthesia and surgery, how would you describe it?* (3–6 y); *If one of your friends was about to be operated on, how would you explain about anaesthesia and surgery?* (7–11 y); *What was your experience of hospitalisation, anaesthesia and surgery?* (12 years and older).[185] To increase the children's influences they were given the opportunity to manage *(when to start, when to pause and when to stop)* the cellphone on which the interviews were recorded as well as without influences from the researcher navigate the website. All children were encouraged to interrupt the interviews if

they wanted to take a break, did not understand the questions or wanted to continue the interviews.

## Research design

The present research project was conducted using both quantitative and qualitative approaches. The aim for the quantitative part included was to compare children's and parents' level of knowledge after receiving either interactive web-based information or traditional brochure material preoperatively. The qualitative interpretative parts of the research aimed to elucidate the importance of including an educational framework and children's own perspectives in web-based learning design in paediatric perioperative care. The included qualitative studies built on each other and the result from the first qualitative study guided the design and objective for the following. The basis for all included studies was the Anaesthesia-Web (AW) (www.anaesthesiaweb.org) representing a comprehensive and worldwide used web-based preparation portal in paediatric perioperative care.

### THE ANAESTHESIA-WEB

The Anaesthesia-Web (*Figure 1*) represents a comprehensive, interactive, age-different multimedia web-based portal to prepare and educate children and families prior to contact with paediatric care. On the Anaesthesia-Web children can learn about the body and how it works, what it is like to be hospitalised and what happens before, during and after anaesthesia and surgery.

The Anaesthesia-Web aims to provide preparation and learning possibilities for children in different ages and parents. The Anaesthesia-Web contains a wide range of communication modalities such as films, cartoons, web-books, games, blogs, videos and interviews with children of different ages. Two characters, *Doctor Safeweb* and *Hilding Vilding* are key features of the Anaesthesia-Web. Doctor Safeweb is available all over the website to guide visitors and to answer frequently asked questions (FAQ). He conveys all information in both writing and with recorded narration. Hilding Vilding works as a curious spy scout in the hospital. He is as tiny as the palm of the hand which means he can be present everywhere and investigate everything without being discovered.

Two notice boards are available on the Anaesthesia-Web, one for younger children and one for adolescents. On the notice boards children can ask each other questions and share experiences in text and drawings.


*Figure 1. The Anaesthesia-Web.*

The Anaesthesia-Web (2006) was developed and produced, at Astrid Lindgren Children's Hospital, Karolinska University Hospital, Stockholm, Sweden, by a multidisciplinary team including health care professionals, children in different ages and with different experiences of perioperative care, parents, computer programmers, web-designers, journalists, authors, TV producers, advertising agencies and photographers recruited from children's magasines and TV shows.

The information on the Anaesthesia-Web was developed to be generally applicable to make it possible to be used in different health care settings. The Anaesthesia-Web is available in Swedish and three major world languages (English, Arabic, and Spanish) and contains written information in 27 languages. The Anaesthesia-Web has open access via three URL addresses. (www.anaesthesiaweb.org, www.webanestesia.org, www.narkoswebben.se)

The Anaesthesia-Web has an average of 120,000 visitors from approximately 100 different countries annually.

## OVERVIEW OF THE STUDY DESIGN

An overview of the studies, the participants and methods used for data collection and analyses is presented in *figure 2*. Study 1 and 3 were performed at the outpatient clinic at Astrid Lindgren Children's Hospital, Karolinska University Hospital, Stockholm. Study 4 was performed in children's home. Study 2 refers to the content and design of the Anaesthesia-Web itself which were analysed based on a theoretical educational framework related to children's learning. The studies should not be regarded as chronological or sequentially ordered but as integrated parts related to each other.

| Study | Study focus | Participants | Data collection | Data analysis |
|---|---|---|---|---|
| **1.** | Differences in children's and parents level of knowledge about perioperative processes after receiving either interactive web-based information or traditional brochure material preoperatively. | 103 children (3–12 y) and 115 parents scheduled for outpatient surgery. | Prospective observer-blinded randomised controlled trial.<br><br>Study specific questionnaire. Questions relevant to anaesthesia where answers could be found in both information options. | Descriptive statistical analysis using Spearman rank correlation test, Mann-Whitney U-test, Friedman test and Fisher exact test. |
| **2.** | Key educational principles in the development and design of websites for children in paediatric care. | | Data consisted of the content and design of a website developed to prepare children for anaesthesia and surgery. The Anaesthesia-Web (www.anaesthesiaweb.org). | Directed qualitative content analysis based on a defined theoretical educational framework. |
| **3.** | Children's perspectives, experiences and perceptions facing anaesthesia and surgery. | Phase 1 and 2:<br>22 children (4–15 y) scheduled for outpatient surgery.<br><br>Phase 3:<br>6 children (5–13 y) scheduled for outpatient surgery. | Individual semi-structured interviews in three different phases. Before and after anaesthesia and surgery (phase 1 and 2) and a month after the hospitalisation (phase 3). | Inductive interpretative manifest and latent content analysis. |
| **4.** | Children's use and experiences of a web-based perioperative preparation program. | 6 children (5–13 y) who underwent outpatient surgery and participated in interviews (phase 1 and 2) one month earlier. | Semi-structured interviews based on observations, one month after the hospitalisation (phase 3) when children, without guidance and influence of the interviewer, visited and maneuvered the actual website. | Directed qualitative content analysis based on the theoretical themes describing children's learning on a website identified in study 2. |

*Figure 2. Overview of the study design.*

## Data collection and participants

### STUDY 1

All children (3-12 years) and parents scheduled for outpatient surgery were approached to participate in the study. A total of 125 children and parents were recruited, of which 103 children and 115 parents were included in the final analysis (*Figure 3).* There were no differences in the demographic variables between children in the study groups. After regular medical assessment followed by structured, standardised verbal preoperative information children and parents were randomised to get further preoperative information through the Anaesthesia-Web (AW) or conventional brochure material (BM) until the day of outpatient surgery.

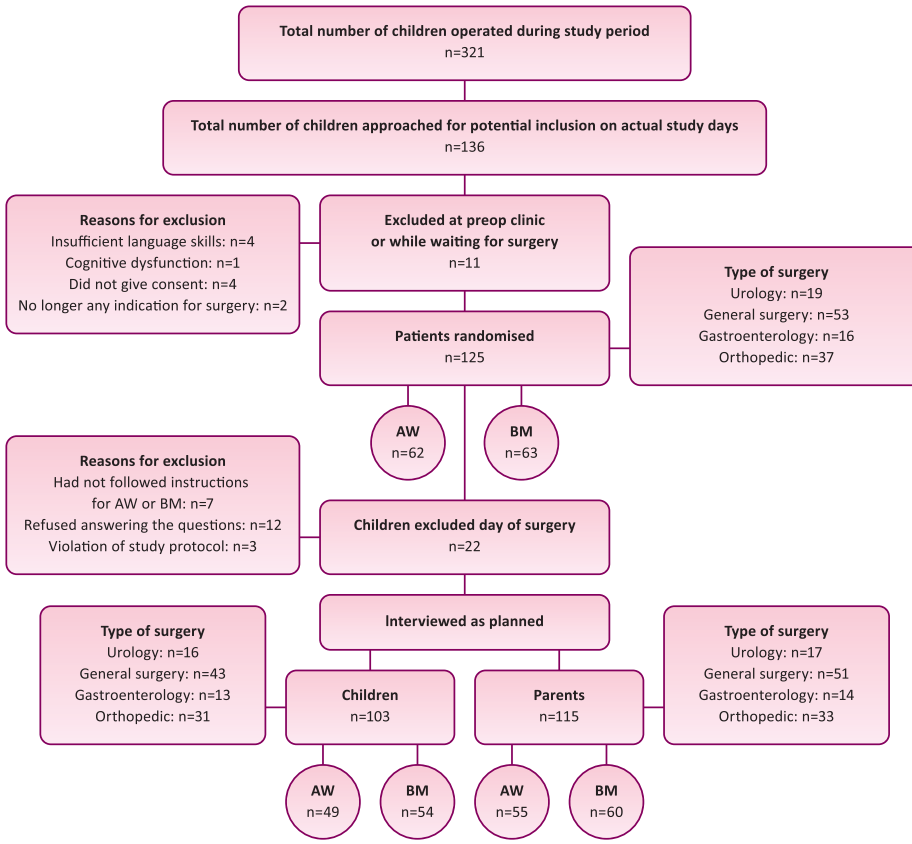



*Figure 3. CONSORT flow diagram.*

On the day of surgery children and parents were separately asked six different questions with answers available in both information options. All questions were relevant to anaesthesia and validated with content validity methodology. The primary end-point was to compare the total question score (TQS) in children between the two information options. Secondary end-points were TQS for parents and the influence of age, sex and time between the preoperative visit and day of surgery.

A power analysis based on the primary end-point of the study estimated 200 participants in total to detect a 20% difference between the two study groups. In the event of a bigger difference than expected an interim analysis was planned after 120 children were included. To stop the trial at the interim point a p-value < 0.02 was necessary. The study was stopped in agreement with the stipulation of the interim analysis after including 120 children.

### STUDY 2

In study 2 the design and the coherent content of the Anaesthesia-Web constituted the data being analysed. The data were analysed based on a theoretical educational framework related to children's learning.[108, 138, 139] The educational concepts of ***pre-understanding, motivation, learning processes and the outcome of learning*** were used to investigate the learning possibilities for children on the actual website in association with perioperative care.

### STUDY 3

The data collection for study 3 was obtained by interviews performed with children in three different phases. All families with children, 3-16 years of age (n=32), admitted for outpatient surgery during five days, were asked to participate in the three-phased study. Twenty-two children (4-15y) were interviewed before and after anaesthesia and surgery (Phase 1 and 2) and six children (5-13y) representing a variation of ages and perioperative experiences, where interviewed in their homes a month after the hospitalisation (phase 3) (*Figure 4*). The families had visited the preoperative assessment clinic a month before admittance, received information from an anesthesiologist and been advised to take part of written brochure information and visit the Anaesthesia-Web. The families were asked to participate in the study on arrival at the hospital. The parent was present at the interviews at the hospital but not during the interviews in the home. The semi-structured interviews followed an interview guide based on common perioperative areas for

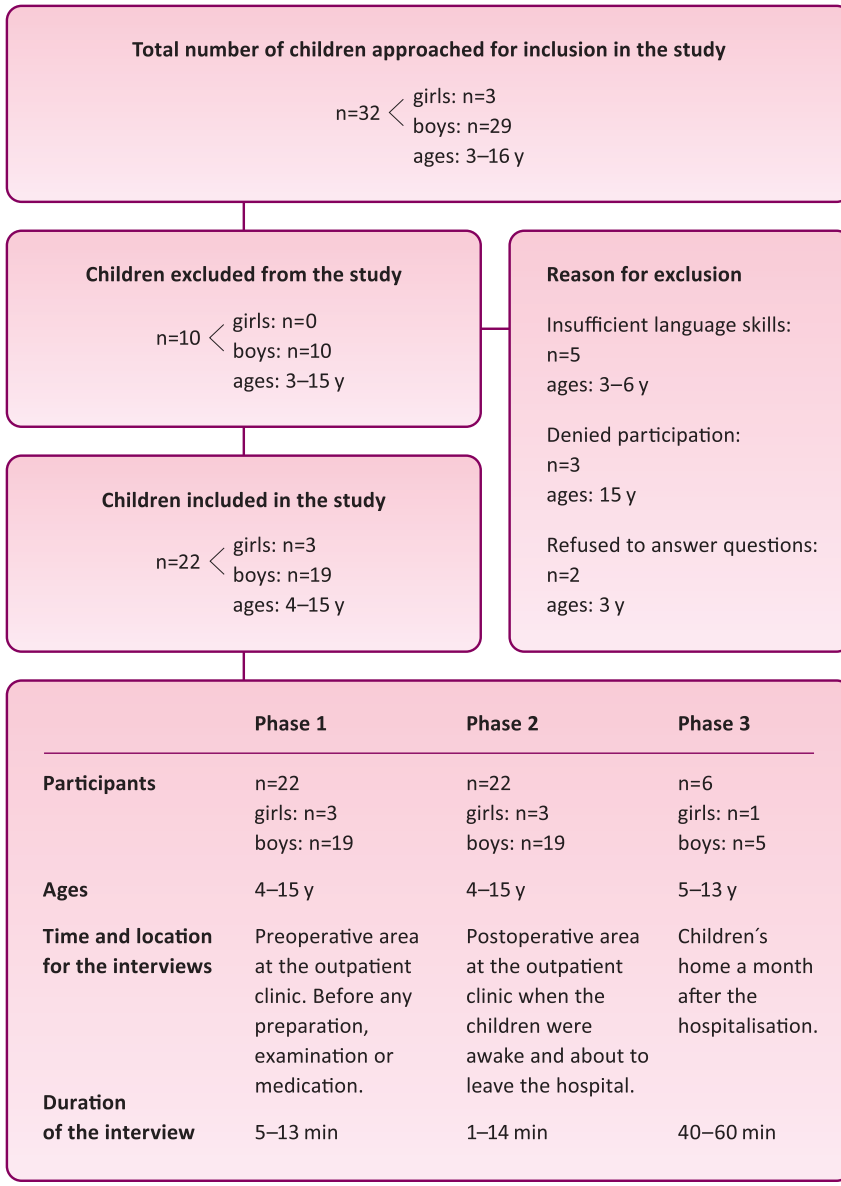
questions and concerns from children.[102] The interviews in phase 1 were conducted on children's admission to the hospital and in phase 2 before their departure for home. The interviews in phase 3 were conducted when children, without guidance and influence of the interviewer, visited and maneuvered the actual website.

The duration of the interviews varied in accordance with each child's eagerness to participate from 5-13 minutes (phase 1), 1-14 minutes (phase 2) and 40-60 minutes (phase 3). A nurse specialising in anaesthesia and paediatrics (GL), with extensive experience of preparing families for perioperative procedures, performed all interviews. The interviewer had no previous contact with the families and was not informed about the child's medical condition.

### STUDY 4

The data collection for study 4, which was the last part of the three-phased study (*Figure 4*), relates to six children (5-13 y) who participated in follow up interviews and observations in their homes a month after the hospitalisation. The included children were selected from the 22 primarily interviewed children (phase 1 and 2) to represent a variation of ages and perioperative experiences.

The interviews were conducted in a semi-structured manner when children, without guidance and influence of the interviewer, visited and maneuvered the actual website. Field notes of children's actions were taken. The interviews were based on children's performances when they were visiting the website and described the content in relation to their experiences of the perioperative care. The interviews were performed in children's home, without any parent present, in a room chosen by the child.




| | Phase 1 | Phase 2 | Phase 3 |
|---|---|---|---|
| **Participants** | n=22<br>girls: n=3<br>boys: n=19 | n=22<br>girls: n=3<br>boys: n=19 | n=6<br>girls: n=1<br>boys: n=5 |
| **Ages** | 4–15 y | 4–15 y | 5–13 y |
| **Time and location for the interviews** | Preoperative area at the outpatient clinic. Before any preparation, examination or medication. | Postoperative area at the outpatient clinic when the children were awake and about to leave the hospital. | Children´s home a month after the hospitalisation. |
| **Duration of the interview** | 5–13 min | 1–14 min | 40–60 min |

*Figure 4. Overview of the participants and interviews conducted in the three-phased study.*

## Methods of analysis

As described previously, the theoretical standpoint for the *quantitative study* included in this research was based on a positivistic tradition with an epistemological belief that asserts there is an absolute truth or reality that can be discovered and knowledge is therefore objective and neutral. The *qualitative studies* were based on a constructivist and interpretative tradition assuming a subjectivist epistemology, which means there are multiple realities and that the participants constructs meanings of their experiences in interaction with other people, including the researcher.[173, 175]

### QUANTITATIVE METHODS

#### *Statistical analysis*

All statistical analysis in study 1 was performed using GraphPad InStat Ver.3.04 (GraphPad Software Inc. San Diego, USA) and Microsoft Excel. Correlations were established by Spearman rank correlation test. Mann-Whitney U-test was performed for comparison of two independent groups of samples. Classified data from two independent populations were compared using the Fisher exact test. The Friedman test with Dunn's multiple comparison test was used for the comparison several related groups. Calculations of nonparametric 95% confidence intervals for difference between two location parameters were based on the Mann-Whitney test. Reported p-values are from two-sided tests.

### QUALITATIVE METHODS

Qualitative research contributes to an understanding and meaning making of the participants experiences and perceptions in different contexts. Qualitative methods correspond well with research with children in various cognitive developmental stages since it allows for an individual freedom of expressions of what is meaningful. Qualitative methods can provide insight in children's experiences, understanding and perceptions of the perioperative processes through a collection of valid and meaningful data expressed from their own view.[184]

#### *Qualitative content analysis*

Qualitative content analysis (QCA), is a widely used research technique analysing written and verbal communication. Qualitative content analysis is defined as a method for interpreting data through an iterative, systematic coding process, focusing on differences between, and similarities within, parts of

the text, and by identifying categories and themes on different interpretation levels. With the emphasis for variation qualitative content analysis search for *"the what, who, why and how"*.[186-188]

***Inductive reasoning*** is developing conclusions from the collected data by weaving together new information into themes and patterns. The analysis is performed with an open mind to identify meaningful subjects answering the research questions. In ***deductive reasoning*** the researcher looks for predetermined, existing subjects by testing principles or a hypothesis.

Qualitative content analysis involves interpretation of data at several stages during the analysis process. The degree of interpretation in QCA can differ depending on the aim for the analysis and be placed along a continuum, from interpretation of the ***manifest*** content, which stays close to the text, describe the visible and obvious and what the informant actually says, to an interpretative latent level in which the researcher seeks to find the underlying meaning of the content. The depth of the analysis will depend on how the data is collected, from showing patterns in the manifest content, to a ***latent*** interpretation, in an attempt to theorise the significance of the patterns and their broader meanings and implications.[186-188]

Current applications of content analysis show three distinct approaches: Conventional, directed and summative content analysis.[189] Summative content analysis involves the counting of words or content and the interpretation of that quantification. The approaches used for analysis in this research refer to ***conventional content analysis*** in which coding categories emerge direct from the data rather than from preconceived categories being imposed on the data. In ***directed content analysis*** the analysis starts with a theory or relevant research findings as guidance for application of conceptual categories and coding of the text.

### Conventional content analysis

The conventional qualitative content analysis used for analysis of the interviews in all phases in study 3 was performed with an inductive approach including open coding, creating categories and abstraction.[186-188] When working inductively without a theory based matrix it is important that the data used are as unstructured as possible. The ***manifest content*** in the analysis refers to the visible and obvious components which answers the question "*What?*", thought of as *"what the children says*", identified as a read throughout the codes, presented on a descriptive level as categories. Conversely, the ***latent content*** answered the question "*Why?*", notes the underlying meaning of

what the children says and "*what the text is talking about*". The latent content is presented as themes and is considered to be a thread of an underlaying meaning through, condensed meaning units, codes and categories, on an interpretative level.

The analysis of the transcribed text was performed in several steps. The recordings were listened to and the transcripts were read, separately by members of the research group, several times to ensure familiarity with the data and get a sense of the whole. The text was divided in meaning units, related to each other through their content and context. After the meaning units were identified the research team checked whether all aspects of the content were covered in relation to the aim. The meaning units were condensed, while still preserving their core meaning, and labelled with a code. The text was then discussed in a research group with different experience and expertise. Codes that deviated from the aim were excluded and the remaining codes were compared based on similarities and differences, arranged to sub-categories and abstracted into categories. Finally, the underlying meaning of the categories were reflected on, and two themes, constituting a thread of the latent meaning running through the codes on an interpretative level, was identified and formulated with consensus in the research group.

All themes were supported by data from children in different ages and with different experiences. Although some children tended to respond just with one or two short sentences, these provided a rich insight into their own thoughts and experiences. To ensure the participatory approach and to retain the flavor of the spoken word children's quotations were used, without minimal editing, in the coding process. The members in the research team continuously returned to the transcribed text to ensure that the analysis and the coding accurately reflected what the children stated and to confirm the consistently off the themes in the interviews. A diagram on the themes and their relationship was created and revised until the researchers agreed the data to be satisfactorily and thoroughly described.

### Directed content analysis

The analysis in ***study 2 and 4*** were performed with directed content analysis primarily guided by Hsieh and Shannon.[189] The chosen approach of content analysis is signified by applying predetermined variables or concepts to interpret data and used when existing theoretical and/or empirical knowledge about a subject is judged to enhance the understanding of a certain research question. The aim is to describe common themes characterising the object

being studied. Directed content analysis can be used when existing theory or prior research exists about a phenomenon which is incomplete or would benefit from further refinement or description. By using already existing research, a directed content analysis can extend, validate, support, or not support the evidence of a theoretical framework. Further be used to guide the process of the analysis and the discussions of findings.

In ***study 2***, the directed qualitative content analysis[189] was applied to illuminate and explain prerequisites for children's learning on a website in association with perioperative care. In this study the directed qualitative content analysis had a theoretical approach in which the design and the coherent content of the Anaesthesia-Web constituted the data being analysed. The predetermined concepts applied in this analysis were derived from a theoretical educational framework based on a combination of learning theories and especially considered in relation to research about children's learning.[108, 138, 139] The educational concepts of ***pre-understanding, motivation, learning processes*** and the ***outcome of learning*** were used to analyse the learning possibilities for children on the Anaesthesia-Web.

In the *first stage* of the analysis the predetermined concepts to be applied on the Anaesthesia-Web were chosen and described according to the basic theoretical educational framework. In the *second stage* the learning concepts were systematically applied on the Anaesthesia-Web to identify the salient web-based learning opportunities. In the *third stage*, the salient learning opportunities were analysed using a combination of the learning concepts and knowledge about children's learning in the context of health care and especially related to the analysis of web-based learning. The research group comprised different perspectives as web-based learning, medical education, technology-enhanced learning, paediatrics and anaesthesia. Two researchers (GL and CS) performed the initial analysis and the whole group negotiated and agreed on the results to ensure trustworthiness.[170, 190]

In ***study 4*** the directed qualitative content analysis[189] was applied to illuminate and explain children's use and experiences of a web-based preparation program in association with perioperative care. The data was analysed based on a combination of the transcribed interviews and field notes. The predetermined themes applied for analysis in this study were based on the central concepts for children's learning processes on the Anaesthesia-Web derived in study 2; ***In charge of my learning, Discover and play, Recognise and identify,*** and ***Getting feedback***. The directed approach to content analysis also includes an interpretation of the underlying meaning of the text.[189]

In the *first stage* of the analysis the recordings were listened to and the transcripts were read several times by one of the authors (GL) to ensure familiarity with the data and get a sense of the whole. In the *second stage* those parts of the text that appeared to be related to the predetermined themes were highlighted. In the *third stage*, the predetermined concepts for children's learning processes on the website, were analysed related to children's expressions, experiences and use of the website during the interviews. Data which primarily couldn't be related to the predetermined themes were identified and saved. The data were interpreted to elucidate additional dimensions of children's experiences and usage of the website. The interpretations were compared with the predetermined themes and described as a new theme. The analysis comprised descriptions of the manifest, concrete content focus on the visible, obvious components and what the children expressed as well as interpretations of the latent, abstract messages, yet still close to the children's experiences.[186-188] The research team continuously reviewed the data to ensure that the analysis accurately reflected children's statements and performances on the website and to validate the predetermined themes reconciling any differences using the theoretical framework.

## Quality criteria in quantitative and qualitative research

Good research is characterised by evidence that is trustworthy regardless of whether a qualitative or a quantitative approach is used. However, while qualitative and quantitative research share similar standards for good evidence, the conception and operationalisation of these criteria differ between the research approaches.[191, 192] Whilst validity (*the degree to which an instrument measures what is intended to measure*) and reliability (*the degree to which findings are consistent and replicable*) are important criteria for assessment undertaken in quantitative research the credibility of qualitative research results has to be evaluated in relation to the procedures used to generate the findings.[175, 190]

### CONTENT VALIDITY

Content validity, which is also called *definition validity, face validity* and *logical validity*, estimates how representative instrument items are of the content or subject they are supposed to measure. Content validation can be estimated qualitatively, quantitatively, or by using a combination of both methods to determine a degree of consensus among experts about the instrument in

question. An oral indication of consensus by experts in the content area at hand can provide qualitative content validity.[177, 193] Since no appropriate standardised questions or research tool was found suitable for study 1, two sets of research questions were constructed by perioperative providers with extensive experience in the research field. Consensus was reached that the questions developed were relevant for the specific study and covered the area they were supposed to access.

## TRUSTWORTHINESS

The quality criterion for the included qualitative research processes will be discussed below using trustworthiness incorporating the concepts of: ***credibility, dependability, transferability*** and ***reflexivity*** described by Elo and Kyngäs[190] and Patton.[170] By addressing similar issues as in quantitative research trustworthiness correspond to credibility with preference to internal validity, transferability to external validity/generalisability and dependability to reliability.[194]

### *Credibility*

Credibility refers to the confidence and truth in the whole research project including the choice of methodology, selection of participants, data collection, analysis and how well all these aspects addressed the focus and aim for the study. Credibility also deals with the selection of suitable units of analysis and how well the categories and themes developed cover the included data. In other words; *Are the researchers investigating what they intended to investigate, and are the findings congruent with the research question and the participant's utterances?*

With reference to credibility all different parts of the included studies were methodologically driven by the aim. All children were interviewed by the same interviewer. To capture the multiple realities of of children in various ages, and with different experiences and perspectives of perioperative care, suitable methods for the data collection were chosen. In the process of the analysis credibility was pursued by selecting meaning units that consisted of an adequate data size to be explored, though neither too extensive nor too fragmented. The analysis process was documented in notes and memos and remained transparent to all members of the research team. The research team continuously reviewed the data to ensure that the analysis accurately reflected children's experiences and perspectives (study 3) and statements and performances on the website (study 4) and to validate the pre-

determined themes reconciling any differences using the theoretical framework. The analysis process and the results were described in detail for the reader to have a clear understanding of how the analysis was carried out and the strengths and limitations of the study. The credibility was heightened by presenting the findings and processes in figures and with quotes thus showing that the results covered the range of variation found in the data.

Both data and investigator triangulation were used to reveal the various ways of understanding, describing and conceptualising the phenomenon studied. The data was triangulated by including interviewees with various experiences and perspectives of perioperative processes and by including multiple research processes and methods for data collection. Collecting data from multiple perspectives and sources resulted in rich descriptions of the phenomenon from different angles. Being a part of children's experiences and perspectives when performing the interviews and observations gave the researcher access to their perceived reality of perioperative care which was of importance for the interpretations of the collected data.

Investigator triangulation was included as an attempt to bring in several perspectives to enhance the richness of the description of preparation and learning in association with paediatric perioperative care. The research team consisted of researchers with different professional backgrounds (paediatrics, anaesthesia, education and qualitative research) which contributed to a variety of expertise, experiences and perspectives valuable for the research process. The team also compromised experience and perspectives including both quantitative and qualitative research traditions. Methodological and theoretical issues were continuously discussed and consensually derived in the research group. Continuous discussions and scrutinising of the research process with colleagues and academics from the same and other research field made it possible to refine the research methods and broaden the theoretical perspectives of the research.

### *Dependability*

Dependability refers to the extent to which findings are consistent in relation to the context in which they are generated. Since qualitative inquiry often is explorative, in which the data collection is an evolving process, dependability also refers to the stability of data over time and alterations made during the analysis process. To ensure dependability all data in this research was collected during a restricted period since collection over a long time can lead to inconsistencies. The data collection in the present studies were evolving pro-

cesses in which each interview, despite guidance of an interview guide, differed both within the specific interviews and between the interviews of the included children. With awareness of the importance for the researcher to be consistent in the data collection, even if new insights arise into the phenomenon studied during the timeframe for the research, efforts were made to not affect the outcome of the interviews performed at later stages in the process. During the research process there was thus an endeavor to make the method employed as structured, transparent and clear cut as possible. A continuous note-taking and tracking of changes and decisions where essential since recoding and re-labelling where necessary during the analysis process. All reflections were communicated within the research group for transparency and assurance of the process to continue according to the plan. To make the research process transparent, the data collection and analysis method were described in sufficient detail, to make it possible for readers to follow the *"trail for decisions"* and make judgements about consistency.

### *Transferability*

The findings of a qualitative study are not intended to be generalisable as are the results of quantitative studies. They may however be transferable to other contexts and the term transferability refers to the usefulness of the findings in other contexts or groups. Transferability in qualitative research also relates to the usefulness of study results to extend or modify existing theories across domains and research areas. The findings of qualitative inquiry are dependent to the specific context in which the investigation is performed, but transfer may be possible, and the findings may be used to understand or shed light on similar phenomena in other settings. Conversely only the recipient can truly judge whether there are similarities between contexts and whether the findings can be conveyed. Transferability in this research was facilitated by inclusion of rich data which will allow the reader to understand the phenomenon studied. To further facilitate for the reader to judge the transferability, participants, methods and processes were described thoroughly. Figures of the analysis processes and illustrative quotations were provided. The results were also related to existing evidence in the context. To help the reader make sense of findings the theoretical framework underpinning the perspectives taken for the different research processes were clearly described and supplemented in the articles. To ensure transferability to other settings the data collection in the included studies were obtained from a representa-

tive group and were reflecting common situations in clinical practice. Transferability were also enhanced by a variation in the sampling in terms of children with different ages and experiences of the perioperative care. Qualitative research results in interpretations and analytical themes which can be recognised in other situations and settings where the context is more or less similar to the original. The findings in all four studies in this research can be viewed as patterns which can be recognised, useful and transferred to other settings.

### *Reflexivity*

The researcher's self-reflection is an essential part of all research whatever chosen method. Reflexivity refers to the process in which the researcher critically reflects on own preferences, preconceptions and the potential power relationships between the researcher and participants. A clear and transparent description of the contextual intersecting relationships not only increases the credibility of the research but also deepens the readers understanding.

With a background of over 20 years working as a nurse anaesthetist within paediatric perioperative care and as the developer and owner of the non-profit website, which constituted the base for the included studies, reflexivity has been central in all phases of this research. Familiarity with the context can be an advantage as long as it not affects the informants or the interpretations of the results. From the perspective of a PhD-student and researcher the knowledge within the context served as an advantage for most of the included parts of the research. The experience of meeting children in different ages and their parents, at a highly stress-point as during perioperative procedures, was invaluable and, in most cases decisive to understand and get access to feelings and experiences during the interviews. The preconceived knowledge about the context was also an advantage during the interpretations of all different dimensions of experiences and perspectives expressed by the children. Further to detect and take misrepresentations into account during the analysis process. The familiarity with the research context and procedures was another advantage which facilitated both the patient recruitment and data collection. However, during the process of data collection the researcher was excluded from all clinical work and a clear distinction was made between the clinical nurse and the researcher.

Even though the existing relationship between the context and the researcher mostly served as a benefit it was sometimes difficult to maintain distance and balance to already existing experience and knowledge. The combination of the researcher's familiarity with the context, the role in the data

collection and analysis thus might have resulted in taking things for granted and relevant data been missing. To evade this, the interview guide consisted of broad questions intended to get as much rich material as possible. Also, recurring discussions and reflections within the research group, consisting of members with neither knowledge and contacts in the context of perioperative care nor connection to the actual website, continuously challenged the researchers pre-understanding and perspectives. Since reflexivity is a process that permeates the whole research endeavour transparency throughout the process and within the research group is a key component.

With full awareness of the controversial aspects associated with the researcher's personal connections to the website evaluated, the research team continuously considered and discussed the importance of neutrality and objectivity in the research processes. On the other hand, the researcher's knowledge of both the content and design of the website were of great importance during all phases of the research. Not at least during the data collection where the knowledge about the content of the website contributed to understanding of what preparation the children had received made the researcher to easily relate to their descriptions and level of understanding.

By enhancing the overall knowledge within different research approaches, familiarising with previously research in the field and by acquiring a theoretical background for children's learning with web-based technology, the researcher continuously tried to reduce the impending risk for being bias. Reflexivity is constructed in an interactional process over time and best learned through repeated awareness and reflection in a mentoring process. The collaboration within the research team constituted an invaluable role for reflection as part of building trustworthiness.

## Ethical considerations

Ethical issues in research with children can be related to three main issues: ***power relations***, ***informed consent*** and ***confidentiality***. These issues include important differences in how they are approached with children due to children's understanding, experience of the world, their ways of communication and the power asymmetry between the adult researcher and the child participant. These unequal relationships require negotiation with the children involved, as well as with potential gate-keepers or other adults participating in the research processes.[71] Developmental limitations, the imbalance of power between children, parents and health care providers and children's compromised health status were taken into consideration throughout all included studies.[195]

The four main features of ***informed consent*** in research with children can be described as; consent as an explicit art, which must be informed, given voluntarily and negotiable.[177] All participants were provided with information about the purpose of the studies and their expected involvement, by using forms designed and adapted for children in different ages and with different linguistic and cognitive ability.[195-198] Children's and parent's agreement to participate were carefully considered and informed and written consent were obtained from both parents and children in all ages.[198] Obtaining children's consent directly signals respect for their participation in decisions that affects them as well as for autonomy and for basic human rights.[195, 196] In health care situations children more often is seen to be assent (*to agree*), instead of being competent to consent (*agree to disagree*).[199] Information about informed dissent was thus included as important as information about the informed consent. Both children and parents were informed that consent was voluntarily, negotiable and possible to withdraw at any point without affecting care or treatment. Full respect were taken to decisions about participating as well as to dissent or unwillingness to participate.[195, 198] Consent was treated as an ongoing and renewed process prior to the different phases of the studies. One important aspect considering children's consent is whether they have understood what they have agreed to be involved in. To address this concern, all interviews began with repeated explanation of the purpose of the research combined with an account of how the interviews would proceed.

***Confidentiality*** was obtained by asking children and parents question separately (study 1) and by obtaining a separate space for the interviews in children's home (study 4). The interviews associated with study 3 (phase 1 and 2) performed at the hospital where, due to logistics, performed with both children and parent's available. However, parents were respectfully asked to allow their child to independently participate in the interview.

During the interviews the researcher was aware of boundaries to confidentiality because of the potential risk for a child to disclose information that suggested themselves other children may be put in a risky position. In addition, the researcher was aware of the ethical responsibility to make sure that children didn't suffer harm from participation in the interviews and were prepared for how to handle content with negative emotions that may have appeared during the interviews.

Privacy and confidentiality when conducting research using technological media is important to consider.[177] Of respect for children's privacy all participants were assured that their participation were anonymous, all material would be treated confidentially, not identifiable in research reports, presentations and other means of disseminating findings.

The increased use of the internet open new ways of reaching children and young people also within the research field.[200] Research using the internet raises special challenges because it is part of children's activities, which are often beyond the control of adults. Internet research thereby obligates the researcher to reflect on different considerations and norms in research ethics.[200-203] It is important to be aware of is the distinction between the private and the public arenas in relation to the information that is disseminated and stored on the internet. All information used from the website was therefore carefully de-identified.[200, 203]

The studies were approved by the Regional Ethical Review Board in Stockholm (2015/1162-31/5, study 1) (2014/309-31/3, study 3 and 4) according to the Helsinki Declaration.[204]

# FINDINGS

## Study 1

The analysis from this study provides clear evidence that web-based interactive preoperative information results in better levels of knowledge in children than conventional brochure material whereas no striking difference was found regarding parents.

At the pre-determined interim analysis the total question score (TQS) in children was found to be substantially higher in the Anaesthesia-Web (AW) group than in the brochure material (BM) group (median score: 27; IQR: 16.5-33 and median score: 19.5; IQR: 11.25-27.75, respectively, p= 0.0076). The median difference in score was 6; (95% CI: 0-9). The total question score in parents was also higher in the AW group than in the BM group (median score 27, IQR: 23-30 and median score: 23; IQR: 19-27, respectively, p = 0.0017). The median difference in score was 3; (95% CI: 1-5) (*Figure 5*).

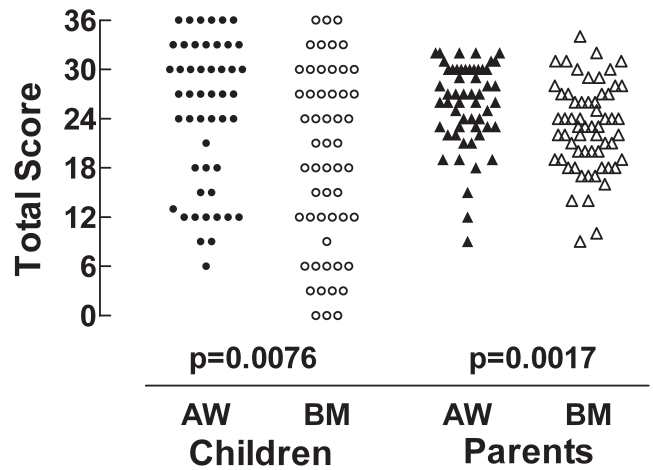



*Figure 5. Total score of questions.*
*The total question score is significant higher for AW than for BM in both groups. Filled circle: AW Children. Open circle: BM Children. Filled triangle: AW Parents. Open triangle: BM Parents*

Increasing child age was associated with a higher total question score in both groups ($r_s$ = 0.4619, 95% CI: 0.1994-0.6625, p = 0.0008 and $r_s$ = 0.5786, 95% CI: 0.3607-0.7366, p < 0.0001, respectively) (*Figure 6*).

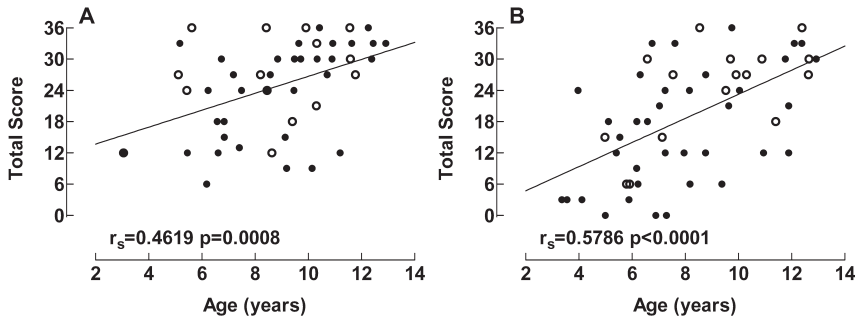



*Figure 6. Total score as a function of age. The Spearman rank correlation test shows that the total score increases significantly with age both in the AW and the BM groups. The regression lines are given by ordinary linear regression. Filled circle: Males. Open circle: Females*

Gender did not influence the total question score in the AW group (p = 0.3645) whereas girls scored better than boys in the BM group (median score: 27; IQR: 15.75-30 and median score 18; IQR: 6-24.75, respectively, p = 0.0255). The median difference in score was 6; (95% CI: 0-15). No correlation was found with regards to the time between the preoperative assessment and the day of surgery and the total question score. The results were similar for both adults and children (data not shown). Both in children and adults it was obvious that some questions got a higher correct answer than others (all p-values <0.0001).

## Study 2

In the analysis of the Anaesthesia-Web related to the central learning concepts; ***pre-understanding, motivation, learning processes*** and ***learning outcome*** four themes characterising children's learning opportunities on the Anaesthesia-Web were found; ***In charge of my own learning, Discover and play, Recognise and identify*** and ***Getting feedback.*** The correspondence between the concepts and the themes is presented in *figure 7.*

### IN CHARGE OF MY LEARNING

This theme involves the central learning concepts, ***pre-understanding*** and ***motivation.*** The analysis shows that the Anaesthesia-Web provides crucial prerequisites for any visitor the be in charge of their own learning. The website offers children control and enables use based on interest and ability. This

is important in terms of motivation and each child's individual preunderstanding. The content is presented and designed to provide different kinds of learning opportunities offering multimedia diversity and ease of access for the visitor to make individual choices. By offering multiple approaches to solve problems, answer questions and investigate information, meaningfulness and motivation to learn can be triggered.

### DISCOVER AND PLAY

This theme involves the central learning concepts, ***motivation*** and ***learning processes***. Through discovery and play children can receive, process, and apply the information on the Anaesthesia-Web cognitively, emotionally and by active participation. Play stimulates motivation and is very important in the child's learning process. By processing new information and analysing old, new understanding and knowledge can be constructed.

The interactive parts of the Anaesthesia-Web enable children to not only prepare for upcoming events but also process what has happened. The Anaesthesia-Web provides children with tools to help them understand, manage procedures and transfer experiences to the real-world context.

### RECOGNISE AND IDENTIFY

This theme involves the central learning concepts, ***pre-understanding, motivation*** and ***learning processes***. The analysis shows that the Anaesthesia-Web helps children to recognise experiences and despite pre-understanding and cognitive developmental level find something or someone with whom to identify.

The Anaesthesia-Web provides opportunities for children to recognise and identify first with the provided content and design on the website and second with themselves as in need to learn and prepare for the expected procedures. The Anaesthesia-web also offer children opportunities to experience authentic situations and at the same time learn about processes and procedures in a way that would otherwise be impossible. Recognition and identification are important factors for children to experience the visit at the website as meaningful to enter and use and to maintain the motivation to learn.

### GETTING FEEDBACK

This theme involves the central learning concepts, ***motivation*** and ***learning outcome***. Several features on the Anaesthesia-Web promote feedback which is necessary to judge the learning achievements, confirm understanding and the need for repetition. Features promoting feedback on the Anaesthesia-Web

include quiz games, answers to frequent asked questions (FAQ), and performance feedback for practical skills. The notice board offers the possibility to discuss, share experiences, receive feedback and learn from others facing similar situations.

From an educational perspective, feedback is crucial in giving the visitor the opportunity to not only test their level of knowledge but also to reduce fear and generate trust and confidence.

| In charge of my own learning | Discover and play | To recognise and identify | Feedback |
|---|---|---|---|
| Pre-understanding | Motivation | Pre-understanding | Motivation |
| Motivation | Learning process | Motivation | Learning outcome |
| | | Learning process | |

*Figure 7. Correspondence between learning concepts and the themes.*

## Study 3

The analysis of children's own perspectives of perioperative care uncovered two contrasting themes: **Fearful in association with anaesthesia and surgery** and **Confident in association with anaesthesia and surgery.** Children's experiences of fearfulness rest on two sub-themes, ***Apprehensive about the situation*** and ***Doubts and queries*** whereas children's experiences of confidence rest on the sub-themes ***Comfortable with the situation*** and ***Grasping the situation.***

The subthemes within each of the themes are connected. Doubts and queries relates to experiences of being Apprehensive about the situation, while Grasping the situation relates to experiences of being Comfortable with the situation (*Figure 8).*

Overall the confident children described an awareness of the situation, preparations and procedures in the context of illness and need for anaesthesia and surgery. The opposite was the case for children displaying fearfulness. Their experiences were related to not being prepared for the expected procedures, they were lacking understanding of context for procedures and the terminology used. The fearful children expressed apprehension about pain and potential risks for mistakes in relation anaesthesia and surgery. On the contrary the confident children were capable to relate symptoms and experiences to anatomical and physiological knowledge and the performed preparations and procedures.

| Category | Sub-theme | Theme |
|---|---|---|
| Feelings of distrust | Apprehensive about the situation | Fearful in association with anaesthesia and surgery |
| Environmental uneasiness | | |
| Body-related worries | | |
| Afraid of losing control | | |
| Lack of information and understanding | Doubts and queries | |
| Questions and concerns | | |
| Security and trust | Comfortable with the situation | Confident in association with anaesthesia and surgery |
| Strategies for distraction | | |
| Awareness of the situation | Grasping the situation | |
| Using various sources for information and learning | | |

*Figure 8. Overview of the themes, sub-themes and categories describing children's experiences when facing anaesthesia and surgery.*

## FEARFUL IN ASSOCIATION WITH ANAESTHESIA AND SURGERY

### *Apprehension about the situation*

*Feelings of distrust* were related to interactions with the medical providers and to the information received. Increased distrust was voiced when children's experiences did not match received information and expectations. *Environmental uneasiness* was mostly related to the operating room. In terms of *body-related worries* the needle-related procedures were most central. When children pictured treatments and investigations they expressed worries and concerns for mistakes being made. Worries for an altered body image and the risk for visible scars or lifelong punishment were also highlighted. A central source for worry by teenagers was the discomfort of having a stranger affect their physical integrity. *Being afraid of losing control* was described in terms of the physical and psychological mechanisms and to the loss of control of daily structures and context.

### *Doubts and queries*

A general *lack of information and understanding* about the cause for hospitalisation and procedures were mentioned as the main reasons for being apprehensive. Needle-related procedures, were associated with most *questions and concerns* in all interviews.

### CONFIDENT IN ASSOCIATION WITH ANAESTHESIA AND SURGERY

#### *Comfortable with the situation*

*Security and trust* were related to the positive interactions with the health care providers and understanding of the information received. Children portrayed various *strategies for distraction* to cope with the stressful situation.

#### *Grasping the situation*

The confident children displayed an *awareness of the situation*, understanding about preparations and procedures and were able to situate them in the context of the perioperative care. Children described how they were using *various sources for information and learning* to get information about anaesthesia and surgery. Parents, specifically their mothers, were the ones who had mainly provided them with information.

Despite the themes reflecting opposite experiences similarities were found. The perioperative environment caught children's attention in terms of the sights, sounds and smells of the surroundings as well as to actions and attitude of the health care providers. Events considered as major from a health care perspective may be of no importance to the child, while events considered as less important by health care providers may be the most significant to the child. Comprehension of the perioperative procedures, continuous information and interaction with the health care providers were decisive factors for children's expressions of confidence or fearfulness.

## Study 4

The analysis of this study showed that children's use of the website to a great extent can be explained through the predetermined educational themes on which the analysis is based; ***In charge of my learning, Discover and play, Recognise and identify*** and ***Getting feedback***.

The analysis contributed with pictures of how children based on these themes utilise the website's possibilities for both preparation and processing of experiences before, during and after the hospitalisation. The analysis also clearly revealed a new dimension of recognition and feedback where children interactions with other visitors on the notice boards came to the fore as very important. These encounters were described under the additional theme; ***Interaction with other children.***

### IN CHARGE OF MY LEARNING

Children's entrance into the multimedia diversity of the Anaesthesia-Web was based on individual choices characterised by a non-systematic search to get an overview of the structure and content. Without instructions children surfed around the website and independent of routes and choices finally made individual choices and returned to parts they wanted to explore further. In their individual choices of how to receive the information children used the opportunity of the open access of the website. Children's interest was captured by colors, sounds and movement. Parts of the website perceived as committed to interactivity were described as fun, curious and triggered their motivation for further exploration. Children's choices on the website reflected their desire to take command of decisions and actions. Simultaneously as children were interacting on the website they discussed and confirmed their own positive and negative experiences and proposed changes for the perioperative care.

### DISCOVER AND PLAY

The interactive parts of the website were central and the most visited by all children. With help of the interactive elements, children explored the hospital environment and perioperative processes and compared them to their own experiences. They discovered the playful interactive parts simultaneously as they described what they were doing and the reason for their actions taken. It was prominent that play and interactivity were important for children's processing of events and a useful tool in their description and explanation for others about procedures and perioperative care. Children's play was permeated by practical applications of their own experiences of undergoing treatments and procedures. They confirmed the need for procedures and convinced themselves it would be less painful and frightening than expected. When children were playing at the website their need for understanding of the procedures surrounding the insertion and use of the intravenous needle was prominent.

### RECOGNISE AND IDENTIFY

After children's initial tour around the website their individual choices resulted in focusing on what they could identify and recognise from their own hospitalisation. Children recognised the hospital environment, technical equipment and procedures. Assured were also the website's reliability. It was obvious that orders of procedures were noticed and that these were important for

children's identification and recognition. Adjustments to processes were another factor that children recognised and expressed as important.

### GETTING FEEDBACK

The different possibilities for children to getting feedback on the website were expressed as most important to confirm their experiences and understanding, expand and judge their learning. By receiving feedback children were given opportunities to apply ideas, correct and learn from errors, improve performances and achieve goals. They also highlighted the importance of having different levels of the challenge and frequent opportunities to apply their ideas. When children were testing their knowledge in games and quizzes, they were triggered and motivated to continue when they received immediate answers making their progresses visible in any way.

### INTERACTION WITH OTHER CHILDREN

Children's identification with others in the same situation was very prominent when they were visiting the notice board. Children expressed the advantage of being able to chat, ask questions and receive answers from others. They confirmed that many of the children writing on the notice board shared their own experience of being uninformed, having many questions and being afraid for what to expect at the hospital. They highlighted the importance for these children to receive information before their admission as it had been crucial for their own preparation. Noteworthy for children's use of all the opportunities to feedback on the website was that they were not only receiving feedback but were, on the notice board, also giving feedback on other children's questions and concerns. Advices on how to best relate to events and procedures were frequently exchanged with others.

# DISCUSSION

The perioperative period is a landmark event in children's lives affecting them both in the short-term and the long-term. This is confirmed by the results of this thesis as well as by previous research. Children's perspectives presented in study 3 indicated that those expressing confidence experienced comprehension with the perioperative care, were well prepared and described the communication and interaction with the health care providers as satisfactory. However, the contrary was found, with children expressing apprehension for the situation. They expressed a lack of information and participation, a confusing communication and distrust to procedures and health care providers when their expectations and the preparation given did not match their experiences.

Despite a wide base of evidence proclaiming the role of preparation in reducing preoperative anxiety,[27, 34, 61, 62] many children continue to report lack of understanding[4, 64, 102] and participation[19, 20, 99] and are forced to experience perioperative procedures with fear and anxiety.[1, 3, 31, 46]

The overall aim of this thesis was to provide a deeper understanding of how web-based technology can support children to learn about and be prepared for the perioperative care. The aim was based on the assumption that a shift, regarding children's possibilities to process the information provided in order to understand and learn, is crucial. Another assumption was that web-based technology may provide opportunities for such learning processes. Study 1, 2 and 4 provided insights about how web-based technology, depending on content, configuration and with consideration of an educational framework, can support children's learning in relation to preparation for perioperative care. The aims of the included studies were investigated based on children's perspectives.

Children of today have the unique experience of being enveloped in technology from birth. Growing up with a vast array of technology children's voices thus are invaluable in the development of perioperative preparation programs. Children's views also provide precious insights for the improvement of the health care providers' communication and interaction, and for the incorporation of their right to participate in all aspects of the health care deliv-

ery, also when they are facing anaesthesia and surgery. Health care provider's awareness and integration of children's perspectives were revealed as important to help them adjust to the highly technological perioperative environment and to ensure a safe and trustful perioperative care.

The results from study 3 displayed that children have their own individual perspectives and interpretations of the perioperative care which significantly differ from the views of adult's and perioperative providers. In line with existing research[4, 18, 19, 64, 102] children reported to have many unanswered questions, a desire to be consulted and heard in relation to their informational needs and be involved and prepared for their perioperative care. Unfortunately, most children expressed that they didn't understand what was going to happen and described how an improved knowledge would have helped them to minimise fear and be prepared for the different perioperative phases. Children in study 3 and 4 also expressed a lack of trust and confidence both to the perioperative providers and procedures. These statements have to be highlighted out of many reasons, partly because children's lack of confidence was shown to be difficult to reverse and the fact that distrust in one area was spread to others.

Preparation was revealed as crucial for the establishment of children's understanding, trust and confidence during the perioperative processes. Interaction and communication with the health care providers also came to the fore as being of great importance in order to mediate and achieve trust and confidence in the preparation provided. However, despite this result and a wide base of evidence proclaiming the role of preparation of children prior to perioperative care[34, 61, 102] most of existing preparation programs are based on provision of information and only few on empirical evidence of what type of information is provided, the manner in which it is provided and how children perceive such information.[61, 102] It was clearly manifested that preparation of children for perioperative care is a complex and multifaceted task including more than just provision of information. With the results from study 1, providing significant differences in children's level of knowledge after receiving interactive web-based information compared to conventional brochure material, unidirectional information can be interpreted as insufficient for children's understanding.

Several learning theories point out that receiving information does not mean one has learned and understood. Learning is a process about constructing one's own understanding,[138, 139] Children need time to process the information given to learn and fully understand.[108, 109] Careful consideration

thus needs to be given to *what* sort of preparation children should receive, *when* it should be received, and *how* and *by whom* it should be provided.[54, 61, 62]

The perioperative processes take place in a highly technical environment characterised by strictly defined routines performed at a fast pace. In this context, children's possibilities for interaction with the perioperative providers and time for preparation are often given a lower priority in favor of actions with more visible, immediate and cost-effective results.[205, 206] In combination with the decreasing numbers of children having access to and attending preoperative preparation programs[207] and an increasing shift towards outpatient surgery children's opportunities to prepare and learn about procedures as well as their opportunities for follow up of questions and concerns are considerably decreasing.[66, 67, 205, 208] The move towards cost- and time efficiency also jeopardise the utility of multicomponent behavioral strategies.[117, 209] To avoid children continuing to voice apprehension to a higher extent than confidence, and to reduce the use of pharmacological interventions to hide deficiencies in children's preparation for procedures[54] new approaches of preparation of children for the perioperative care have to be considered.

Web-based technology represents a rapidly expanding alternative, with almost unlimited opportunities for development and distribution of preparation programs to children in paediatric care.[66, 67] To constitute more than just another website in an infinite range of others, the content, conformation and development of such websites need to change from simply providing information to embracing the importance of children's need to process the information received to learn and be prepared .[108, 109] Careful consideration also has to be given to the specific context of learning for which the website is aimed. Unlike school situations, hospitalisation and perioperative procedures are situations filled with unfamiliar, frightening and emotional components. By developing web-based preparation programs that include children's perspectives and educational principles, we argue that web-based technology can be used to its fullest advantage as a learning resource for children in paediatric care.[108, 138, 210]

In study 2 and 4 the meaning of including a theoretical educational framework of children's learning in the development and design of websites in paediatric perioperative care was investigated. The analysis showed that children's web-based preparation and learning for perioperative care to a great extent can be supported by considering the educational themes; ***In charge of my learning, Discover and play, Recognise and identify*** and ***Getting***

***feedback*** built on the central learning concepts pre-understanding, motivation, learning processes and learning outcome. Study 4 also revealed dimensions of recognition and feedback highlighting children's need for interaction with other visitors. These findings were described under the additional theme; ***Interaction with other children***.

As was revealed in study 1 children's level of knowledge was significant higher after receiving interactive web-based information. This can probably be explained by the fact that children on the website were given several opportunities to receive and process the information provided. Another explanation might be that children after being brought up in a web-based generation can be assumed to be well prepared to attain content presented in an interactive web-based format. Despite all content on this website being adapted to children's different cognitive and developmental levels the total score of questions in children increased significantly with the age of the child. Even though children increase their cognitive abilities, making older children to be able to perform better than younger, configuration of preparation aimed also for the younger ones, have to be secured. This is not least important due to studies reporting that web-based activities can be effective for reasoning, problem-solving, recognition of words, concepts and situations at earlier ages than expected.[154, 155, 165, 169] The levels of correct answers for the questions in study 1 differed. Even though the reason for this is unclear, the overall score of a simple explanation of the word anaesthesia, which few of the participants understood, highlights the importance of receiving children's perspectives of the information given. It also points out the significance for health care providers to consider existing communication strategies and avoide incomprehensible vocabulary both in interactions with children and in the development of paediatric preparation programs.

The analysis of children's use of the website in study 4 showed that children took advantage of all available opportunities of making own choices to manage their experiences from the perioperative processes. The different possibilities for them to be in charge of their own learning were shown as important driving forces both to start and proceed with their search for new discovery and learning. Considering the educational perspectives of pre-understanding and motivation for children's learning this indicates that prerequisites for individual interactions and triggers stimulating different learning activities is important when designing web-based learning opportunities in paediatric care. This can be achieved by offering children free access to the

multimedia diversity so they can choose when, how and what information to receive.[210]

Children's pre-understanding will direct their attention and choices when they are navigating on the website. The content and configuration thus have to be adapted to provide preparation for children including a wide spectra of pre-understanding by offering opportunities for meaningful learning suitable for everyone.[108] It is a challenge to develop and refine systems which both are attractive to capture children's interest and make them stay at the website.[135, 211-213] Another factor to be aware of is that children of all ages are extensive media consumers which may have resulted in a distorted picture of sickness and hospitalisation. It has been shown that providing children with reality-based information is important to help them regulate their expectations and alleviate their fears.[135, 214]

Exploration and play are well documented learning activities stimulating motivation and processes involved in children's learning.[156, 215] Creating possibilities for play and interactivity are thus cornerstones in the development of web-based learning opportunities for children in paediatric care.[158, 216] This was also confirmed in study 4 where a large proportion of the time children spent on the website were related to play and interactivity where they confirmed and processed experiences and let their curiosity find out and learn new things related to their body, perioperative processes and the hospital environment. It was obvious that the website's openness in combination with the opportunities to discover and play stimulated children's motivation and continuously exploration of the content. This highlights the importance for websites in paediatric care to be developed filled of fun and excitement to discover and explore. The theoretical investigation of a website in study 2 shows that content and design should preferably be developed to stimulate and motivate children's curiosity, creativity, engagement, incidental learning and active participation.

Children's use of the website to learn about surroundings and procedures, that would otherwise be inaccessible for them,[165] was obvious in study 4. With the help of interactive elements children virtually practiced skills, prepared for and processed experiences. Children described the experiences and pain associated with the needle-related procedures and simultaneously as they played with the interactive needles explained both the reasons for the actions taken and how their fears had been linked to lack of information and understanding. The surprising finding of children's descriptions of fear for removal of the patch with anaesthestic cream was, even though the phe-

nomena have been described earlier,[58] a reminder to continuously re-evaluate existing perspectives when meeting children in the perioperative care.

Children's need for identification and recognition were prominent. They interacted with the diversity of characters and perioperative procedures and displayed ability and a need to express, engage and compare with own experiences. As was displayed in study 3 and 4 children were not satisfactory prepared for the psychological experiences they encountered. Important parts of the development of websites in paediatric care thus also include opportunities for children to recognise and identify with the emotional aspects they may will come to experience during the perioperative processes.[66, 67]

Children's use of the website displayed their need for feedback on processes and performances to help them understand what was going to happen and to experience safety and confidence. Children's usage of the website not only revealed their need to receive feedback on own experiences but also to interact and give feedback on other visitor's questions and concerns. Identification with others seemed to create interest and engagement which in turn may lead to meaningfulness and an increased motivation to learn about their own situation. According to social learning theories[217] certain behaviour can be learned and reproduced, under similar conditions, by observing the actions performed by others. Since children's need for access to a platform where they could identify and learn from others perspectives was apparent opportunities for interaction with other visitors carefully have to be considered in future developments of websites in paediatric care.

Despite available opportunities for feedback on the investigated website it was obvious that this area constitutes a challenging part of the development of websites in paediatric care. Children's web-based learning processes mostly takes place at home, where correction of misunderstandings and possibilities for feedback cannot be taken for granted, and the result of children's learning outcome will not be obvious until the day of admission. A crucial part of children's preparation on a website thus has to consist of health care providers follow up and continuation on their learning both on arrival and during the entire perioperative care. Even though children are prepared for the expected procedures they will constantly be exposed to unexpected and for them new experiences requiring a continuous receptiveness and support from the medical providers. This was clearly demonstrated in study 3 in which also the confident children expressed increased fear when they were entering the operating room and were exposed to the strange technical equipment, sounds, smells and the covered,

unrecognisable health care providers. This highlights the importance of not restricting children's need of information and preparation to a single event but to be viewed as a continuous process signified by flexibility and individualised adjustments which has to be emphasised during all the perioperative phases. The importance of the preparation to constitute an ongoing process is also confirmed in the literature[104, 113] and in study 3 where the confident children emphasised the importance of be given time to prepare as well as the preparation to be available during all the perioperative phases. This confirms that web-based technology never will replace but rather constitute a support for children's preparation, learning processes and contact with the health care providers.

Communication and interaction with the health care providers were interpreted as prominent factors to support children's learning and achieve trust and confidence during the perioperative care. Creating trust and confidence require adjustments to children's perspectives, flexibility and well developed communication skills. Even though this study was performed in a paediatric perioperative setting children expressed the communication with the health care providers as confusing and a significant part of children's expressions of fear could be derived from misunderstandings based on incomprehensible terminology and vocabulary. Children in study 3 mostly described the verbal information, received at the preoperative meeting, as focused on biological and physiological information and as primarily being directed to their parents. The issues of the information not being oriented direct to children and focused on physiological information with minimal exploration of the psychological or practical implications are previous defined problems in paediatric care.[104, 113, 206] Children also expressed how they were unsure of what to ask and how to convey their questions and concerns to the health care providers. Defensives in the verbal and non-verbal communication skills of health care providers are earlier described problems resulting in children not understanding the information provided.[18, 78]

The result showed that even though health care providers are taking a child perspective, with the child's best in mind, they may not always be aware of neither how they communicate with children nor how their attitudes affect their interactions and children's perceptions. To be supportive and able to individualise the care given, health care providers need to be sensitive, observant and learn how to interpret children's different expressions and experiences. They also need to critically examine both their approaches and attitudes, verbal and non-verbal communication strategies.[18, 218]

The fact that the attitudes of health care providers have a direct impact on children's coping process during perioperative care[218, 219] were clearly manifested by children's expressions of how friendly communication and interaction helped children to ease the stress experienced. As expressed in this research, communication involving distracting behaviors, as talk about non-procedural topics and humor, have been shown as positively related to children's coping whereas behaviors such as reassurance and empathy have been found to be related to higher stress levels.[206, 218 219]

The results from the studies included in this research and previous evidence reporting on children's preoperative anxiety, lack of preparation participation and the impending risk for their needs and perspectives to be neglected call for extensive changes. We would argue it is time to consider new approaches when meeting children during perioperative care. Based on children's perspectives it is time to scrutinise existing perioperative structures and communication strategies as well as the content, conformation and distribution of the preparation provided. Preparation programs in perioperative care have to change from simply providing information to embracing the importance of children's need to process the information provided to learn and fully understand. By developing web-based preparation programs including children's perspectives and educational principles, web-based technology best can be utilised as a perioperative learning resource complementing the individual interactions between children and the health care providers.

Although this research was aimed to be carefully prepared and accomplished, some ***methodological limitations*** and shortcomings needs to be highlighted and discussed. The theoretical educational framework used in this research has directed the attention of the researchers in the analysis process and thus also permeates the interpretations. To ensure trustworthiness the framework used were described in detail, applied systematically and together with the results continuously discussed and refined by an experienced multidisciplinary group.[170, 190] However, the use of other educational frameworks and inclusion of professions from other disciplines and settings probably would have contributed with additional important aspects on children's web-based preparation and learning in association with perioperative care.

Limitations in study 3 and 4 can be drawn from that children were recruited from the same health care setting, were relatively healthy and undergoing routine surgeries. The imbalance of gender is also a limitation which is explained by the type of surgeries performed during the week for the data collection. Furthermore, the data collection in the interviews performed before

children departing the hospital could have been affected by children's post-operative tiredness and medical status. Although the number of participants was small the configuration of the study provided continuity of children's experiences which in combination with the qualitative approach can be assumed to provide deep insights of children's perspectives. However, to receive additional perspectives of the phenomenon a larger number of participants with a wider distribution in ages, ethnicities, medical background and diagnoses should have been included. Moreover, a larger group of participants would allow for examination of the effects of the outcome of adherence to the intervention on perioperative outcomes as well as to better understand the effective components on a website. It should furthermore be proposed that preparation of children is complex consisting of various components. This can make it difficult to assess whether one of the multimedia components have affected children's experiences and compliance and may have contributed to the final outcomes more than others.

We also would like to highlight some methodological issues related to the design of study 1. Since no standardised questions or research tool was found matching the study the questions were subjected to content validity.[193] Following that we believe that the questions adequately reflected the primary aim of the study. For obvious reasons a double blind design was not possible. By making sure that the observer evaluating the answers to the questions was kept strictly isolated from the randomisation and information process we feel confident with regards to the integrity of the observer blinding used.

Parents' experiences of their child's perioperative care are obviously of great importance also for children's perceptions. Exclusion of parents' experiences can thus be involved as another disadvantage in this research. To benefit children's perspectives the decision to exclude parents' experiences was deliberately taken after consensus in the research group. As mention earlier children's involvement in research previously have been questioned due to their supposed limitations to provide trustworthy accounts to their experiences due to limited developmental capabilities.[68] Although younger children may have more limited communication capabilities, as compared to older, younger children included in this research clearly proposed to be competent to express their experiences of the perioperative care.

The researchers perceptiveness, flexibility, communication skills and ability to recognise both the culture of childhood and the culture of the individual child[71] were concluded as decisive both for the interviews to be conducted and for the results to be credible and trustworthy interpreted according

to children's perspectives. Interviews with children are filled of excitements and surprising happenings. Rarely, children included in this research sat quietly and answered the questions posed. The unexpected events taking place during the interviews ranged from children refusing to talk, vomiting, crying, and hiding under the blanket to children climbing on furniture, being hungry, having to eat, cellphones ringing and friends coming by wanting to participate in the interviews. Instead of trying to alter and control all these unforeseen situations they were considered and included as a necessary part of children's world which we as researchers had to find the best route to relate to and include as a part of the authentic research venue with children. It was also particularly important to never adapt a patronising approach to children's expressed experiences and perspectives, to be aware of both the verbal and non-verbal communication and give children time to reflect over questions without trying to force or carry out the interviews based on time.

Obvious in this research was also the methodological difficulties associated with children suffering psychologically from the present or previous care given. The researchers ethical responsibility to be prepared to contend with children's negative emotions and stress arising during the research became obvious during some interviews. For this the researcher was prepared with an alternative plan to be able to continue the interviews as well as with a plan of how to help children for the future.

Finally, the central methodological consideration of what we are interpreting when we are performing research with children, needs to be highlighted; *Is it possible for an adult at all to make an accurate representation of children's perspectives? Or, are we only producing interpretations of the child's world through various layers of our own experiences of childhood?* [71, 178]

# CONCLUSIONS

The results from this research have provided a deeper understanding of how web-based technology can support children to learn about and be prepared for perioperative care. Conclusions that can be drawn from the studies included are:

- Web-based technology can function as a significant resource for preparation and learning in paediatric perioperative care.
- An interactive design of web-based preparation programs has been proven to support children to obtain higher levels of knowledge about perioperative care compared with conventional brochure material.
- Analysis of children's use of and experiences with a web-based preparation program emphasises the importance of including children's perspectives and a theoretical educational framework of children's learning in the development and design of websites in paediatric perioperative care.
- Important characteristics supporting children's learning on a website, in association with perioperative care, were found to let the child be; *In charge of own learning*, to *Discover and play*, to *Recognise events and situations and to identify with others* to *Get feedback in the learning process* and to facilitate *Interaction with other children.*
- Children perceive the perioperative care with all their senses, and their interpretations differ from adults and health care providers. Understanding children's perspectives, and awareness of their need to process the information provided to help them understand and be prepared, are significant factors in establishing trust and confidence in a highly technological perioperative environment.
- Web-based technology constitutes an important part of children's preparation but helping children to become confident also requires awareness of preparation as a continuous process, signified by perceptiveness and individualised adjustments during all phases of the perioperative care.

# IMPLICATIONS

The overall results from this research highlight the importance of including children's perspectives and educational principles in the development of preoperative preparation programs with the goal of optimising understanding, cooperation and compliance as well as to reduce preoperative anxiety and postoperative trauma. The results provide important insights about the content, conformation and distribution of information in association with preparation of children for perioperative care. The complexity of preparing children and families for perioperative care requires high levels of competence in the field.[110] The limited time health care providers spend with the families before anaesthesia and surgery[206] implies that alternatives are needed to secure adequate preparation of children.[66]

Web-based preparation programs including children's perspectives and educational principles constitute new important resources. The aim with web-based preparation programs is however never to replace but to support children's preparation, learning processes and contact with the health care providers. When children arrive for the perioperative care, more time will be available for individual interactions since the preparation has already started.

Preparation of children and parents represent an important, often unvalued part, of the perioperative care, which we claim must become compulsory and classified in equality to other preoperative preparations. This is not least important since it in this research was apparent that few families had participated in the preoperative meeting, neither had followed the request from the anaesthesiologist regarding utilisation of existing preparation programs, making most children and parents arriving unprepared to the hospital on the day for surgery.

Children included parents as the primarily information providers. This is unfortunate since the information provided might be based on parents self-perceived experiences and parents neither can be assumed to feel comfortable preparing their child nor having the necessary knowledge of what to say and how to do.[106, 220, 221] In addition, since parental anxiety is strongly related to the child's anxiety,[28, 50] uninformed and anxious parents may be less able to take on the principal role in children's preparation.[29]

During children's performances and use of the website in study 4 it was prominent that their processing of experiences and learning included both an active participation and a verbal reasoning about feelings, experiences and the routes taken on the website. Children's need to reflect their experiences on the website with an adult manifest the importance of encouraging parents to sometimes visit the website together with their child. This will also benefit parents since it has been shown that preoperative preparation programs may reduce parental anxiety not only when provided directly to them but also indirectly through their child's preparation.[3] Conclusively, we suggest future development of websites in paediatric care should include possibilities for children to both interact with other visitors and chat and receive feedback on questions and concerns directly from health care professionals.

In order to secure children's rights and different needs we additionally suggest the structure and configuration of the preoperative meeting to be included as a teamwork. For this, participation of health care providers from different professions with complementary expertise and experience is necessary.[53, 102, 113, 222] Extensive knowledge about children's cognitive development and reactions during stress as well as trained skills and senses to understand children's different signals and expressions are compulsory prerequisites for all involved.[61, 64, 102] Based on children's experiences in study 3 and 4 we would also suggest the preoperative meeting to be extended to more than a collection of medical information but to also include inquiring into children's individual level of knowledge, need for preparation and learning as well as a follow up of their understanding and trust.

Children experiencing confidence in this research expressed how the perioperative providers' communication to them in a calm and friendly manner reduced their feelings of distress. These expressions are in accordance with earlier descriptions of how behavior and attitudes of health care professionals influences children's experiences of stress during the perioperative period.[223] The confident children described how the health care providers have showed they had time to listen by sitting by the child and opening up for questions. They also described them to be able to answer questions and explain procedures in an understandable way. Even though it may seem obvious and trivial to give children time to voice their perspectives the results from this research reveal that these actions can make a significant difference in their wellbeing and satisfaction, preparation and learning and for the outcome of the perioperative care.

# FUTURE PERSPECTIVES

The results of this thesis may advice future development and design of websites in paediatric care. Extensive research is still needed to understand the promising potential and possible disadvantages of interactive web-based technology targeting children and parents in relation to paediatric care. It is important to find out more about how different content and configurations of such programs affect and relate to children's experiences, preparation and learning, and how web-based preparation is related to quantitative measurements of stress, behavior and pain. It would also be valuable to find out if and how tailored web-based preparation can help children with severe preoperative anxiety to prepare for procedures and how increased opportunities for web-based interaction with other visitors and health care providers would affect the outcome of the perioperative procedures.

To fully understand the complexity of children's perioperative experiences and the underlying reasons for their fear and anxiety children's perspectives must be further investigated in relation to several factors. *First*, in relation to the entirety of the hospitalisation; *second*, to the structure of the entire perioperative care; and *third,* in relation to the content, configuration and distribution of perioperative preparation programs. It would also be of great value to understand more about the significance of the constitution of the professions involved in the preparation team and how their ability to communicate and interact affects children's experiences and outcomes of perioperative procedures. Finally, it is urgent to investigate if the use of preoperative pharmacological interventions could be reduced by implementing structured preparation programs consisting of web-based preparation in combination with a multi-professional preoperative meeting.

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